Overview of the HIV/AIDS Epidemic with an Introduction to Public Health Surveillance
Module 1

Overview of the HIV/AIDS Epidemic with an Introduction to Public Health Surveillance

Participant Manual

2007

World Health Organization
Regional Office for South-East Asia
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*Module 4* - Surveillance for sexually transmitted infections: participant manual

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We are grateful to all the national and international experts who reviewed earlier versions of the module.

**Bangladesh:** Dr Motiur Rahman, Associate Scientist & Head of RTI/STI Laboratory, ICDDR, B; Dr Md Hanif Uddin, Deputy Programme Manager, National AIDS/STD Programme; Dr Khondoker Mahbuba Jamil, Senior Scientific Officer, Department of Virology, Institute of Epidemiology, Disease Control and Research;

**Bhutan:** Ms Neyzang Wangmo, Associate Lecturer of Royal Institute of Health Sciences.

**China:** Ms Wang Lan, National Center for AIDS/STD Control and Prevention;

**Cambodia:** Dr Ly Penh Sun, Deputy Director, National Center for HIV/AIDS, Dermatology and STD.

**India:** Dr Shashi Kant, Additional Professor, Centre for Community Medicine, All India Institute of Medical Sciences (AIIMS); Dr A.S. Rathore, Joint Director (Training), National AIDS Control Organisation; Dr B.S.N. Reddy, Head, Dermatology Department, Maulana Azad Medical College; Dr Madhulekha Bhattacharya, Professor and Head Department of CHA National Institute of Health & Family Welfare; Dr Jagadeeshan, Tamil Nadu State AIDS Control Society.

**Indonesia:** Ms Naning Nugrahini, Technical Officer for STI and Surveillance, Monitoring and Evaluation, Directorate of Direct Transmitted Disease Control; Dr Dicky Budiman, Sub-Directorate of AIDS & STI; Dr Dyah Erti Mustikawati, Head of Section for Evaluation and Reporting, Sub-Directorate of AIDS/STI.

**Maldives:** Mr Mohammed Rameez, Programme Coordinator, Department of Public Health.

**Myanmar:** Dr Min Thwe, National AIDS Programme Manager, Ministry of Health, Government of the Union of Myanmar; Dr Tun Myint, Divisional AIDS Officer, Mandalay AIDS/STD Prevention and Control Programme; Dr Htay Naing, Medical Officer, National AIDS Control Programme.

**Nepal:** Dr K. N. Thakur, Dermatologist, Koshi Zonal Hospital; Dr Devi Prasad Bhusal, Teku Hospital.

**Srilanka:** Dr N. Punchihewa, National STD/AIDS Control Programme; Dr K.A.M. Ariyaratne, National STD/AIDS Control Programme; Dr Srijakanthi Beneragama, Epidemiologist, National STD/AIDS Control Programme.

**Thailand:** Ms Thanapan Fongsiri, AIDS Cluster, Bureau of AIDS, TB and STI, Department of Disease Control, Ministry of Public Health; Dr Tanarak Plipat, Medical Officer, Head
of HIV, TB and STD Surveillance Section, Bureau of Epidemiology, Department of Disease
Control, Ministry of Public Health; Mr Surasak Thanaisawanyangkoon, Health Technical
Officer, Bureau of AIDS, TB and STIs, Ministry of Public Health; Mrs Mattana Herber,
Health Technical Officer, Office of Disease Prevention and Control;

**Timor-Leste:** Mr Virgilio Soares, HIV/AIDS Officer, Ministry of Health.

**Vietnam:** Dr Phan Thi Thu Huong, Deputy Head of HIV/AIDS/STI Surveillance, Viet Nam
Administration of HIV/AIDS Control (VAAC).

United States Department of Health and Human Services, Centers for Disease Control
and Prevention (HHS-CDC), Global AIDS Program (GAP) Surveillance Team.

University of California at San Francisco (UCSF), Institute for Global Health, AIDS Research
Institute through the University Technical Assistance Program (UTAP) with CDC/GAP.
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How to Study this Module

What you should know before the course?
This course is meant primarily for district-level surveillance officers. As a participant, you should have a basic medical understanding of HIV/AIDS and public health surveillance before taking the course.

Module structure
The module is divided into units. The units are convenient blocks of material for a single study session.

This module can also be used for self-study.

Because you already know quite a bit about HIV/AIDS, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, you may try to guess the answers. Answer the questions as best you can. You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions and you can check your work.

Summary
This module provides an introduction to the HIV/AIDS epidemic and public health surveillance, with a focus on South-East Asia.

Appendices
More information is provided:

Appendix A: Answers to Warm-Up Questions and Case Studies

Appendix B: Differences between Public Health and Research Methods
Additions, Corrections, Suggestions

Do you want to suggest changes to this module? Is there additional information you would like to see? Please write or email us. We will collect your letters and emails, and consider your comments in the next update to this module.

Address
HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House
Indraprastha Estate
Mahatama Gandhi Marg
New Delhi 110 002, India
Email: hiv@searo.who.int
Fax: 91 11 23370197
Overview

What this unit is about

This unit focuses on the HIV/AIDS situation in South-East Asia. We will consider recent data from Country Reports, World Health Organization (WHO), UNAIDS and other agencies.

Warm-up questions

1. True or false? By December 2005, nearly 39 million people were infected with HIV worldwide. Circle your answer below:

   True        False

2. In Asia, the two main factors driving the epidemic are ______________________
   and __________________________

3. List risk factors that contribute to the spread of HIV in South-East Asia.

Introduction

What you will learn

By the end of this unit, you should be able to

• describe the overall HIV/AIDS situation in the world;
• describe the HIV/AIDS situation in South-East Asia.

Worldwide Epidemic

AIDS is unique in human history in its rapid spread, its extent and the depth of its impact. Since the first AIDS case was diagnosed in 1981, the world has struggled to come to grips with its extraordinary dimensions. Early efforts to mount an effective response were fragmented, piecemeal and vastly under-resourced. Few communities recognized the dangers ahead, and even fewer were able to mount an effective response. The HIV epidemic continues to grow worldwide, destroying people’s lives and in many cases seriously damaging the fabric of societies.

At the end of 2006, there were an estimated 39.5 million people living with HIV (PLHIV), globally. More than 95% of the new infections in 2006 were in low and middle income countries. Among the WHO regions, Sub-Saharan Africa is the most affected followed by South-East Asia.

The scale of the epidemic varies immensely across the South-East Asia Region—India with the highest number of PLHIV (2.5 million), while Maldives with less than 100. Injecting drug use and commercial sex are the two drivers of the epidemic in this Region. In most countries, HIV started among injecting drug users and perpetuated through sexual networks. In general, HIV has remained uncontrolled in populations with high-risk behaviours, such as men who have sex with men, injecting drug users and sex workers. In countries with long-standing epidemics, such as Thailand, HIV has spread to
the lower-risk general population; 43% of estimated new infections in 2005 were among women infected through their husbands or partners.

**Prevalence in South-East Asia**

The WHO South-East Asia Region (SEAR) has the second highest number of people living with HIV/AIDS (PLHA) in the world, after sub-Saharan Africa. SEAR includes 11 Member Countries:

- Bangladesh
- Bhutan
- DPR Korea
- Indonesia
- India
- Myanmar
- Nepal
- Sri Lanka
- Thailand
- Timor Leste

**HIV prevalence in SEAR, 2005**

The overall adult HIV prevalence in South and South-East Asia is less than 1%. This is relatively much lower than sub-Saharan Africa, where the overall adult HIV prevalence is 5.8%. Because the population of many Asian countries are so large, even low HIV prevalence means large numbers of people living with HIV. Table 1.1 below shows some statistics on HIV burden and modes of transmission in each country.

<table>
<thead>
<tr>
<th>Country</th>
<th>Adult HIV prevalence (%)</th>
<th>Estimated number of people living with HIV/AIDS</th>
<th>Predominant mode of transmission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>&lt;0.1</td>
<td>7 500</td>
<td>+</td>
</tr>
<tr>
<td>Bhutan</td>
<td>&lt;0.1</td>
<td>&lt;500</td>
<td>+</td>
</tr>
<tr>
<td>DPR Korea</td>
<td>n/a</td>
<td>n/a</td>
<td>--</td>
</tr>
<tr>
<td>Indonesia</td>
<td>0.1</td>
<td>193 000</td>
<td>+</td>
</tr>
<tr>
<td>India</td>
<td>0.36</td>
<td>2.5 million</td>
<td>+++</td>
</tr>
<tr>
<td>Maldives</td>
<td>&lt;0.1</td>
<td>&lt;100</td>
<td>+</td>
</tr>
<tr>
<td>Myanmar</td>
<td>1.3</td>
<td>339 000</td>
<td>+++</td>
</tr>
<tr>
<td>Nepal</td>
<td>0.55</td>
<td>70 000</td>
<td>+</td>
</tr>
<tr>
<td>Thailand</td>
<td>1.4</td>
<td>541 000</td>
<td>+++</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>&lt;0.1</td>
<td>5 000</td>
<td>+</td>
</tr>
<tr>
<td>Timor Leste</td>
<td>&lt;0.1</td>
<td>&lt;100</td>
<td>n/a</td>
</tr>
</tbody>
</table>

(-- ) Unknown or minimal HIV transmission; (+) limited HIV transmission; (+++) moderate HIV transmission; and (++++) major HIV transmission

Source: Country Reports, National AIDS Programmes, Ministries of Health.

The first few HIV/AIDS cases in the Region were reported among homosexual men in Thailand in 1984. Since then, the HIV epidemic in South-East Asia has grown massively and is still evolving. Currently, South-East Asia faces multiple and diverse epidemics occurring in different population groups and in different geographical areas at varying rates—India with the highest number of PLHIV in the world and DPR Korea from where an HIV infection case has not yet been reported. There are examples of successful
reversal of the epidemic in Thailand and indications of decreasing HIV prevalence in Myanmar and Tamil Nadu State of India (Figure 1.1), as well as rapidly growing epidemics in Indonesia and Nepal.

**Figure 1.1**

HIV prevalence among antenatal attendees in selected countries of South-East Asia, 1991-2005

Vulnerable Population Groups

**Sex workers**

The majority of HIV infections in the South-East Asia Region are due to unsafe sex between female sex workers and their clients. More than 20 years after the start of the epidemic in South-East Asia, HIV infection rates among female sex workers remained very high and are still increasing (Figure 1.2).

**Figure 1.2**

HIV prevalence among female sex workers in selected countries, South-East Asia, 1995-2005

Note: Data unavailable for some years is reflected by dotted line.
Injecting drug users

IDUs kick-started and gave momentum to the HIV epidemic in many countries in South-East Asia. In Kathmandu, Nepal, HIV among IDUs increased sharply from less than 5% in the early 1990s to 40% in 1999, and 68% in 2003 (Figure 1.3). A similar pattern was noted in Jakarta, Indonesia—in 1999, 16% of the IDUs were infected and by 2001 nearly half of IDUs were infected with HIV. In Dhaka, Bangladesh, HIV steadily increased from nil to 5% over five years. The early IDU epidemics in India were in the north-eastern states where up to 70% of the IDUs were infected. Recently, increasing HIV infection rates are being observed among IDUs in other urban areas, namely, Delhi, Mumbai and Chennai. Despite an overall successful reversal of the HIV epidemic in Thailand, HIV prevalence among IDUs has remained consistently high over the past 15 years, ranging between 30% and 50%.

Men who have sex with men

More than 20 years after Thailand’s first AIDS case was reported in a young homosexual man in 1984, MSM remain at a high risk for HIV infection in South-East Asia (Figure 1.4). In India, HIV prevalence among MSM ranged from 1% to 40% across the 18 targeted intervention sites. In Bangkok, the overall HIV prevalence among MSM increased from 17.3% (95% confidence interval [CI] = 15.1-19.7%) in 2003 to 28.3% (95% CI = 23.9-33.0%) in 2005.

![Figure 1.4](image)

**Figure 1.4**

**HIV prevalence among men who have sex with men in selected South-East Asian Countries, 2003-2005**

- Chennai (2004) - India: 6.8%
- Mumbai (2004) - India: 12.8%
- Pune (2005) - India: 16%
- Andhra Pradesh (2004) - India: 9.6%
- Kathmandu (2005) - Nepal: 4.7%
- Phuket (2005) - Thailand: 5.5%
- Chiang Mai (2005) - Thailand: 15.3%
- Bangkok (2003) - Thailand: 17.3%
- Bangkok (2005) - Thailand: 28.3%

Prisoners

The prevalence of HIV in prisons is usually higher than in the surrounding communities. Risky behaviours (such as injecting drug use, unprotected male-to-male sexual activity) that occur in prisons compound the risk of spreading HIV in prisons. Surveillance data from 2005 showed a wide variation between Indonesian provinces, with HIV prevalence among prisoners ranging from 3% in Lampung Province to 36% in Banten Province. This is much higher than the national adult HIV prevalence in Indonesia (0.2%). No national data exist for Thailand, but in 2003, a quarter of the 689 inmates surveyed in Klong Prem Prison, Bangkok, were HIV-infected.
Migrants

Migrants and their spouses are at a high risk of HIV infection. Employment related seasonal and short-term migration of Nepali youth and adult men to cities of Nepal, India and other countries is emerging as a major inducing factor of the HIV epidemic. In a survey conducted in 2001 in Doti District in west Nepal, 10% (10/97) of Nepali migrant returnees from Mumbai, India were found to be infected with HIV.

Youth

Young people aged 15-24 years are not only the most threatened—globally accounting for 40% of new HIV infections—but also potentially the most likely group to influence the future course of the epidemic. An estimated 2 million youth aged 15-24 years live in the South-East Asia Region. Early sexual debut and risky sexual behaviours are contributing to HIV transmission among the youth in this Region. Data from the 2004 Behavioural Surveillance Survey of Thailand indicated that the average age of sexual activity for both boys and girls was 13 years. In 2002, although 88% male youth in Merauke, Indonesia were aware of the use of condoms for HIV prevention, only 15% used a condom at the last commercial sex encounter.

Women

Although HIV prevalence among women is lower than among men in the Region, women are increasingly being infected. In Thailand, with the epidemic having matured and the patterns of HIV transmission changed, the proportion of women among reported AIDS cases has increased from 15% in 1990 to 38% in 2005.

Factors that affect HIV prevalence

Various factors may account for the high burden of HIV/AIDS in the Region and the subregional variations. The two main factors driving the HIV/AIDS epidemic in Asia are injection drug use and commercial sex. Often these groups are marginalized and put at an increased risk due to isolation and stigmatization.

Away from their community and their regular sexual partners, migrant and mobile workers (such as truckers and rickshaw pullers) are more likely to become clients of commercial sex workers. The involvement of girls and women in sex work often results from coercion and/or the need to provide a source of economic survival for themselves and their families.

Other factors accounting for the situation in the Region may include:

- high prevalence of other sexually transmitted infections (STIs) increasing the risk of acquiring and transmitting HIV;
- lack of care-seeking for STIs due to the associated stigma;
- illicit drug trafficking;
- poverty;
- cultural taboos preventing open discussion and sex education among the youth;
- limited access to or social non-acceptance and non-availability of condoms;
- low status of women and their inability to influence partner’s behaviour;
- low literacy rates;
- increasing urbanization, migration, mobilization and separation of families as a result of economic reasons and/or other social circumstances.
Summary

The SEAR accounts for the second largest number of infections worldwide. The HIV epidemic in Asia is being driven by commercial sex work and injecting drug use.

Exercises

Warm-up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to.

Small group discussion

Get into small groups to discuss these questions. Choose a speaker for your group who will report back to the class.

1. Which provinces and districts are most affected by the HIV/AIDS epidemic in your country?
2. What might be the factors contributing to the high rate of HIV in these provinces or districts?
3. Which sub-populations are most affected by the HIV/AIDS epidemic in your region?

Apply what you have learned/case study

Try this case study individually. We’ll discuss the answers in class.

A country in South-East Asia had its earliest cases of AIDS recognized in 1984. Data below are based on estimates of HIV prevalence by province. Study the data and answer the questions follow:

Table 1.2

HIV prevalence (%) by province, 1998-2004

<table>
<thead>
<tr>
<th>Province</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samad</td>
<td>2.10</td>
<td>2.30</td>
<td>1.56</td>
<td>1.60</td>
<td>1.18</td>
<td>1.06</td>
<td>1.05</td>
</tr>
<tr>
<td>Panga</td>
<td>5.50</td>
<td>5.25</td>
<td>2.22</td>
<td>3.50</td>
<td>3.75</td>
<td>5.00</td>
<td>8.75</td>
</tr>
<tr>
<td>TopinagarH</td>
<td>0.5</td>
<td>0.55</td>
<td>0.50</td>
<td>0.50</td>
<td>0.25</td>
<td>0.25</td>
<td>0.25</td>
</tr>
<tr>
<td>Bijarta</td>
<td>1.30</td>
<td>1.24</td>
<td>1.08</td>
<td>1.11</td>
<td>0.91</td>
<td>1.18</td>
<td>0.95</td>
</tr>
<tr>
<td>Jawara</td>
<td>1.99</td>
<td>2.03</td>
<td>1.58</td>
<td>1.50</td>
<td>1.5</td>
<td>1.06</td>
<td>0.96</td>
</tr>
</tbody>
</table>

a. In 2004, which province had the highest prevalence?
b. Comment on the HIV infection trends.
Impact of the HIV/AIDS Epidemic on South-East Asia

Overview

What this unit is about
In this unit, we will learn how AIDS is affecting the countries of South-East Asia. HIV/AIDS has had a profound impact on morbidity and mortality worldwide, especially in South-East Asia. To begin this unit, try the questions below.

Warm-up questions
1. The chimney effect refers to population loss due to HIV that occurs predominantly in which part of the population? Circle your answer below.
   a. young children
   b. adolescents
   c. adults
   d. the elderly
2. True or False? For most of this decade, nearly half a million people will die because of AIDS every year in Asia. Circle your answer below.
   True     False
3. What is the impact of HIV/AIDS on children?
4. What is the economic impact of HIV/AIDS on individuals, families and nations?
5. What is the burden of HIV/AIDS in terms of disability-adjusted life years (DALYs) and deaths in SEAR countries?
6. List some of the effects stigma has on HIV prevention, care and support for individuals with HIV, and their families.

Introduction

What you will learn
By the end of this unit you should be able to:

• describe the impact of HIV/AIDS on individuals and families;
• describe the impact of HIV/AIDS on sustainable development.

As shown in Figure 2.1, life expectancy in Asia has changed with the AIDS epidemic. It is estimated that Thailand, Cambodia and Myanmar lost two to five years of life expectancy by 2002. It is likely that these countries will lose another two to four years of life expectancy by 2010, as shown in Figure 2.2.
Impact of HIV/AIDS in Asia

Increase in annual AIDS deaths
In high HIV-prevalence countries of Asia (Cambodia, Myanmar, Thailand, and some states in India), it is estimated that annual AIDS deaths will increase the total number of annual deaths in the 15-49 year-old population by up to 30 - 40% (WHO, 2003).

- In Phayao province in northern Thailand, the crude death rate increased dramatically, from 5.3 per 1000 in 1986 to 6.8 in 1993 and 9.5 in 1996.
- No condition other than HIV/AIDS could explain that increase.
- By 1994, AIDS had become the leading cause of mortality in the province. It represented 11.3% of all deaths, and 18.2% of all deaths if those cases where AIDS was the suspected cause of death, but was not medically confirmed, were included (WHO, 2003).
- However, more recently, the annual number of HIV/AIDS-associated deaths in Thailand have declined due to increased access to antiretroviral treatment.

The clinical impact of AIDS and other HIV-related conditions in the five Asia-Pacific countries (Papua New Guinea, India, Nepal, Malaysia and Vietnam) with estimated HIV prevalence rates of > 0.1% and < 1% of the 15-49 year-old population will increase annual adult deaths by about 5% during the coming decade. Most of these AIDS deaths will occur in young male injecting drug users (IDUs) and male clients of female sex workers (FSW) (WHO, 2003).

Projections to 2010
By 2010, AIDS mortality is projected to continue to result in lower life expectancies in Asia. Life expectancies are projected to be two years lower in Thailand and four years lower in Cambodia and Myanmar (Figure 2.2).
Figure 2.2
Projected mortality with and without AIDS in selected Asian countries: 2010

Source: U.S. Census Bureau, International Programs Centre, International Data Base and unpublished tables.

AIDS as a cause of death
AIDS is the fourth leading cause of death in the world. It is the seventh leading cause of death in SEAR countries, as shown in Figure 2.3.

Figure 2.3
Leading causes of death in SEAR countries, 2004


Loss of work
Globally, HIV/AIDS accounts for 84.5 million DALYs. In SEAR countries, up to 10.6 million DALYs are lost due to HIV/AIDS. It is the sixth leading cause of DALYs in SEAR countries (Figure 2.4).
Table 2.1

Leading causes of DALYs lost in SEAR countries, 2004

<table>
<thead>
<tr>
<th>Disease</th>
<th>Disability-adjusted life years (DALYs) lost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower respiratory infections</td>
<td>30,551</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>18,817</td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>17,930</td>
</tr>
<tr>
<td>Unipolar depressive disorder</td>
<td>17,671</td>
</tr>
<tr>
<td>Other unintentional injuries</td>
<td>15,128</td>
</tr>
<tr>
<td>HIV</td>
<td>10,628</td>
</tr>
<tr>
<td>Cerebrovascular diseases</td>
<td>8,714</td>
</tr>
<tr>
<td>Road traffic accidents</td>
<td>7,601</td>
</tr>
<tr>
<td>Cataract</td>
<td>7,562</td>
</tr>
<tr>
<td>Hearing loss, adult onset</td>
<td>7,029</td>
</tr>
</tbody>
</table>


Family Impact

Household income impact

The impact of HIV/AIDS goes far beyond individual suffering and death. The high mortality rate has a major impact on families. The impact of HIV/AIDS on a household’s income is disastrous.

- Those who contract the virus are generally from the most productive age groups in society, between 15 and 40 years of age. At these ages, people are usually earning at the peak of their capacities, so the loss of their income has a major impact on the household.
- At the same time, family incomes are eroded because other family members stop working to care for the sick.
- The death of parents has increased the burden and stress on the extended family. Grandparents are being left to care for young children.
- There is also an increased burden on society to provide orphanages, healthcare facilities and schools for these orphans.

Study data

- One study shows how Thai families can spend the equivalent of a single person’s entire average annual income during the last year of a patient’s life.
- Another study indicates that the incomes of households with a person living with HIV/AIDS can fall by as much as 80%.

Standards of living fall sharply as household savings are eroded to meet the healthcare costs associated with HIV/AIDS. Studies in the Region suggest that over half of all households affected by HIV/AIDS reduced their consumption of goods and services by 40 to 60% to help meet healthcare costs. About 60% of Thai households with an AIDS-affected member have to draw upon their savings.
Figure 2.4 shows the change in the pattern of monthly expenditure in Delhi and Manipur in India after HIV is detected in a patient. Individuals and families usually cope up with the increase in expenditure for care by using past savings, borrowing money, and selling and mortgaging assets.

Figure 2.4

**Monthly household expenditure after detection of HIV status**

![Change in Average Monthly Household Expenditure after Detection of HIV Status (Delhi and Manipur)](image)


In some countries, population losses from HIV/AIDS will change the demographic pyramid by 2020 from one in which children predominate to one in which adolescents and young adults predominate, the so-called “chimney effect.” This is seen dramatically in the demographic pyramid for Botswana, seen below.

Figure 2.5

**Projected population structure, with and without the AIDS epidemic, Botswana, 2020**

![Projected population structure in 2020](image)

Looking at Figure 2.5 above, answer the following questions:

a. Describe the differences in the impact of AIDS among men and women.
b. Which age groups are most strongly affected by AIDS?

**Impact on children**

Children’s education suffers when a family member is infected with HIV. The children are likely to be kept home to care for sick family members or to take over their domestic duties.

- Children are often forced to drop out of school because reduced household income means that families can no longer pay school fees.
- Girls’ education may be placed at particular risk in this context, since young adolescent girls may have to enter sex work to earn money for school fees or they may exchange sex for gifts.
- World Bank studies show that school attendance by young people is reduced by half if the household has lost an adult family member to HIV/AIDS in the previous year.

In Cambodia, a recent study by the Khmer HIV/AIDS NGO Alliance and Family Health International found that about one in five children in AIDS-affected families reported that they had to start working in the previous six months to support their family.

- One in three had to provide care and take on major household work. Many had to leave school, forego necessities such as food and clothes, or be sent away from their home.
- All of the children surveyed had been exposed to high levels of stigma and psychosocial stress, with girls more vulnerable than boys.

AIDS is threatening children as never before. Children under 15 in South and East Asia are the largest group of children living with AIDS and dying from the disease outside of sub-Saharan Africa.

- In those countries most affected by AIDS in Asia, infant mortality rates are higher than they would have been without AIDS.
- Based on current trends, child mortality rates in 2010 will be around 10% higher in Myanmar, Cambodia and Thailand than they would have been without AIDS.
- Infant mortality is 1 to 3% higher in Thailand, Myanmar and Cambodia (US Census, The AIDS Pandemic in the 21st Century, 2000).

The increasing number of child deaths due to AIDS threatens to reverse many of the recent gains of child survival programmes. Moreover, the socioeconomic impact of HIV/AIDS on children is profound.
As their parents fall sick and die of AIDS, children undergo a long trail of painful experiences such as:

- economic hardship, withdrawal from school;
- lack of love, attention and affection; psychological distress, stigma, discrimination and isolation;
- malnutrition and illness.

**Workforce and Health Services Impact**

**Effect on the workforce**

Employers in several countries will note the largest cost of the epidemic. These are the indirect costs of:

- absenteeism
- loss of productivity
- the need to replace skilled workers and train new ones
- increasing benefits payments

Economic wealth in the form of gross national product could drop in some areas by as much as 40% by 2020. Such losses translate to billions of dollars in the Region.

A 1997 Thailand study found that when a person with steady employment died of AIDS, the lifetime household income loss was 20% greater than a household with non-AIDS related deaths.

**Pressure on health services**

The increasing number of persons with symptomatic HIV infection, AIDS and AIDS-related diseases have dramatically increased the demand for care and treatment, putting extreme pressure on health services.

In Thailand, a study found that the annual cost of anti-retroviral therapy (ART) in Khon Kaen province was $5,674,629 in 2002, equivalent to 20% of the universal care budget for adults in the province.

Research conducted in Papua New Guinea (PNG) found that even when HIV/AIDS affected just 0.2% of the population, related illnesses accounted for 5% of beds in Port Moresby General Hospital.

The United Nations estimated that the average annual healthcare cost for a person living with HIV/AIDS in the Pacific islands was about US $5,000 in 1996, compared to average spending of between US $20 and U $30 per person on health by Pacific island governments. In this context, even a moderate HIV/AIDS epidemic will put huge strains on government budgets in these countries and on household healthcare spending.

**Social stigma**

AIDS-related stigma remains one of the greatest obstacles to people living with HIV being able to realize their human rights. Stigma is also a major barrier to creating and implementing HIV programming.
Discrimination is an infringement of human rights that often leads to people being subjected to various forms of abuse.

- Research among HIV-positive people in India, Indonesia, the Philippines and Thailand found a wide and persistent range of discrimination against people living with or perceived to be living with HIV.
- This included discrimination by friends and employees in workplace and healthcare settings, as well as exclusion from social functions and being denied benefits, privileges or services.

Stigma is a major barrier to people coming forward to have an HIV test, and protective behaviours. For example, the silence around HIV can prevent the use of condoms or can lead to HIV-positive women breastfeeding their infants for fear of being identified.

Stigma is not only directed towards people living with HIV. In many cases, HIV stigma has attached itself to pre-existing stigmas – to racial and ethnic stereotypes and to discrimination against women and sexual minorities. At the same time, long-standing patterns of racial, ethnic and sexual inequality increase vulnerability to HIV.

Despite the overwhelming evidence that AIDS is everywhere, the impulse to say AIDS is only a problem ‘somewhere else’ is still strong. In such a climate, marginalized people, such as injecting drug users and men who have sex with men, are often badly served by prevention programmes. In some countries, their care and support needs are systematically ignored. Knowledge of HIV status is the gateway to AIDS treatment and has documented prevention benefits; however, the current reach of HIV testing services is poor, largely because of fear of stigma and discrimination.

**Summary**

The burden of HIV/AIDS in South-East Asia has a significant impact on many aspects of life. The deaths of productive family members will destroy many lives and families and strain will be felt on the workforce and health services. These factors will have negative effects on development.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

**Small group discussion**

Get into small groups to discuss these questions.

- Describe the impact of HIV and AIDS on the health system in your district or province.
- Is there any evidence of stigma and discrimination against HIV-infected persons in your district? If yes, provide examples. Discuss how stigma can hamper HIV prevention and treatment interventions in your district.
Apply what you have learned/case study

Try this case study individually.

The five provinces in an Asian country have had different experiences with the HIV/AIDS epidemic. Examine the following data:

Table 2.2

Measures of HIV impact by province, 2002

<table>
<thead>
<tr>
<th>Province</th>
<th>Proportion of deaths in adults due to HIV (estimated)</th>
<th>Life expectancy at birth</th>
<th>Proportion of deaths among working adults due to HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samad</td>
<td>1.3</td>
<td>65.6</td>
<td>1.5</td>
</tr>
<tr>
<td>InyPanga</td>
<td>2.7</td>
<td>55.1</td>
<td>4.8</td>
</tr>
<tr>
<td>Bijarta</td>
<td>1.7</td>
<td>67.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Topinagar</td>
<td>2.5</td>
<td>58.9</td>
<td>3.5</td>
</tr>
<tr>
<td>Jawara</td>
<td>1.5</td>
<td>55.9</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Now try the questions below.

a. In which province has the impact of HIV/AIDS been greatest?

b. Based on the prevalence data in the Unit 1 case study and the data above, which province would you expect to have the greatest impact of HIV/AIDS by the year 2012?
Overview

What this unit is about

Extensive research has shown that HIV is the virus that causes AIDS. This unit discusses HIV types and the prevention and treatment of HIV infection and AIDS.

Warm-up questions

1. Which body cells does HIV primarily infect?
   a. respiratory cells
   b. skin cells
   c. red blood cells
   d. white blood cells
2. How many major strains of HIV exist?
3. Which of the following is NOT a method of HIV transmission?
   a. sexual intercourse
   b. casual physical contact
   c. blood exchange
   d. mother to foetus
4. What type of infectious agent is HIV?
   a. bacterium
   b. virus
   c. prion
   d. none of the above
5. True or false? HIV infection and the onset of AIDS occur simultaneously. Circle your answer.
   True    False
6. Which region of the world has the greatest diversity of HIV subtypes, making the development of one unique treatment or vaccine difficult?
7. Which of the following is associated with increased risk of sexual transmission of HIV?
   a. failure to use a male or female condom
   b. a greater number of sexual partners
   c. a higher viral load in an infected partner
   d. all of the above
8. List the three main types of antiretroviral drugs used to treat HIV infection.
   a.
   b.
   c.
9. True or false? The presence of existing sexually transmitted infections (STIs) increases the risk of acquiring HIV during sexual intercourse.
   True    False
10. Which of the following opportunistic infections commonly occurs in AIDS patients?
   a. herpes zoster
   b. fungal infections
   c. tuberculosis (TB)
   d. all of the above

11. True or false? A vaccine for the prevention of HIV infection is currently available.
   True    False

12. True or false? Some STIs such as Chlamydia are biologically more easily acquired by young women, making them more susceptible to HIV infection.
   True    False

Introduction

What you will learn
   By the end of this unit you should be able to:
   • explain the basic biology of HIV;
   • describe HIV transmission routes;
   • understand the importance of concurrent STIs in increasing risk of HIV transmission;
   • discuss the natural history of HIV and list the major opportunistic infections that occur among AIDS patients in South-East Asia;
   • describe the major elements of HIV prevention and control programmes;
   • recognize that HIV is treated with antiretroviral drugs and that treatment also involves prevention and treatment of opportunistic infections.

Biology of HIV

The virus
   Extensive research has shown that HIV is the virus that causes AIDS. HIV is a retrovirus, a family of viruses that carry their genetic information on a single strand of RNA.

HIV infects a number of different cells in the body. Most important are two classes of white blood cells that are involved in protecting the body against infection:
   • CD4+ lymphocytes
   • macrophages

As the number of these cells is depleted because of viral destruction, patients become immunodeficient, meaning their immune systems are insufficient to ward off infections. They develop opportunistic infections and certain cancers, which may be infectious in origin. Opportunistic infections are illnesses that usually do not occur in persons with healthy immune systems.
**HIV types**

The epidemiology of HIV subtype distribution and evolution worldwide are critical for several reasons, including:

- for vaccine development;
- to trace transmission among individuals and track the spread of the virus through countries.

Two major types of HIV have been recognized, HIV-1 and HIV-2. The following table summarizes the differences between the two types:

Table 3.1  
**Characteristics of HIV-1 and HIV-2**

<table>
<thead>
<tr>
<th></th>
<th>HIV-1</th>
<th>HIV-2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic distribution</td>
<td>Worldwide</td>
<td>Primarily confined to West Africa, although cases have been reported in Europe, Asia, and Latin America</td>
</tr>
<tr>
<td>Subtypes</td>
<td>Major group, M, is classified into 10 subtypes; additional highly divergent strains are known as group O</td>
<td>Five genetic subtypes</td>
</tr>
<tr>
<td>Natural history</td>
<td>More easily transmitted, and faster progression to AIDS</td>
<td>Less easily transmitted than HIV-1, and slower progression to AIDS</td>
</tr>
</tbody>
</table>

**Differences in distribution**

At present, specific subtypes are found more frequently in certain countries or regions of the world. Because people move within and between countries, it is likely that multiple subtypes of HIV-1 will appear in most countries.

- In Asia, three key subtypes of HIV-1 dominate: B, C, and CRF01_AE (genetic mixing of two or more HIV subtypes in individuals who are simultaneously infected with different subtypes can result in what is known as a circulating recombinant form, or CRF).
- C is the predominant type in South Asia, B dominates in East Asia, and CRF01_AE is the most common in South-East Asia.

**HIV Transmission and Natural History**

**How HIV is transmitted**

All strains of HIV are transmitted in the same ways:

- The predominant route of transmission in South-East Asia is through heterosexual intercourse. However, there are significant areas where the HIV epidemic has emerged among injecting drug users and men who have sex with men.
- HIV is also transmitted through blood, blood products and donated organs or semen. Blood-borne transmission occurs primarily through the use of inadequately sterilized
needles, syringes or other skin-piercing instruments and through the transfusion of infected blood.
- HIV may be transmitted from an infected mother to her foetus or infant during pregnancy, delivery or when breastfeeding.

Now answer the following questions:

a. What is the most common mode of transmission in South-East Asia?

b. What does parenteral mean?

Figure 3.1
**Modes of HIV transmission, India, 2003**

![Pie chart showing modes of HIV transmission in India, 2003](image)


Figure 3.2
**Modes of HIV transmission, Indonesia, March 2005**

![Pie chart showing modes of HIV transmission in Indonesia, March 2005](image)

Increased risk of infection

A number of factors increase the risk of becoming infected with HIV through sexual intercourse. These fall into two broad categories.

First, the risk of acquiring HIV is proportionate to one’s risk of being exposed sexually to HIV. This means that a person’s risk of HIV is determined primarily by the risk of having an infected partner:

- Persons whose primary sexual partner is infected have the greatest probability of infection through repeated sexual exposure.
- Among persons with multiple sexual partners, the greater the number of partners an individual has, the greater his or her likelihood of having intercourse with someone with HIV infection.

Second, a variety of biological factors appear to increase the risk of becoming infected. These include:

- the viral load of the infected patient (the amount of virus present in blood, semen, cervicovaginal fluids and amniotic fluid);
- type of intercourse (anal intercourse is riskier than vaginal intercourse, and vaginal intercourse is substantially riskier than oral intercourse);
- the coexistence of inflammatory (such as gonorrhoea or Chlamydia) or ulcerative (such as syphilis, chancre or herpes simplex type 2) STIs;
- failure to use prevention methods such as condoms.

Role of STIs

STIs are of particular importance in the rapid transmission of HIV during the growth phase of an epidemic in a country. There is ample evidence that viral STIs, such as HSV-2 and acute bacterial STIs are cofactors in HIV transmission:

- STIs cause inflammation and ulceration. This leads to an increased risk of acquiring infection through recruitment of uninfected lymphocytes to the site of the inflammation or from disruption of the genital epithelium and endothelium.
- Some STIs such as Chlamydia are more easily acquired by adolescent women, making young women also more susceptible.

Aggressive STI control

Several interventions in Asia have integrated and examined the potential role of aggressive STI control on HIV infection. Studies add up to a fairly consistent picture of falling HIV prevalence following successful prevention efforts. STIs are an important individual risk factor for acquiring HIV infection. Investments in large-scale STI treatment and control programmes have greatest value during the phase of early epidemic growth. Here are several examples of aggressive STI control.

Thailand’s 100% condom programme, implemented in 1989, has been successful in promoting condoms among sex workers and clients.
• The 100% condom programme began as a pilot in Ratchaburi province. All owners of sex establishments cooperated.
• The programme was initiated jointly by government officials and owners of sex establishments.
• Owners instructed sex workers about use of condoms in all sexual encounters. Penalties were imposed on owners for non-compliance.
• Condom use increased gradually and STDs declined. In 1991, the programme was expanded nationwide. In 1992, condom quality control measures were instituted.

Cambodia has also implemented a condom use campaign.

• Direct sex workers’ condom use rose from 62% in 1997 to 78% in 1999, while police personnel condom use increased from 65% to 81% in the same time period.
• Available data indicate a downward trend in HIV among high-risk groups and decreasing STIs.

A comprehensive package of interventions in Sonagachi, India, within the sex worker’s cooperative resulted in an increase in condom use, a decrease in syphilis, and continuing low levels of HIV prevalence.

• Condom use in Sonagachi has risen as high as 85% in 2004.
• HIV prevalence dropped from 11% in 2001 to 4% in 2004.

An integrated condom promotion and STI control programme has been operating along the East-West highway in the Terai region of Nepal since 1994.

• Results through the year 2000 show that condom use increased among female sex workers, male transport workers, and male labourers.
• From a low of 35% in 1994, reported condom use with last client increased among sex workers to 62% in 1998 and 86% in 2000. The client groups show similar increases.
• Transport workers have increased their consistent condom use with sex workers from 36% in 1998 to 48% in 2000; male labourers increased their use from 23% in 1998 to 43% in 2000.
• An HIV/STI prevalence survey conducted in 1999 in the same region confirmed that overall HIV prevalence remained low: 3.9% among female sex workers and 1.5% among truckers.

Natural history

AIDS is the late stage of HIV infection. AIDS is characterized by a severely weakened immune system that can no longer ward off life-threatening infections and cancers. The risk of AIDS is related to the length of HIV infection. The vast majority of HIV-infected individuals will eventually develop AIDS.

A review of cohort studies in developing countries, including Thailand, found that the median interval from HIV infection to death was 9 years (WHO 2003).

• One study in Thailand found that the median interval between AIDS diagnosis and death was 19.9 months.
• In South-East Asia, individuals diagnosed with AIDS die from opportunistic diseases, usually tuberculosis (TB).

The advent of effective antiretroviral therapy has considerably reduced the rate of progression to AIDS in areas where these drugs are accessible and has been associated with changes in the types of opportunistic infections that appear with AIDS.

Preventing Transmission of HIV/AIDS

Prevent sexual transmission

The best long-term solution for controlling the HIV/AIDS epidemic is a low-cost, highly effective vaccine but it will not be available in the near future. Therefore, the best options remain changes in behaviour and a handful of prevention technologies.

The goal of prevention is to decrease the risk for HIV transmission from infected to uninfected individuals. The basic approach to prevention involves:

• decreasing the risk of being exposed through sexual intercourse or sharing injection equipment with an infected person;
• decreasing the risk of transmission, if exposed.

Basic approach

The most basic approach to prevention, other than abstinence, is to

• delay age of sexual debut;
• decrease the numbers of sexual partners;
• consistently use male or female condoms;
• undergo voluntary testing and counselling to know your HIV status;
• treat STIs.

Avoid blood-borne transmission

Blood-borne or parenteral transmission of HIV may account for many of the new HIV transmissions in Asia and typically occurs in injecting drug users through reuse and sharing of injection equipment without sterilization.

HIV can be transmitted in medical settings through transfusion, reuse of needles and surgical equipment without sterilization, and needlestick injuries to health-care workers.

Parenteral transmission can be prevented by sterilizing or not reusing needles, screening blood and blood products for HIV prior to administration, sterilization of surgical instruments and universal precautions for health-care workers.

Injection drug use

In some parts of Asia, the principal means of parenteral transmission has been people who share needles and syringes when injecting illegal drugs. Sharing injecting equipment is a very efficient way of passing on HIV.
Because of this, HIV prevalence can rise rapidly among injecting drug users (IDUs) who share needles. Data show that in many settings, needle- and syringe-sharing are very common.

- In Indonesia, around nine out of every 10 injectors said they had used a needle that had been previously used by someone else.
- In Nepal, injectors commonly report using needles that are hidden in places such as public toilets, for use by any IDU in need of injecting equipment.

These behaviours definitely contribute to the very high levels of HIV recorded in these populations.

- Close to half the IDUs in treatment in the Indonesian capital, Jakarta, were living with HIV in 2003, while in Nepal, HIV prevalence among male injectors ranged from 22% to 68% across the country in 2002.
- Parts of China, India, Myanmar, Thailand and Vietnam have all recorded very high levels of HIV infection among IDUs. In some places (including Myanmar, Thailand and the Indian state of Manipur), HIV infection rates have “stabilized” among IDUs, but they have stayed at levels of between 40% and 60% for nearly a decade.

The evidence suggests that large-scale programmes that provide substitutes (e.g., methadone) for injected drugs and that increase access to clean needles reduce new HIV infections among injectors.

While HIV prevention services for drug injectors remain controversial politically, there are now good examples from Asia (including Bangladesh and parts of China and Vietnam) to suggest that these programmes can be effective in Asian settings. If injectors are to avoid contracting or passing on HIV, they must have easy access to clean needles.

Surveillance data from injecting drug users in Yunnan, China, shows that although over half of IDUs are being “reached” with some kind of programme, virtually none are receiving clean needles or condoms. Clean needles or condoms are the two things that can most immediately interrupt HIV transmission among IDUs.

Table 3.2  
**Avoiding blood-borne and injection-use transmission of HIV**

<table>
<thead>
<tr>
<th>Method of transmission</th>
<th>How to prevent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfusion</td>
<td>• Sterilizing or not reusing needles</td>
</tr>
<tr>
<td></td>
<td>• Screening blood and blood products for HIV prior to administration</td>
</tr>
<tr>
<td></td>
<td>• Selection of volunteer blood donors at low risk for HIV</td>
</tr>
<tr>
<td>Reuse of needles and surgical instruments</td>
<td>• Sterilization of surgical instruments</td>
</tr>
<tr>
<td>without sterilization</td>
<td>• Sterilizing or not reusing needles</td>
</tr>
<tr>
<td>Needlestick injuries to healthcare workers</td>
<td>• Universal precautions for health-care workers (for example, use of gloves and eyewear, proper disposal of needles)</td>
</tr>
</tbody>
</table>
Prevent mother-to-child transmission

Perinatal transmission, or HIV transmission during pregnancy, childbirth, and breastfeeding, accounts for very few HIV transmissions in Asia. A short-course antiretroviral regimen, if given to the mother and the newborn baby, substantially reduces the risk of transmission.

HIV-positive mothers can avoid the risk of transmission through infected breast milk by using breast milk substitutes. However, significant health risks are associated with this practice. These include:

- malnutrition
- exposure to other infections.

The WHO/UNICEF/UNAIDS have developed several documents that address HIV and breastfeeding. A summary of their recommendations follows:

- When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-positive mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life.
- All HIV-infected mothers should receive counselling about the risks and benefits of various infant feeding options. Whatever a mother decides, she should be supported in her choice.
- When HIV-infected mothers choose not to breastfeed from birth or stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child’s life to ensure adequate replacement feeding.
- Breastfeeding should be discontinued as soon as feasible. This is known as “early weaning,” and it should take into account local circumstances, nutritional considerations, the individual woman’s situation and the risks associated with replacement feeding.

HIV/AIDS Treatment

Antiretroviral drugs

Antiretroviral drugs are used to treat HIV infection. In the past, due to the high costs, these drugs were rarely used in South-East Asia. The new Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) and other organizations are now making funds available for antiretroviral and other therapies. There are three classes of first-line antiretroviral drugs:

- nucleoside reverse-transcriptase inhibitors
- non-nucleoside reverse transcriptase inhibitors
- protease inhibitors

The regimens that will most likely be used in South-East Asia include a combination of three antiretroviral drugs, according to the WHO SEARO publication *The Use of Antiretroviral Therapy: A Simplified Approach for Resource-Constrained Countries.*

If available, tests for the level of CD4+ cells and plasma viral load (a measure of how much HIV is replicating in the body) can be used to make judgments about when to
begin therapy. Treatment is started when patients develop clinical symptoms from their immunodeficiency or reach a CD4+ cell count of less than 200 cells per mm³.

Preventing and treating opportunistic infections
In addition to antiretroviral drugs, the treatment of HIV infection includes diagnosis, prophylaxis (treatment to prevent or suppress infection) and treatment of selected opportunistic infections.

- Anti-tuberculosis (TB) drugs extend the life of patients with HIV and TB.
- Cotrimaxazole prophylaxis has been used successfully to prevent the onset of opportunistic infections in HIV-positive patients in South-East Asia.
- Vaccines are available for some potential opportunistic infections, such as pneumococcal disease.

Summary
HIV is a virus that can be transmitted sexually, parenterally or perinatally. There are means to prevent each type of transmission, including condom use, needle sterilization, and short course antiretroviral treatment during pregnancy. Treatment includes antiretroviral drugs, and the prevention and treatment of opportunistic infections.

Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups to discuss these questions. Choose a speaker for your group who will report back to the class.

1. What is the predominant subtype of HIV-1 in your country?

2. What are the risk factors associated with sexual transmission of HIV in your country?

3. What are the most common opportunistic infections in your country?

4. What are the major HIV prevention programmes that are operating in your province or district? What proportion of the population do these programmes reach?

Apply what you have learned/case study
Work on this case study independently.
Panga province has experienced rapid expansion of the HIV epidemic. Examine the data and answer the questions below.

**Table 3.3**  
*Incidence of various STIs over time, Panga province*

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea*</td>
<td>2.0</td>
<td>5.4</td>
<td>10.5</td>
</tr>
<tr>
<td>Syphilis*</td>
<td>1.5</td>
<td>2.5</td>
<td>8</td>
</tr>
<tr>
<td>Reported cases of urethritis from STI clinics</td>
<td>2,987</td>
<td>3,452</td>
<td>6,784</td>
</tr>
<tr>
<td>HIV incidence (estimated)</td>
<td>0.5%</td>
<td>1.2%</td>
<td>1.6%</td>
</tr>
</tbody>
</table>

* Cases per 1,000 population 15-49 years old

a. Do you think that STIs may be playing an important role in the spread of HIV infection? Why?

b. Would an STI prevention programme be an important part of the province's HIV control efforts?

c. Given the HIV incidence in Panga province, what do you think will happen with tuberculosis rates in the next several years and why?
Notes
Overview

What this unit is about
To achieve HIV prevention and control, AIDS control programmes need information on infection trends and on demographic and behavioural characteristics of the affected population in a geographic area. This information is being collected through surveillance systems. This unit discusses the techniques of public health surveillance.

Warm-up questions
1. Which of the following terms indicates the number or proportion of persons in a population who have a disease at a given point in time?
   a. sensitivity
   b. prevalence
   c. negative predictive value
   d. none of the above

2. True or false? One-time cross-sectional surveys are valid methods of HIV/AIDS surveillance.
   True   False

3. Match the following terms with their definitions:
   Sentinel surveillance a. surveillance system in which the reports of cases come from clinical laboratories as opposed to health-care practitioners or hospitals
   Laboratory-based reporting b. clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes
   Case definition c. surveillance system in which reports are obtained only from certain selected facilities and populations

4. Which of the following terms indicates the number of persons who newly develop a disease within a specified time period?
   a. specificity
   b. positive predictive value
   c. incidence
   d. none of the above.

Introduction

What you will learn
By the end of this unit you should be able to:

- describe the components of a surveillance system;
- define sentinel surveillance, laboratory-based surveillance, and case definitions;
- define incidence and prevalence.
What is surveillance?

*Surveillance* is the systematic, regular collection of information on the occurrence, distribution and trends of a specific infection, disease or other health-related event. Surveillance must occur on an ongoing basis with sufficient accuracy and completeness for data analysis and dissemination that can lead to effective prevention and control of that infection, disease or health-related event.

**Public Health Surveillance**

**Surveillance events**

Surveillance involves the following main components:

- the systematic collection, analysis and evaluation of morbidity and mortality reports and other relevant data;
- timely and regular distribution of information about the trends and patterns of disease to those who need to know;
- use of the information for disease prevention and control measures.

An important part of the definition is that surveillance systems involve ongoing collection and use of health data. In other words, *one-time cross-sectional surveys are not surveillance.*

**Information loops**

A surveillance system is an information loop or cycle that involves:

- health-care providers
- public health agencies
- the public

The cycle begins when cases of disease occur. It is complete when information about these cases is made available and used for prevention and control of the disease.

Analysed and interpreted data must be communicated to the people and agencies that need to use them.

Figure 4.1 shows the information loop. Think about how HIV/AIDS surveillance (or choose a different disease) is conducted in your country as you look at the figure.
Figure 4.1
The flow of surveillance data

For each block in the loop, write two events that might occur. Collection has been done as an example.

Collection:
1. ANC clinic hand out forms to midwives
2. ANC technician draws blood and sends it for testing.

Collation:
1.
2.
3. Analysis/Interpretation
1.
2.

4. Dissemination/Utilisation
1.
2.

Surveillance terms
Information from surveillance is used to make decision about the best ways to prevent and control the disease. The term surveillance implies information for action. Let us review some basic surveillance terms.

Universal case reporting - A surveillance system in which all cases of a disease are supposed to be reported.

Sentinel surveillance - A surveillance system in which reports are obtained from certain selected facilities or populations. Sentinel surveillance can apply both to reports of cases of disease or periodic surveys, such as antenatal HIV surveys.
**Laboratory-based reporting** - A surveillance system in which the reports of cases come from clinical laboratories instead of physicians, other health-care practitioners or hospitals.

**Case definition** - The clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes.

**Prevalence** - The proportion of persons in a population who have a disease or condition at a given point in time.

**Incidence** - The number of persons who newly develop a disease or condition within a specified time period. Incidence is expressed as a rate with the time period in the denominator.

**Passive surveillance** - A passive system refers to data generated without solicitation, intervention or contact by the health agency carrying out the surveillance. Other agencies initiate reporting. Example: normal disease case reporting by health facilities.

**Active surveillance** - The organization conducting surveillance initiates procedures to obtain reports. Example: making telephone calls or visits to health facilities to obtain information.

There is a relationship between disease and case definition. Look at Table 4.1 and the four terms after it.

<table>
<thead>
<tr>
<th>Table 4.1</th>
<th>Relationship between disease and case definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Table" /></td>
<td><img src="image" alt="Table" /></td>
</tr>
</tbody>
</table>

**Sensitivity** - Referring to Table 4.1 above, the ability of a case definition or laboratory test to predict true disease \((a/(a+c))\).

**Specificity** - The ability of a case definition or laboratory test to predict absence of true disease \((d/(b+d))\).

**Positive predictive value** - The proportion of persons meeting a case definition, having a positive laboratory test that have true disease \((a/(a+b))\).

**Negative predictive value** - The proportion of persons not meeting a case definition, having a negative laboratory test that do not have true disease \((d/(c+d))\).
Examine the table and definitions above, and answer the following question:

Determine the specificity of this case definition:

\[ a = 10, \quad b = 10, \quad c = 30 \quad \text{and} \quad d = 150. \]

Using these numbers, what is the negative predictive value of the case definition? What does this figure represent?

**Past Approaches**

In the past, national communicable disease surveillance systems in many regions have not approached surveillance in an effective way. Here are some of the problems:

- **Duplication of effort.** Vertical or categorical surveillance systems, were established to report a single disease as a component of specific disease intervention programmes. This resulted in duplication of effort and resources. Different programmes approached the same agency for similar surveillance activities.

- **Delay in reporting.** Health workers failed to report on time the first cases of epidemic-prone diseases that fit standard case definitions. This delay in reporting the earliest suspected cases significantly slowed identification of outbreaks and impeded the effectiveness of response.

- **Inadequate data collection, analysis, use and dissemination.** Collection, analysis, utilization and dissemination of surveillance data at the district level were inadequate. Usually, surveillance data were passed from district to national level without adequate analysis. Feedback was also generally inadequate at each level.

- **Lack of integrated training.** Little attention has been given to seeking opportunities to combine surveillance training activities to increase efficiency. As a result, each programme organizes programme-specific training courses (including surveillance) for the same health personnel, especially at district and health-facility levels.

- **Lack of evaluation.** Inadequate attention has been given to the evaluation of programmes using surveillance data. Many resources are invested in interventions that are not adequately evaluated.

- **Lack of laboratory involvement and coordination.** Involvement of laboratories in the surveillance system is inadequate. Neither national nor inter-country laboratory networks have been established to fulfil important public health functions, including the confirmation of cases and outbreaks when the specificity of clinical diagnosis is low.

- **Lack of supervision.** Supervisory support, completeness and timeliness of reporting are generally inadequate.

**Integrated Disease Surveillance**

**IDS strategy defined**

SEARO is encouraging Member States to adopt the *Integrated Disease Surveillance* (IDS) strategy. Towards this goal, a strategic document has been prepared for implementation of IDS in Member States. Country assessments and implementation of IDS have begun in Sri Lanka, Bangladesh, India, Indonesia and Maldives.
The IDS strategy integrates priority communicable disease surveillance activities at the district level with support for training, supervision and resources from all programmes, streamlined and delivered in an integrated way. It was developed by WHO as an approach to strengthen communicable disease surveillance.

In an integrated system the district level is the focus for integrating surveillance functions. This is because the district is the first level in the health system with full-time staff dedicated to all aspects of public health such as:

- monitoring health events in the community;
- mobilizing community action;
- encouraging national assistance;
- accessing regional resources to protect the health of the district.

Rather than using scarce resources to maintain separate activities, resources are combined to collect information to a single focal point at each level. All surveillance activities are coordinated and streamlined.

**IDS goals**

The IDS strategy aims to provide a basis for decision-making and implementing public health interventions for priority diseases. The strategy seeks to:

- strengthen the capacity of countries to conduct effective surveillance activities;
- integrate multiple surveillance systems so that forms, personnel and resources can be used more efficiently and effectively;
- improve the use of information for decision making;
- improve the flow of surveillance information between and within levels of the health system;
- improve laboratory capacity in identification of pathogens and monitoring of drug sensitivity;
- increase the involvement of clinicians in the surveillance system;
- emphasize community participation in detection and response to public health problems;
- strengthen the involvement of laboratory personnel in epidemiologic surveillance.

**Priority diseases**

The priority communicable diseases that have been identified under the strategy are divided into three categories:

**Epidemic-prone Diseases:**
Cholera, acute diarrhoea, bacillary dysentery, meningococcal meningitis, plague, anthrax, malaria, Japanese encephalitis, dengue/DHF, viral hepatitis, viral haemorrhagic fever, enteric fever, measles, leptospirosis, visceral leishmaniasis, diphtheria and any other cluster of syndromes

**Diseases Targeted for Elimination/Eradication:**
Acute flaccid paralysis/polio, leprosy, neonatal tetanus, measles, lymphatic filariasis and yaws
Other Priority Communicable Diseases:
Tuberculosis, AIDS, and rabies

**Summary**
Surveillance is the ongoing collection of data relevant to public health, which can be analysed to guide prevention and treatment programmes. Sentinel surveillance involves the collection of more detailed data from a smaller sample of sites, while laboratory-based reporting occurs when case reports come from laboratories instead of health facilities. Prevalence is the proportion or number of persons in a certain population who have a particular disease, while incidence measures new infections during a specific time period.

**Exercises**

**Warm-up review**
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

**Small group discussion**
Get into small groups to discuss these questions.

1. Using the HIV or AIDS surveillance systems in your province or district, outline how surveillance data flow. Compared with Figure 4.1, are there elements missing in your system?
2. A case definition has a sensitivity of 80% and a specificity of 90%. Describe what these numbers mean in words.

**Apply what you have learned/case study**
Try this case study. We will discuss the answers in class.

A country in Asia has a surveillance system based on integrated disease surveillance.

- AIDS reporting has been done using the WHO AIDS case definitions (1985 Bangui AIDS case definition or 1994 Expanded AIDS case definition).
- WHO has sponsored a pilot project in the country to examine the sensitivity, specificity and positive predictive value of the Bangui case definition.
- The Bangui case definition results were compared against a complex, laboratory-based, ultra-sensitive WHO pilot case definition, which uses both HIV testing and CD4 cell determination to say whether a patient has AIDS or not.
- One hundred patients were evaluated using the Bangui case definition and the new ultra-sensitive case definition.
Examine the comparison data in the following table:

Table 4.2
Number of patients who meet WHO and Bangui AIDS case definitions, 2002

<table>
<thead>
<tr>
<th>Bangui case definition</th>
<th>New WHO case definition</th>
<th>Present</th>
<th>Absent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition met</td>
<td></td>
<td>65</td>
<td>4</td>
<td>69</td>
</tr>
<tr>
<td>Definition not met</td>
<td></td>
<td>6</td>
<td>25</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>71</td>
<td>29</td>
<td>100</td>
</tr>
</tbody>
</table>

a. If the new WHO case definition is defined as the "gold standard," what are the sensitivity and specificity of the Bangui case definition?

b. What is the positive predictive value of the Bangui case definition in patients similar to those in this study?

c. What proportion of the patients in this study actually have AIDS?

d. What did the 29 patients who did not meet the new WHO case definition have?
Overview

What this unit is about

The two core elements of HIV/AIDS surveillance include:

- AIDS case reporting;
- HIV seroprevalence surveys in selected clinic populations, such as antenatal clinic attendees and STI patients, and in selected high-risk populations such as injecting drug users and commercial sex workers.

These two elements provide basic information on the distribution of HIV, very basic data on trends in the epidemic and data that can be used to evaluate prevention programmes.

Warm-up Questions

1. True or false? HIV/AIDS surveillance can be used to identify groups or geographic areas for targeted interventions. Circle your answer.

   True    False

2. _______________ provides detailed, high-quality data about a more specific population by using a smaller, more reliable system.
   a. universal AIDS case reporting
   b. sentinel surveillance

3. True or false? Prevalence and incidence data can be directly compared.

   True    False

4. Name two sentinel populations that can be sampled for HIV sentinel surveillance activities.

5. _______________ is the rate at which new HIV infections occur in a population in a given period of time, while prevalence is a unitless proportion that measures the level of HIV infection in a population.

6. Which of the following is/are core elements of an HIV/AIDS surveillance system?

   a. AIDS case reporting
   b. HIV seroprevalence surveys in selected populations
   c. both a and b
   d. neither a nor b
Introduction

What you will learn

By the end of this unit you should be able to:

- discuss the purpose of HIV/AIDS surveillance;
- describe the core elements of an HIV/AIDS surveillance system;
- explain the difference between prevalence and incidence;
- discuss the two approaches to HIV/AIDS surveillance.

Purpose of HIV/AIDS surveillance

The uses of HIV surveillance data include:

- advocacy;
- mobilization of political commitment;
- educating the public;
- prevention and care programme planning and resource allocation;
- targeting and developing new prevention and care programmes;
- monitoring and evaluating existing prevention and care programmes;
- estimating and projecting new and total HIV infections, AIDS cases, AIDS deaths, HIV-positive pregnancies and births, and numbers of orphans;
- tracking the leading edge of the epidemic and monitoring trends over time;
- guiding scientific research.

HIV/AIDS Surveillance Systems

Core elements

The core elements of HIV/AIDS surveillance include:

- AIDS case reporting, which involves routine reporting of specific data elements for persons diagnosed with AIDS in all or selected health facilities in the country. The goal of AIDS case reporting is to monitor AIDS morbidity in the general population and identify needs for antiretroviral therapy in order to plan appropriate health system response. In some countries, HIV cases (i.e. whether the HIV-infected patient has AIDS or not) are also reported.
- In contrast, HIV serosurveillance seeks to estimate the prevalence of HIV infection in selected populations such as antenatal clinic (ANC) attendees, STI patients and blood donors by conducting seroprevalence surveys in these populations on an ongoing basis.

AIDS case surveillance and HIV serosurveillance are complementary. Each type of surveillance has advantages and disadvantages (Figure 5.1).
Table 5.1
Comparison of AIDS case surveillance and HIV serosurveillance

<table>
<thead>
<tr>
<th>HIV/AIDS Case Surveillance</th>
<th>HIV Serosurveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advantages</strong></td>
<td></td>
</tr>
<tr>
<td>• Measures clinical disease burden.</td>
<td></td>
</tr>
<tr>
<td>• Provides information on relative importance of HIV transmission categories.</td>
<td></td>
</tr>
<tr>
<td>• AIDS has a long latent period.</td>
<td></td>
</tr>
<tr>
<td>• Less specificity of case definition.</td>
<td></td>
</tr>
<tr>
<td>• Under-reporting may be severe.</td>
<td></td>
</tr>
<tr>
<td>• Does not accurately indicate levels of HIV infection in population groups.</td>
<td></td>
</tr>
</tbody>
</table>

| **Disadvantages** | |
| • Provides no information on morbidity. | |
| • Less information on relative importance of HIV transmission categories. | |

Discussing AIDS and HIV surveillance

When AIDS case reporting is comprehensive and thorough (currently it is not in the Region), it describes:

• clinical disease burden caused by the HIV epidemic;
• relative importance of various HIV transmission modes, such as injection drug use and heterosexual transmission.

Estimating the ratio of the number of AIDS cases to HIV cases helps analyse the trend of the epidemic. However, because of the long latent period from HIV infection to the development of AIDS:

• AIDS case surveillance alone may severely under-represent the magnitude of the epidemic, especially when the HIV epidemic is emerging in a location.
• AIDS cases may rise for a long time, even when prevention efforts have greatly reduced the rate of new HIV infections.

HIV serosurveillance more accurately describes current levels and trends in the HIV epidemic because the diagnosis of HIV infection can be made with high certainty.

Prevalence and incidence

It is essential to have a clear understanding of the difference between prevalence and incidence.

• **Incidence** is the rate at which new HIV infections occur in a population in a given period of time. Because it is a rate, its unit of measurement always has time in the denominator.
• **Prevalence** measures the level of HIV infection in a population. It is measured as a unitless proportion, such as the percentage infected or the number of infections per thousand persons tested. The prevalence rate is influenced by both the rate of
new infections (incidence) and the rate that infected people leave the population by death, cure or migration.

Because the units of measurement are different for prevalence and incidence, they cannot be directly compared. For example, it makes no sense to say that the prevalence is four times the incidence in a population. This would be the equivalent of saying that 80 kilometres is four times 20 kilometres per hour.

**Approaches to Surveillance**

**Two approaches**

There are two distinct approaches for organizing surveillance systems for AIDS, HIV and STIs - *universal case reporting* and *sentinel surveillance*. Both approaches are recommended under the IDS strategy. Table 5.2 below describes each system and its advantages.

<table>
<thead>
<tr>
<th>Description</th>
<th>Advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal case reporting</td>
<td>Provides data that can be generalized to the entire population of a nation.</td>
</tr>
<tr>
<td>Sentinel surveillance</td>
<td>Provides detailed, high-quality data about a more specific population by using a smaller, more reliable system</td>
</tr>
</tbody>
</table>

Because of the two types of data, countries in the Region should establish both systems to obtain the most comprehensive picture of the spread of HIV, AIDS and STIs.

**Summary**

The purpose of HIV/AIDS surveillance is to provide an accurate picture of the epidemic, which will then help to guide prevention and treatment programmes. It helps to identify population sub-groups that are at higher risk for infection. Also, more information is provided on the distribution of disease over time and space.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.
Small group discussion
Get into small groups to discuss these questions.

1. What is the approximate HIV prevalence in your district or province?
2. What type of HIV or AIDS surveillance is being conducted in your province or district?

Apply what you have learned/case study
Try this case study. We will discuss the answers in class.

In Panga province, the Ministry of Health has conducted a long-term cohort study of 1,000 residents who were originally uninfected with HIV in 1997 to measure the incidence and prevalence of HIV infection.

Examine the data in the table below:

<table>
<thead>
<tr>
<th>Table 5.3</th>
<th>HIV infections in Panga province Cohort Study, 1998-2002</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1998</td>
</tr>
<tr>
<td>New HIV infections</td>
<td>10</td>
</tr>
<tr>
<td>Total HIV infections</td>
<td>55</td>
</tr>
<tr>
<td>Population at risk (non-infected)</td>
<td>1000</td>
</tr>
<tr>
<td>Total population (infected and non-infected)</td>
<td>1000</td>
</tr>
</tbody>
</table>

a. What is the prevalence of HIV infection in 2002?

b. What is the incidence of HIV infection in 2002?

c. In which year was the incidence highest?
Notes
Overview

What this unit is about

Second-generation HIV surveillance systems are designed to collect and integrate data reported from a variety of other sources, such as behavioural surveillance, HIV/AIDS case reporting, death registration and STI surveillance. Additional data are added to sentinel and universal case reporting to provide a more complete picture of the HIV/AIDS epidemic. This unit discusses elements of the secondary-generation surveillance approach.

Warm-up questions

1. Which of the following is the goal of second-generation HIV surveillance?
   a. better understanding of behaviours driving the epidemic
   b. surveillance more focused on subpopulations at highest risk for infection
   c. surveillance of the children of patients who acquired HIV in the first wave of infections
   d. a and b
   e. none of the above

2. The types of elements included in second-generation surveillance vary according to the type of epidemic. List the three types of HIV/AIDS epidemics.

3. True or false? Second-generation surveillance is flexible and can change with the needs and state of the epidemic in a particular country.

   True  False

4. Which of the following is not yet a regular element of second-generation HIV surveillance?
   a. screening of donated blood
   b. behavioural surveillance
   c. surveillance for coexisting opportunistic infections
   d. AIDS surveillance

Introduction

What you will learn

By the end of this unit you should be able to:

• describe the concept of second-generation surveillance;
• discuss the various elements of a second-generation HIV surveillance system.

Second-Generation HIV Surveillance

Definition

For much of the early part of the epidemic, HIV surveillance consisted mainly of case reporting and, in some areas, unlinked anonymous serosurveys. Second generation HIV
surveillance builds upon existing systems, recognizing their limitations and improving the explanatory power of their results. In order to accomplish this, information from different behavioral and biological data sources are compared and interpreted together to provide a comprehensive picture of the epidemic. The approach can identify gaps in available information and guide and prioritize new surveillance activities. The mix of activities of second generation HIV surveillance will vary, depending on local epidemic conditions and needs. The following describes the basic principles and sources of data for second generation HIV surveillance systems:

The principles of second generation HIV surveillance are:

- Better understanding of trends over time;
- Better understanding of the behaviours driving the epidemic in the country;
- Surveillance more focused on sub-populations at highest risk of infection;
- Flexible surveillance that moves with the needs and state of the epidemic;
- Better use of data to increase understanding and to plan prevention and care.

Second generation HIV surveillance includes the collection and integration of data from multiple sources, including:

- Sentinel serosurveillance in defined sub-populations;
- Regular HIV screening of donated blood;
- Regular HIV screening of occupational cohorts or other sub-populations;
- HIV screening of specimens taken in general population surveys;
- HIV screening of specimens taken in special population surveys;
- Repeat cross-sectional surveys in the general population;
- Repeat cross-sectional surveys in defined sub-populations;
- HIV and AIDS case surveillance;
- HIV/AIDS morbidity and mortality;
- STI surveillance;
- TB surveillance;
- Qualitative;
- Programmatic data, such as VCT, ART, PMTCT;
**Figure 6.1**

The components of second-generation surveillance*

![Diagram showing the components of second-generation surveillance](image)

*Monitoring and Evaluation is ongoing

**Discussing the figure**

Examine Figure 6.1, then answer the questions below.

a. What process should be occurring throughout the surveillance process?

b. What components feed into data management?

**Major indicators**

The major indicators shown in Table 6.1 include biological indicators, behavioural indicators and sociodemographic indicators. These form a relatively standard set of data elements that allow for comparison across time and among geographic areas.
### Table 6.1

**Major indicators used in second-generation HIV surveillance**

<table>
<thead>
<tr>
<th>Biological indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>• HIV prevalence</td>
</tr>
<tr>
<td>• STI incidence and prevalence</td>
</tr>
<tr>
<td>• TB prevalence</td>
</tr>
<tr>
<td>• Number of adult AIDS cases</td>
</tr>
<tr>
<td>• Number of paediatric AIDS cases</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavioural indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Sex with a non-regular partner in last 12 months</td>
</tr>
<tr>
<td>• Condom use at last sex with a non-regular partner</td>
</tr>
<tr>
<td>• Age at first sex</td>
</tr>
<tr>
<td>• Use of unclean injecting equipment reported by drug injectors</td>
</tr>
<tr>
<td>• Reported number of clients in the last week by sex workers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sociodemographic indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age</td>
</tr>
<tr>
<td>• Sex</td>
</tr>
<tr>
<td>• Socioeconomic and educational status (may include occupation)</td>
</tr>
<tr>
<td>• Residency or migration status</td>
</tr>
<tr>
<td>• Parity (for antenatal sites)</td>
</tr>
<tr>
<td>• Marital status</td>
</tr>
</tbody>
</table>

### Data collection methods

Various data collection methods can be used for second-generation HIV surveillance. These include:

- expanded biological surveillance for HIV (primarily seroprevalence surveys in defined and general populations);
- serial behavioural surveys in defined and general population;
- other sources of information.

An overview of data collection methods is shown in Table 6.2.
Table 6.2
Data collection methods for second-generation HIV surveillance

<table>
<thead>
<tr>
<th>Basic components</th>
<th>Additional components</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Sentinel surveillance in defined subpopulations (such as antenatal clinic attendees, STI clinic patients, sex workers)</td>
<td>• Regular screening of occupational cohorts or other subpopulations (for example, factory workers, military recruits)</td>
</tr>
<tr>
<td>• Serial cross-sectional behavioural surveys in high-risk subpopulations</td>
<td>• HIV screening of specimens taken in general population surveys</td>
</tr>
<tr>
<td>• Regular HIV screening of donated blood</td>
<td>• HIV screening of specimens taken in special population surveys</td>
</tr>
<tr>
<td>• AIDS case surveillance</td>
<td>• Serial cross-sectional behavioural surveys in general populations</td>
</tr>
<tr>
<td></td>
<td>• Data from other programmes such as voluntary counselling and testing</td>
</tr>
<tr>
<td></td>
<td>• HIV case surveillance</td>
</tr>
<tr>
<td></td>
<td>• Death registration and mortality surveillance</td>
</tr>
<tr>
<td></td>
<td>• Sexually transmitted infection (STI) surveillance</td>
</tr>
<tr>
<td></td>
<td>• Tuberculosis (TB) surveillance</td>
</tr>
<tr>
<td></td>
<td>• Data from treatment programmes</td>
</tr>
</tbody>
</table>

Tables 6.1 and 6.2 show major indicators and data collection methods that are used in a basic second-generation HIV/AIDS surveillance round. Look at those tables and answer the questions below. Based on the tables above:

a. Would you expect health clinics to routinely test blood for HIV?
   True                  False

b. Military recruits are routinely tested.
   True                  False

c. Describe a behavioural surveillance event. How might you find out the indicators listed in Table 6.1?

How the data are used
Figure 6.2 below is an example of how data from HIV behavioural and biological surveillance systems can be used together. The figure shows the prevalence of HIV and other STIs and the percentage of police personnel reporting recent unprotected commercial sex in Cambodia. Lower risk translates directly into fewer STIs, and over time into lower HIV levels.
Looking at Figure 6.2, answer the following questions:

a. Describe the relationship between HIV prevalence and the percentage of police personnel reporting recent unprotected sex with sex workers.

b. In 1997, what was the prevalence of HIV among the police?

Low, Concentrated and Generalized Epidemics

Epidemic classification

To choose the most appropriate surveillance systems, UNAIDS and WHO suggest a classification that describes the HIV epidemic by its current state: low, concentrated, or generalized. Epidemics may shift from one state to another over time but such a shift is not inevitable. Although the issues for planning HIV surveillance are similar for each state of the epidemic, the actual surveillance needs will differ.

For each epidemic classification, the pages that follow:

- describe the characteristics and give examples;
- provide a surveillance approach in table form.

Low-level epidemic

- Although HIV infection may have existed for many years, it has never spread to significant levels in any subpopulation.
- Recorded infection is largely confined to individuals with higher risk behaviour, such as sex workers, drug injectors, and men having sex with other men.
• This epidemic state suggests that networks of risk are rather diffuse (with low levels of partner exchange or sharing of drug injecting equipment) or that the virus has been introduced only very recently.
• HIV prevalence has not consistently exceeded 5% in any defined subpopulation.

Examples of low-level epidemics in the South-East Asia Region include Sri Lanka, Maldives, DPR Korea, Timor Leste, Bangladesh, and Bhutan.

Table 6.3
Surveillance approaches to low-level epidemics

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Basic second-generation HIV surveillance activities</th>
<th>Additional second-generation HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there groups with risk behaviour?</td>
<td>• Formative research and mapping of groups with potential risk behaviour</td>
<td>• Mapping to cover a larger geographical area, and to be conducted more frequently</td>
</tr>
<tr>
<td></td>
<td>• Analysis of available STI surveillance data</td>
<td>• Estimate size of groups with potential risk behaviour</td>
</tr>
<tr>
<td>What are the main risk behaviours?</td>
<td>• Risk behaviour surveys in groups considered at high risk for HIV infection</td>
<td>• Increased geographical coverage of risk behaviour surveys</td>
</tr>
<tr>
<td></td>
<td>• HIV serosurveillance in identified groups with risk behaviour</td>
<td>• STI prevalence and incidence studies in groups with risk behaviour</td>
</tr>
<tr>
<td>How much HIV infection is there?</td>
<td>• Analysis of available blood donor screening data</td>
<td>• Larger coverage and increased frequency of HIV sero-surveillance in identified groups with risk behaviour</td>
</tr>
<tr>
<td></td>
<td>• AIDS case reporting</td>
<td>• HIV sentinel serosurveillance in pregnant women in urban areas</td>
</tr>
<tr>
<td>Who else might be affected and to what extent?</td>
<td>• HIV case reporting</td>
<td>• Risk behaviour surveys focused on potential bridging populations</td>
</tr>
</tbody>
</table>

Concentrated epidemic
• HIV has spread rapidly in a defined subpopulation, but is not well established in the general population.
• This epidemic state suggests active networks of risk within the subpopulation.
• HIV prevalence consistently over 5% in at least one defined subpopulation. HIV prevalence is below 1% in pregnant women in urban areas.

Examples of concentrated epidemics in the South-East Asia Region include three states in India (Gujarat, Pondicherry and Goa), Indonesia, and Nepal.
Table 6.4
Surveillance approaches to concentrated epidemics.

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Basic second-generation HIV surveillance activities</th>
<th>Additional second-generation HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much HIV infection is there?</td>
<td>• HIV serosurveillance in groups with risk behaviour</td>
<td>• Wider geographical coverage and increased frequency of HIV serosurveillance in identified groups with risk behaviour</td>
</tr>
<tr>
<td></td>
<td>• Annual sentinel serosurveillance in pregnant women in urban/high exposure areas</td>
<td>• HIV surveillance in bridging populations (such as clients of sex workers) and pregnant women</td>
</tr>
<tr>
<td></td>
<td>• Analysis of available blood donor screening data</td>
<td>• Wider geographical coverage and increased frequency of repeated behavioural surveys in groups with risk behaviour and bridging populations</td>
</tr>
<tr>
<td>What are the main risk behaviours and how do they change over time?</td>
<td>• Repeated risk behaviour surveys in groups with risk behaviour</td>
<td>• Surveys of health-seeking behaviour for STI</td>
</tr>
<tr>
<td></td>
<td>• Repeated risk behaviour surveys in bridging populations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Analysis of STI data in groups with risk behaviour and bridging populations</td>
<td></td>
</tr>
<tr>
<td>Who else might be affected and to what extent?</td>
<td>• Repeated risk behaviour surveys in the general population in urban/high exposure areas</td>
<td>• Repeated risk behaviour surveys in the general population in all areas</td>
</tr>
<tr>
<td></td>
<td>• AIDS case reporting</td>
<td>• HIV case reporting</td>
</tr>
</tbody>
</table>

**Generalized epidemic**

- HIV is firmly established in the general population.
- Although subpopulations at high risk may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of subpopulations at higher risk for infection.
- HIV prevalence is consistently over 1% in pregnant women.

Thailand, Myanmar and six states in India (Andhra Pradesh, Karnataka, Tamil Nadu, Maharashtra, Manipur and Nagaland) are examples of areas in the South-East Asia region with a generalized epidemic.
<table>
<thead>
<tr>
<th>Main questions</th>
<th>Core HIV surveillance activities</th>
<th>Expanded (second-generation) HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the trends in HIV infection?</td>
<td>• Annual sentinel serosurveillance in pregnant women in urban and rural areas</td>
<td>• HIV sentinel serosurveillance in pregnant women in a larger number of sentinel sites</td>
</tr>
<tr>
<td></td>
<td>• Increase sample size in high volume sites to enable analysis by age groups</td>
<td>• HIV serosurveillance in groups considered at high risk</td>
</tr>
<tr>
<td></td>
<td>• AIDS case reporting</td>
<td>• Population-based prevalence studies to validate surveillance data</td>
</tr>
<tr>
<td>Is behaviour changing?</td>
<td>• Repeated behavioural surveys in groups considered at high risk for HIV infection</td>
<td>• Larger coverage of behavioural surveys by expanding populations and age groups</td>
</tr>
<tr>
<td>Do recorded changes help explain trends in HIV infection?</td>
<td>• Analysis of STI surveillance data in groups considered at high risk for HIV infection</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Repeated risk behaviour surveys in the general population with a focus on young people</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Analysis of STI surveillance data in the general population</td>
<td></td>
</tr>
<tr>
<td>What is the impact of HIV?</td>
<td>• Vital registration data</td>
<td>• Other death data (census and studies)</td>
</tr>
<tr>
<td></td>
<td>• Surveillance of TB and other HIV/AIDS-related illnesses</td>
<td>• Studies of access to care</td>
</tr>
</tbody>
</table>
Figure 6.3 depicts HIV prevalence among ANC attendees at sentinel sites across India.

**Future surveillance systems**

With the widespread use of antiretroviral therapy, additional surveillance systems will be developed to assist in:

- the management of diagnostic programmes, such as voluntary counselling and testing;
- treatment programmes, including:
  - prevention of mother-to-child transmission (PMTCT) programmes
  - clinical monitoring of antiretroviral use and associated laboratory tests;
  - adherence monitoring;
  - antiretroviral resistance monitoring (Resistance is the ability of a pathogen such as HIV to overcome the inhibitory effect of a drug).

Surveillance for opportunistic infections, especially TB, will become more important as access to care improves. These changes will take place in the future.
Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups to discuss these questions.

1. What is the stage of the epidemic in your country, province/state or district (low, concentrated, generalized)? What data do you base your assessment on?
2. What second-generation HIV surveillance activities have been implemented in your province or district? How has the information generated from these activities been integrated and used in your AIDS control programme? Suggest some second-generation HIV surveillance activities that could be incorporated into your current system.

Apply what you have learned/case study
Try this case study individually.

A country in Asia has a generalized HIV epidemic but has yet to move beyond AIDS case surveillance, research projects and an occasional HIV prevalence survey.

There is limited funding from the World Bank to expand surveillance activities in Panga province, where HIV incidence and STI rates are reported to be high.

a. How would you suggest investing these funds?
b. What is your goal, and what benefits do you expect from an investment in surveillance?
Overview

What this unit is about

Persons with HIV/AIDS and persons and groups at increased risk for HIV/AIDS are vulnerable to a number of social, legal and physical harms. Because of this, surveillance and special studies need to address a unique set of ethical issues. This unit discusses those issues, and facilitates a more uniform approach to common ethical issues relating to HIV/AIDS surveillance.

Warm-up questions

1. True or false? Because of the urgent need to treat and prevent HIV/AIDS, issues such as confidentiality and informed consent do not need to be addressed.
   
   True    False

2. The principle of beneficence refers to minimizing risk to individuals in the areas of:
   
   a. physical risk
   b. psychological harm
   c. stigmatization
   d. all of the above

3. True or false? Providing large monetary or in-kind incentives is an ethical way to ensure that more participants agree to give informed consent. Circle your answer below.

   True    False

4. True or false? In low-level epidemics, information about HIV infection in high-risk or marginalized groups should be widely publicized to prevent further spread of the disease.

   True    False

5. The process by which potential threats to confidentiality are discussed with subjects before they decide to participate is known as ____________________.

6. List three potential risks to participants in a behavioural surveillance study.

   a.

   b.

   c.
7. True or false? Surveillance is an academic exercise. Investigators should not become involved as advocates in the communities in which they work.

   True   False

8. List two types of programmes or services that can be developed as a result of surveillance activities.

   a. 
   b. 

9. If _____________ about HIV infection is violated, subjects may suffer discrimination and stigmatization. They may even be subject to criminal charges.

   a. privacy  
   b. informed consent  
   c. confidentiality  
   d. beneficence

10. True or false? In unlinked anonymous testing, informed consent is not obtained. Some information identifying the sample with the patient remains.

    True   False

Introduction

What you will learn

By the end of this unit you should be able to:

- discuss the ethical principles of respect for persons, beneficence, and justice in the context of HIV surveillance of high-risk populations;
- use correctly the terms related to ethical treatment of study participants;
- identify potential harms caused by HIV and behavioural surveillance;
- identify potential benefits resulting from HIV and behavioural surveillance;
- describe issues of confidentiality and how they relate to HIV surveillance;
- explain issues of informed consent and institutional review boards and how they relate to HIV surveillance among high-risk populations.

Addressing Ethical Issues

What are the issues?

People and groups with increased risk for HIV/AIDS are vulnerable to a number of social, legal and physical harms. Because of this vulnerability and the stigma (mark of disgrace or shame) attached to the disease, surveillance and special studies need to address a unique set of ethical issues. These include:
• elevated risk of harm for people in high-risk populations, especially if their behaviour is illegal or stigma surrounds the behaviour;
• stigma;
• confidentiality (protecting personal information of a study participant);
• informed consent (the permission granted by a participant after she has been informed about the details of the study);
• access to prevention and care services.

Three ethical principles
Ethical issues do not always have clear right or wrong answers, but three universally accepted ethical principles exist:

1. ‘Respect for persons’ requires public health officers and biomedical research investigators to see study subjects as persons whose rights and welfare must be protected, and not just as passive sources of data.
2. ‘Beneficence’ refers to balancing the benefits and risks to individuals. This includes not only physical risk but also risk of psychological harm and stigmatization.
3. ‘Justice’ means that risks and benefits from studies should be distributed fairly and evenly in populations.

These ethical principles should be applied within the context of public health surveillance for HIV/AIDS.

Surveillance study ethics terms
When you plan a surveillance round, there are ethical considerations and issues to consider. Some of those issues have been listed above. The terms below are used throughout this unit to describe how to protect individuals from harm while ensuring that the study results are accurate.

Participation bias - This is the error due to differences in characteristics between those who participate in a survey and those who do not.

Informed consent - It is based on the principle that competent persons are entitled to make decisions on whether or not they want to participate in studies or surveillance events. Informed consent protects the person’s freedom of choice and respects his/her autonomy with regard to decisions affecting his/her body and health.

Unlinked anonymous testing - In this type of testing, a sample of blood is tested for HIV after all information that could identify the source of the blood is eliminated from the sample.

• Unlinked anonymous testing without consent is ethically acceptable if:
  • the blood is routinely collected for a reason other than HIV testing;
  • all information that could potential link the source of the blood to an individual has been removed before the blood is tested for HIV;
  • no other non-routine interventions are carried out.
• Unlinked anonymous testing with informed consent is used if:
  • the testing is solely for surveillance purposes;
all information that could potential link the source of the blood to an individual must still be removed before the blood is tested for HIV.

Linked anonymous testing - In this type of testing, the HIV result is linked to a patient’s other clinical data such as STIs. Similar to unlinked anonymous testing, in linked anonymous testing, the HIV test results of individuals should not be able to be identified, either directly or indirectly. Patients should provide informed consent for linked anonymous testing.

Ethical considerations
In many regions and countries, especially those with low-level and concentrated epidemics, the central surveillance activity is reporting cases of HIV/AIDS. Nations may consider implementing or modifying their surveillance HIV/AIDS reporting systems. To do so, they must decide whether or not such systems should employ names, unique identifiers or anonymous codes. The UNAIDS guidelines for public health and HIV surveillance asks you to consider the following questions:

- Who will be required to report? What clinical information and personal identifiers will they report? To whom will they report?
- How will the proposed system contribute to a more accurate characterization of the HIV/AIDS epidemic?
- What is known about the completeness of reporting for other notifiable conditions, including those that bear some stigma? How can such experience be used to anticipate the willingness to cooperate on part of those who will be required to report?
- Given the limits of all reporting systems (such as error rates and failures to report), how will data derived from the proposed reporting system be merged with those derived from other sources, such as blinded seroprevalence studies, to provide the most accurate epidemiological picture that is achievable given the available resources?

Balancing Risks and Benefits

Fear of stigmatization
Infected persons in the general population and high-risk groups have a legitimate fear of the reaction of the larger society based on past reactions. These groups may include:

- sex workers
- injection drug users
- prisoners
- mobile populations
- men who have sex with men

If people fear that information about their behaviour or their HIV status will be used against them, they will either try to confuse investigators or refuse to participate in monitoring studies. Successful surveillance in marginalized populations depends on minimizing participation bias by assuring:

- informed consent;
- absolute confidentiality;
- thoughtful plans about how data generated will be used and disseminated.
Low-level and concentrated epidemic considerations

One of the greatest challenges for surveillance in low-level and concentrated epidemics is gaining access to high-risk groups to track behaviour and infection. High-risk group members are very often marginalized. Sometimes their behaviour is illegal.

An effective surveillance system requires that populations with elevated incidence or prevalence of HIV be identified, then be accessible for:

- regular monitoring of behaviour
- risk markers
- HIV infection

In high-risk populations, many successful surveillance efforts centre on clinics and educational programmes designed to meet the needs of people most vulnerable to HIV and its impact.

These clinics provide services to the high-risk population. In doing so, they provide a sentinel site where serosurveillance can be conducted.

Where sentinel sites do not exist, community members may advise and participate in designing and carrying out cross-sectional biological and behavioural surveys. Such efforts have been invaluable to successful surveillance in the past.

In low-level epidemics, give careful consideration to whether or not to publicize information about marginalized groups’ HIV infection and related behaviour to a wider audience.

Experience has shown that in the early stages of the epidemic, the general public’s reaction to information about HIV infection in high-risk behaviour populations may be to call for restrictive and prohibitive measures. Such measures simply drive risk behaviour further underground, making prevention and care programmes more difficult, encouraging the spread of the virus. Table 7.1 describes some of the potential harms caused by HIV/AIDS surveillance.

Table 7.1
Potential harms caused by HIV/AIDS surveillance

<table>
<thead>
<tr>
<th>Type of Harm</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>• public attack  &lt;br&gt; • spousal/partner abuse  &lt;br&gt; • domestic violence</td>
</tr>
<tr>
<td>Legal</td>
<td>• arrest  &lt;br&gt; • prosecution, (especially with high-risk populations)</td>
</tr>
<tr>
<td>Social</td>
<td>• disclosure to family  &lt;br&gt; • workplace discrimination  &lt;br&gt; • loss of employment  &lt;br&gt; • isolation  &lt;br&gt; • loss of health-care services</td>
</tr>
</tbody>
</table>
**Generalized considerations**

In surveillance of generalized epidemics, there is less focus on highest-risk populations, such as sex workers. In countries where monitoring is done primarily through anonymous unlinked serosurveillance activities, risks to individuals are typically low.

Given the stigmatized nature of HIV infection in many countries, risk of social discrimination and violence are quite real. Case reporting or surveys and programmatic activities, such as voluntary counselling and testing, may diagnose individuals with HIV infection and give them their results.

Individuals may disclose these results themselves or be identified during programme activities. This may put them at risk for social harm and violence from spouses, sexual partners or others. Surveillance activities must protect data that individually identifies infected patients. Great care must be taken to protect such data from public release.

More subtle is the risk of labelling certain sub-groups within the general population, such as members of a particular ethnic group or sub-regions, who have increased rates of HIV/AIDS. This can lead to discrimination, stigmatization and other forms of harm. Take care to avoid inadvertently stigmatizing groups or sub-regions.

**Benefits**

Participating in surveillance holds benefits to society as a whole, especially to highly impacted populations and HIV-infected individuals. Surveillance is not an academic exercise. It is intended to be used as part of a comprehensive programme to prevent and treat HIV. Participating investigators often become advocates for additional prevention and treatment services for the communities they are surveying.

HIV surveillance has numerous potential benefits to a community, including:

- guiding HIV prevention and care programmes;
- guiding STI and other services, raising public awareness about and sympathy for burden of disease in the population;
- reducing stigma and effecting social change, especially around HIV infection;
- special situations for certain high-risk populations, such as STI clinics specifically for men who have sex with men or sex workers;
- HIV treatment services for prisoners.

**Confidentiality**

**Why it is important**

Confidentiality protects subjects from adverse consequences that may arise if their personal information is known, such as their:

- sexual preference
- HIV-positive status

If confidentiality about HIV infection is violated, subjects may suffer discrimination, stigma or arrest. Public health officers must maintain the confidentiality of individuals’ records to guard against inadvertent disclosure.
Laws and confidentiality

Much of HIV surveillance entails special studies. In some countries, laws may exist that protect individually identified research results from discovery during legal proceedings. This is done to encourage participation in high-risk behaviour research. Be aware of the particular provisions in your country’s laws that may:

- complicate participation by certain individuals, for example, the age of legal adulthood may affect results from female sex workers under a certain age;
- require reporting of individuals with HIV infection;
- minimize risk to participants, such as those that protect study results from discovery.

Discuss with participants directly the potential threats to confidentiality and measures that you will take to minimize them. This is part of the informed consent process.

Unlinked Anonymous Testing without Informed Consent

Definition and approach

Unlinked anonymous testing (UAT) without informed consent is conducted only in clinical settings. Earlier in this unit, UAT without informed consent was described. A specimen of blood originally collected for other purposes, such as syphilis testing at antenatal clinics, is used as follows:

- All information that could potentially link the source of the blood to an individual is removed from the specimen.
- The blood is tested for HIV.

Thus, the test result may not be traced back to the patient nor may he or she be informed of the test results.

Ethics and UAT

The ethical debate over UAT without informed consent has shifted over time. UAT is no longer conducted in the United States but continues to be the backbone of ANC HIV surveillance in most countries with generalized epidemics. UAT has been deemed ethical if:

- No interaction takes place with the survey participant solely for the purpose of the surveys;
- Information that may inadvertently identify a person is not kept.

Advantages and disadvantages

The advantages of UAT without consent are:

- Testing is anonymous so the privacy of the individual is maintained.
- The accuracy of HIV prevalence results is improved as participation bias is minimized.
The primary disadvantage is that tested individuals are not aware that they are being tested. They cannot obtain counselling and receive their test results. This disadvantage can be overcome by offering alternative voluntary counselling and testing at the sentinel site.

**Informed Consent**

**What information to provide**

Occasionally, surveillance activities require the formal informed consent of subjects. In these situations, investigators should disclose information that will be relevant to the subject’s decision on whether or not to participate. Such information should include:

- the nature of the surveillance system;
- the procedure the project will entail (such as interview, phlebotomy);
- potential risks and benefits;
- assurance that participation is voluntary and confidential.

Whenever informed consent is obtained, participation bias is an important issue and should be considered in the analysis. When HIV test results are to be given to individual subjects, confirmatory testing is required for positive specimens.

**Written consent forms**

Written consent forms are generally required to document that the process of informed consent has occurred.

- In some situations, such as populations with a low literacy rate, verbal consent documented by the investigator may be adequate.
- When individuals are not capable of giving informed consent, surrogate consent should be obtained. For example, a parent should give consent for a child or a guardian should give consent for an adult with severe mental illness.

Different countries have different laws and standards about when an adolescent can participate in research involving sexual behaviours, including biological testing, with his or her parents’ consent. Familiarize yourself with these laws in your country as part of your initial formative research efforts.

**Are participant gifts ethical?**

Providing incentives for study participants may raise ethical issues in some special HIV surveillance studies. Incentives for participation may consist of cash payments or small gifts, such as T-shirts. In general, incentives are appropriate for compensating study participants for time away from work and out-of-pocket expenses, such as transportation.

However, excessive payments create both ethical and methodological problems:

- Participants may choose to participate in a study merely for economic reasons. By providing excessive incentives, investigators create a situation in which an individual’s weighing of risks and benefits has been unduly influenced by money or gifts.
• By creating incentives for participation, the sample may not be fully representative. The sample may include individuals with higher rates of infection who have a greater need for money or health-care.

Respondent-driven sampling is a special case. In respondent-driven sampling, modest incentives are provided to participants to recruit additional members of the high-risk population to the study. This is part of the methodology and may require explanation.

Summary

When conducting HIV surveillance, be mindful of patient confidentiality. Persons with HIV/AIDS are often subject to physical, legal and social harms. Obtain informed consent and make use of institutional review boards. Also, try to take advantage of the potential benefits of surveillance, such as reducing stigma and guiding prevention and treatment programmes.

Exercises

Warm-up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion

Get into small groups to discuss these questions.

1. What are the current regulations for surveillance among minors in your region?
2. Do you know of cases where violence or other problems have occurred when an individual was identified as HIV positive? What happened in that case?
3. What high-risk groups have been identified in your district, region or country? What are some special considerations in dealing with high-risk populations?

Apply what you have learned/case study

Try this case study individually.

You are the health officer in charge of HIV/AIDS surveillance for Panga province in Country X. You have been asked to design and implement a special seroprevalence survey among male patients with acute urethritis attending the STI clinic at the provincial referral hospital.

You are weighing two choices:

• The first would entail a self-administered questionnaire and an additional blood test for HIV and syphilis.
• The second would entail a blinded survey of all patients who have blood drawn for syphilis serologies. Approximately 50% of patients who present with acute urethritis have serum samples drawn for syphilis; syphilis serologies are done at the clinician’s discretion, and there is no standard protocol for when to order these serologies.
a. For which option would you need informed patient consent?

b. How likely are the two options to yield an accurate estimate of the prevalence of HIV infection in this patient population?

c. In which option would patient confidentiality be better protected?

d. If you were to offer an incentive (e.g., reimbursement for transportation) to participants in Option 1, would this be considered ethical?
Overview

What this unit is about
Data derived from public health surveillance systems are analysed to show trends over time and distribution of cases by demographic and geographic variables. This unit discusses how to display data in charts and graphs.

Warm-up questions
1. List two demographic variables by which surveillance data can be analysed.

2. True or false? Compiling all the data into one comprehensive chart or graph is more effective than including many simpler diagrams.

   True    False

3. Which of the following cannot be extracted from public health surveillance data?

   a. changes over time
   b. changes by geographic distribution
   c. differences according to subject’s sex
   d. none of the above

4. Match the type of chart/graph with its example:

   1. scale line graph
      <answer>
      letter ______

   2. area map
      <answer>
      letter ______

   South and South-East Asia: US $670m (15.09%)
   East Asia, Pacific: US$80m (1.80%)
   Latin America, Caribbean: US$550m (12.39%)
   Eastern Europe, Central Asia: US$20m (0.45%)
   North Africa, Middle East: US$50m (1.13%)

   Sub-Saharan Africa: US$,070m (69.14%)

   Number of Children (thousands)
   Age of Children
Introduction

What you will learn

By the end of this unit you should be able to:

• list the variables for analysing surveillance data;
• identify the types of charts and graphs and when the use of each is appropriate.

Analysis focus

Data derived from public health surveillance systems are typically analysed to show trends over time and distribution of cases by demographic and geographic variables are available. The analyses focus on:

Person

• Who has developed the condition, for example, by age group or sex?
• Are these distributions changing over time?

Place

• Where are cases occurring?
• Is the geographical distribution of cases changing over time?

Time

• Is the number of reported cases changing over time?
Displaying Data

Purpose

The purpose of developing clearly understandable tables, charts and graphs is to facilitate:

- Analysis of data
- Interpretation of data
- Effective, rapid communication on complex issues and situations

Those who analyse surveillance data must be able to develop effective tables, charts and graphs that clearly present the important characteristics of complex epidemiologic and programmatic issues.

Types of variables

There are two general types of variables: categorical and continuous. They are described below, along with examples.

- **Categorical** variables refer to items that can be grouped into categories. These include marital status, occupation, level of education and district of residence. These variables can further be divided into *ordinal* variables and *nominal* variables.
  - Ordinal variables are those that have a natural order, such as level of education.
  - Nominal variables represent discrete categories without a natural order such as marital status or occupation. A special type of nominal variable is a *dichotomous* variable. A dichotomous variable has only two categories, such as yes/no or male/female.
- **Continuous** variables are items that occur in numerical order, such as height, weight and age.
  - If a continuous variable has fewer than ten values, it should be treated as an ordinal variable, such as parity or number of wives.
  - Continuous variables are sometimes divided into groups and treated as ordinal variables. Examples of these are age groups (less than one year, one to five years, five to nine years) and numbers of sexual partners in the last three months (less than five, five to 10, 10 to 50, greater than 50).

General rules for tables, charts and graphs

- Simpler is better. Complicated tables, charts and graphs are often not read or understood, especially by policymakers or others who are not subject matter experts.
- Tables, charts and graphs are often used together very effectively. For example, data tables often contain important points that can be illustrated using a graph.
- All tables, charts and graphs should have clear, descriptive titles and labels so the reader knows what data are being presented.
- Provide a descriptive narrative explanation of the highlights of the table, chart or graph to decrease the likelihood that the data will be misinterpreted. However, the major points should be understood without a verbal presentation.
• If the table, chart or graph will be reproduced, ensure that the data points or groups will be distinguishable following multiple reproductions of the original.
• Be careful about comparing variables with different scales of magnitude; using a double Y scale, log scale or interrupted scale can help.

Graphs

Types of graphs

A graph is a diagram that shows a series of one or more points, lines, line segments, curves or areas. The graph represents variations of a variable in comparison with that of one or more other variables.

A scale line graph represents frequency distributions over time where the Y-axis represents frequency and the X-axis represents time (Figure 8.1 below).

Figure 8.1
Trends in HIV prevalence among sex workers in country X, years 1 - 10

Rules

The y-axis (vertical axis) should be selected using the following criteria:

• Y-axis should be shorter than x-axis.
• Start the y-axis with 0.
• Determine the range of values needed.
• Select an interval size.

Charts

Bar charts

A bar chart uses bars to represent different classes. The Y-axis represents frequency, such as HIV prevalence or number of AIDS cases. The X-axis may represent time or different classes.
Figure 8.2
AIDS distribution among different age groups, Country X

Rules for bar charts
- Arrange categories that define the bars in a natural order if such an order exists, such as by age group or educational level.
- If natural order does not exist, define categories by name, such as country, sex or marital status.
- Position the bars either vertically or horizontally.
- Make bars the same width.
- Length of bars should be proportional to the frequency of event.

Clustered or stacked bar charts
Bars can be presented as clusters of sub-groups. These are referred to as clustered bar charts, or stacked bar charts, and are useful to compare values across categories. For example, you can present HIV prevalence levels by region, with sub-groups by year, as in Figure 8.3.

Figure 8.3
HIV prevalence level among IDUs at four clinic sites, City X, Country Y, years 1 - 3
**Rules for stacked bar charts**

Some rules for clustered or stacked bar charts include:

- Show no more than three sub-bars within a group of bars.
- Leave a space between adjacent groups of bars.
- Use different colours or patterns to show different sub-groups for the variables being shown.
- Include a legend that interprets the different colours and patterns.

**Histogram**

A **histogram** represents a frequency distribution using rectangles. In a histogram the frequency is represented on the Y-axis and the *ordinal* variables are displayed on the X-axis. The widths of the bars are proportional to the widths of the variable.

For instance, in Figure 8.4 below, the width of the variable bar for the 5- to 9-year-old age group, which represents a five-year interval, is five times as wide as the width of the bar for the 4-year-old age group, which is only a one-year interval.

**Figure 8.4**

**Children living with HIV, Country X, 2002**

---

**Pie chart**

A **pie chart** is a circular graphic representation that compares subclasses or categories to the whole class or category using different coloured or patterned segments (Figure 8.5).
Figure 8.5
Projected annual expenditure requirements for HIV/AIDS care and support by 2005, by region

<table>
<thead>
<tr>
<th>Region</th>
<th>Expenditure (in millions)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>South and South-East Asia</td>
<td>US $670m</td>
<td>15.09%</td>
</tr>
<tr>
<td>East Asia, Pacific</td>
<td>US $80m</td>
<td>1.80%</td>
</tr>
<tr>
<td>Latin America, Caribbean</td>
<td>US $550m</td>
<td>12.39%</td>
</tr>
<tr>
<td>Eastern Europe, Central Asia</td>
<td>US $20m</td>
<td>0.45%</td>
</tr>
<tr>
<td>North Africa, Middle East</td>
<td>US $50m</td>
<td>1.13%</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>US $3,070m (69.14%)</td>
<td></td>
</tr>
</tbody>
</table>

Total: US$4,440 million


Area map
An area map is used to plot variables by geographic location (Figure 8.6).

Figure 8.6
HIV prevalence in adults in South-East Asia, 2003

Tables

A table is a rectangular arrangement of data in which the data are positioned in rows and columns.

Rules for tables

- Each row and column should be labelled.
- Rows and columns with totals should be shown in the last row or in the right-hand column (Table 8.1).

Table 8.1

Adults and children living with HIV/AIDS by region in Country Y, end year X

<table>
<thead>
<tr>
<th>Region</th>
<th>Adults and adolescents ≥ 15 years</th>
<th>Children &lt;15 years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14 800</td>
<td>2</td>
<td>14 802</td>
</tr>
<tr>
<td>2</td>
<td>4 000</td>
<td>200</td>
<td>4 200</td>
</tr>
<tr>
<td>3</td>
<td>9 970</td>
<td>30</td>
<td>10 000</td>
</tr>
<tr>
<td>4</td>
<td>9 850</td>
<td>150</td>
<td>10 000</td>
</tr>
<tr>
<td>5</td>
<td>14 600</td>
<td>400</td>
<td>15 000</td>
</tr>
<tr>
<td>6</td>
<td>4 650</td>
<td>350</td>
<td>5 000</td>
</tr>
<tr>
<td>7</td>
<td>9 400</td>
<td>100</td>
<td>9 500</td>
</tr>
<tr>
<td>8</td>
<td>3 800</td>
<td>2 200</td>
<td>6 000</td>
</tr>
<tr>
<td>9</td>
<td>9 000</td>
<td>6 000</td>
<td>15 000</td>
</tr>
<tr>
<td>10</td>
<td>5 450</td>
<td>50</td>
<td>5 500</td>
</tr>
<tr>
<td>Total</td>
<td>85 520</td>
<td>9 482</td>
<td>95 002</td>
</tr>
</tbody>
</table>


Looking at Table 8.1, answer the following questions:

- How does the information given by the Total column differ from that given by the Total row?
- Describe how you would use the information in this table to create a pie chart with subdivisions based on region.

Summary

Surveillance data can be analysed by person, place or time. Depending on your data, you can choose from a variety of chart and graph formats, including pie charts, histograms, tables, etc. Using several simpler graphics is more effective than attempting to combine all of the information into one figure.
Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to. We will discuss the questions and answers in a few minutes.

Small group discussion
Get into small groups to discuss these questions.

1. What types of graphs and tables have you used to present your HIV prevalence data in the past?
2. Which types of graphics are most appropriate for presenting the analysis of your results?
3. Design a bar chart based on the data presented in Table 8.1.

Apply what you have learned/case study
Examine the data below to answer questions 1-3. Remember to give a title to every graph.

Table 8.2
HIV prevalence (%) by province among STD attendees, Country X, 2000-2003

<table>
<thead>
<tr>
<th>Province</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>5.0</td>
<td>2.4</td>
<td>7.2</td>
<td>14.4</td>
</tr>
<tr>
<td>B</td>
<td>4.2</td>
<td>2.0</td>
<td>2.3</td>
<td>2.8</td>
</tr>
<tr>
<td>C</td>
<td>6.5</td>
<td>10.4</td>
<td>9.4</td>
<td>5.5</td>
</tr>
<tr>
<td>D</td>
<td>7.6</td>
<td>6.3</td>
<td>7.6</td>
<td>5.8</td>
</tr>
<tr>
<td>E</td>
<td>7.1</td>
<td>6.5</td>
<td>5.6</td>
<td>3.2</td>
</tr>
</tbody>
</table>

1. Create a graph to show prevalence trends by year in province A.
2. Create a bar graph to show prevalence by province by year.
3. Using the data in the following table, create a pie chart showing the number of reported cases of syphilis from five STI clinics in five provinces in Country X in 2002.

Table 8.3
Reported cases of urethritis among males by province, Country X, 2002

<table>
<thead>
<tr>
<th>Province</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>242</td>
</tr>
<tr>
<td>B</td>
<td>298</td>
</tr>
<tr>
<td>C</td>
<td>567</td>
</tr>
<tr>
<td>D</td>
<td>678</td>
</tr>
<tr>
<td>E</td>
<td>198</td>
</tr>
</tbody>
</table>
Overview

What this unit is about
The periodic evaluation of surveillance systems for sexually transmitted infections (STIs), HIV or AIDS is needed to maintain:

- a responsive and relevant system of monitoring shifting disease trends;
- effective disease control and management interventions.

This unit discusses how to conduct an effective evaluation.

Warm-up questions

1. List three stakeholder groups that should be engaged, during the evaluation of the surveillance system.
   a. 
   b. 
   c. 

2. If there is a high probability that cases identified by the surveillance system are actually cases of HIV infection, the system is said to have high:
   a. sensitivity
   b. representativeness
   c. acceptability
   d. positive predictive value

Introduction

What you will learn
By the end of this unit you should be able to:

- list tasks for evaluating a surveillance system;
- develop a plan for evaluating your own country’s surveillance system.

Why evaluate?
Once you have set up an HIV/AIDS surveillance system, you want to make sure that it remains effective as the epidemic shifts over time. If your system is no longer effective, you will not have the right information to control HIV/AIDS.
Evaluating Surveillance Systems

Purpose of evaluation

System evaluation provides information to improve services and delivery. Specific objectives of ongoing surveillance system evaluations may include:

- appraising and prioritizing the disease events to be kept under surveillance;
- assessing how the system can detect and report these diseases;
- assessing the quality of the epidemiologic information produced;
- assessing how the system can respond to these diseases;
- assessing how surveillance results affect disease control and policy;
- identifying which elements of the system can be enhanced in order to improve the quality of information.

See Figure 9.1.

Figure 9.1
Elements of a well-focused evaluation

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Possible outcomes</th>
</tr>
</thead>
</table>
| Documents current state of the surveillance system: | • Additional funding  
| • Identify strengths and weak points. | • More/better training  
| • Recommend improvements. | • Improved surveillance for better disease control  
| • Define training requirements or gaps |                   
| • Justify resources. |                   |

Evaluation Process

Six evaluation tasks

The evaluation process is organized into a series of discrete tasks summarized and then described below. For more details, refer to the Updated Guidelines for Evaluating Public Health Surveillance Systems (Center for Disease Control and Prevention, 2001), available at http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm.

The six tasks for evaluating a surveillance system:

1. Engage the stakeholders in the evaluation. Stakeholders are those with an interest in the surveillance activities.
2. Describe the surveillance system to be evaluated.
3. Focus the evaluation design.
4. Gather credible evidence regarding the performance of the surveillance system.
5. Justify and state conclusions and make recommendations.
6. Ensure use of evaluation findings and share lessons learned.

Each of these tasks is described in the following pages.
Task 1: Engage stakeholders

Stakeholders include:

- Public health practitioners
- Health-care providers
- Data providers and users
- Representatives of affected communities
- Governments at the district, province and national levels
- Professional and private non-profit and donor organizations

Stakeholders may want to define the questions to be addressed by the surveillance system evaluation. They may also want to decide how to use the findings from the evaluation. Therefore, they should be involved in the planning stages of the evaluation.

Examples of ways to engage stakeholders include:

- Hold a community meeting to discuss plans for the evaluation.
- Hold one-on-one meetings with the key people listed above.
- Invite participants to join the evaluation team.

Task 2: Describe the system

- Describe the public health importance of the health-related event under surveillance. Include indices of frequency, indices of severity, disparities associated with the health-related event, costs, preventability and public interest.
- Describe the purpose and operation of the system. Include objectives, planned uses of data, case definition, where in the organization the system resides, and the level of integration with other systems. Draw a flowchart of the system and its components.
- Describe the resources used to operate the system, such as funding sources, personnel requirements, travel and supplies.

Task 3: Focus the design

To focus the evaluation design:

- Determine the specific purpose of the evaluation.
- Identify stakeholders who will receive findings.
- Consider what will be done with the information generated from the evaluation.
- Specify the questions that will be answered by the evaluation.
- Determine standards for assessing the performance of the system.

Task 4: Gather evidence

Gather credible evidence regarding the performance of the surveillance system. Describe the following system attributes:

- Simplicity - Is the surveillance system as simple and as easy to operate as possible?
- Flexibility - Has the system been able to adapt to new case definitions or operating conditions?
• Data quality - Are the data recorded in the surveillance system complete and valid (that is, have they been collected and verified such that they portray the actual epidemic more accurately)?
• Acceptability - Are people and organizations willing to participate in the surveillance system? Consider patients, health-care providers and clinics, and district and provincial health departments.
• Sensitivity - What proportion of cases does the surveillance system detect? Can the system detect outbreaks? Can it monitor changes in the number of cases over time?
• Positive predictive value - Does the system have a high positive predictive value? That is, is there a high probability that cases identified by the system are actually cases of HIV infection?
• Representativeness - Are the prevalence data generated representative of the actual occurrence of cases over time and the distribution in the population by place and person?
• Timeliness - Is the system able to provide data in a timely manner?
• Stability - Does the system collect, manage and provide data properly without failure? Is the system operational when needed?

Task 5: State conclusions
State and justify conclusions and make recommendations.

• Justify conclusions through appropriate analysis, synthesis, interpretation and judgment of the gathered evidence.
• Make recommendations for improvement as modifications to or continuations of the public health surveillance system.

Task 6: Share lessons learned
To share evaluation findings and lessons learned:

• Develop strategies for communicating the findings from the evaluation.
• Tailor recommendations to relevant audiences.
• Recommendations for improvements should be distributed to all partners and sites involved in sentinel surveillance.

Summary

You need to evaluate your HIV/AIDS surveillance system to make sure it remains effective as the epidemic changes over time. The evaluation process includes six tasks: engage stakeholders; describe the surveillance system; focus the evaluation design; gather evidence on the system’s performance; state conclusions and recommendations; and share lessons learned.
Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups to discuss these questions.

1. Has there been a formal evaluation of the HIV sentinel surveillance system in your district or province? If so, which parts of the surveillance system were evaluated?
2. What was the result of the evaluation? What problems were identified?
3. How were the results shared with district surveillance staff and clinics?
4. How was the surveillance system modified as a result of the evaluation?

Apply what you have learned/case study
Try this case study individually.

Panga province is in the coastal area of Country X and has the country’s major port city. A British university has been conducting studies of commercial sex workers in the port city for nearly a decade. For the last five years, they have been conducting serial seroprevalence surveys for HIV and syphilis.

You are the District Surveillance Officer for Panga province. You are asked by the Ministry to evaluate these special studies to determine if the Ministry should take over sponsorship of the studies and include them in the provincial sentinel surveillance system.

Now answer the questions below. Look back in the unit for more information if you wish.

a. How would you start your evaluation?

b. On what would you focus in your evaluation?

c. What criteria would you use to assess the performance of the system?

d. What would you recommend?
You are the HIV Surveillance Officer for the Northern Province. Northern Province is a large province in Serosia, a country with a concentrated HIV epidemic. The Northern Province has three large cities - Indam, the capital; Mandu, a border city; and Tampang, a port city.

HIV seroprevalence surveys are conducted annually in Northern Province in antenatal clinics. You examine data from the past five years and observe the following:

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of ANC attendees</td>
<td>6120</td>
<td>6790</td>
<td>6942</td>
<td>6671</td>
<td>6859</td>
</tr>
<tr>
<td>Median prevalence</td>
<td>2.5%</td>
<td>2.0%</td>
<td>2.0%</td>
<td>1.5%</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

1. What trends do you see?

STI clinic data for the past five years in the Northern Province show a declining trend:

Behavioral surveys have indicated that condom use among sex workers in the Northern Province has increased from 55% in 2001, to 70% in 2003 and 85% in 2005.

2a. How would you present the ANC data, the STI data, and condom use data together?

2b. How would you interpret these data?

Annual seroprevalence surveys have been conducted at five antenatal clinics in the province for the past five years. The survey is conducted between June and September each year. Evaluation of the seroprevalence surveys is one of your responsibilities. This entails assessing the data for quality and completeness. After the first two months of the current annual survey you examine the database and observe the following missing data:
3a. What are your thoughts regarding the data in this table? Is there anything of concern?

b. What are some possible explanations for this finding? How would you investigate these? What steps would you take to correct the problem(s)?

You conduct your investigation and find that the HIV serologic results are missing on the hard copies. You then visit the laboratory and meet the director. In your discussions, you discover that reagents for HIV testing were not available for a period of time. The laboratory director indicates that there is now an ample supply of HIV reagents and that the survey can be completed without any interruptions.

Having identified the problem, how do you address it in the short term and what are some steps you can take to ensure that such a problem does not recur?
• South and South-East Asia have the second highest burden of HIV/AIDS after sub-Saharan Africa.
• Overall, adult prevalence of HIV is relatively low in Asia. But the population size of many Asian countries is so large that even low prevalence means that a large number of people are living with HIV.
• The majority of the infections in SEA are concentrated among populations which engage in high-risk behaviours, such as commercial sex, injecting drug use and men having sex with men.
• Two major types of HIV have been recognized: HIV-1 and HIV-2. HIV-1 is the predominant type worldwide.
• The predominant route of HIV transmission in South-East Asia is through heterosexual intercourse.
• Key risk factors for sexual transmission include:
  • number of sexual partners and high rate of partner change
  • type of sexual contact
  • non-use of condoms
  • untreated genital tract infections
• An effective surveillance system is necessary for prevention and control of HIV infection. Surveillance involves:
  • the collection of information on demographic and behavioural characteristics of affected populations;
  • infection trends.
• Second-generation HIV surveillance systems build upon existing surveillance systems and make the best use of data gathered from different sources.
• There are three epidemic states: low-level, concentrated, and generalized. Tailor surveillance activities to the type of epidemic.
• The ethical conduct of public health surveillance in general and of HIV in particular requires that public health officers and research and investigators should be acutely aware of potential harm to individuals and to populations. Make protection of individual data your highest priority.
• Evaluation of the surveillance system is important for ensuring that the surveillance system is effectively meeting the objectives of detecting changes and trends in STI, HIV or AIDS prevalence.
Appendix A: Answers to Warm-Up Questions and Case Studies

Answers are provided in italics for each unit’s warm-up questions and case study.

Answers to the questions within the unit are not included. Unit questions are designed to stimulate small group discussion among participants in the workshop or class.

Unit 1 Answers

Warm-up questions
1. True or false? By December 2005, nearly 39 million people were infected with HIV worldwide.  
   *True*

2. In Asia, the two main factors driving the epidemic are *commercial sex*, and *injecting drug use*.

3. List risk factors which contribute to the spread of HIV in South-East Asia
   *Risk factors which contribute to the spread of HIV in South-East Asia include the high prevalence of STIs, organized commercial sex, illicit drug trafficking, poverty, low literacy and taboos to discuss sex, migration, and the low status of women.*

Case study

Country X is a South-East Asian nation that had its earliest cases of AIDS recognized in 1984. Data below are based on estimates of HIV prevalence by province, and questions follow:

Table 1.3

<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Province</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Samad</td>
</tr>
<tr>
<td>Panga</td>
</tr>
<tr>
<td>Topinagar</td>
</tr>
<tr>
<td>Bijarta</td>
</tr>
<tr>
<td>Jawara</td>
</tr>
</tbody>
</table>

a. Which province had the highest prevalence in 2004?  
   *Pangalnvo province*

b. What are prominent infection trends?  
   *A steady decline in HIV prevalence was observed in all provinces except Inyo, where after an initial declining trend, there has been an increasing trend observed for the past two years.*
Unit 2 Answers

Warm-up questions

1. The chimney effect refers to population loss due to HIV that occurs predominantly in which part of the population?
   a. young children
   b. adolescents
   c. adults
   d. the elderly

2. True or False? For most of this decade, nearly half a million people will die because of AIDS every year in Asia. True

3. What is the impact of HIV/AIDS on children?
   Children more likely to be kept home, drop out of school, start working to support family, forgo necessities such as food and clothes, be sent away from home, or become head of household.

4. What is the economic impact of HIV/AIDS on individuals, families and nations?
   Drop in economic wealth by as much as 40%, decrease in household income, drain on health services.

5. What is the burden of HIV/AIDS in terms of DALYs and deaths in SEAR countries?
   In SEAR countries, up to 10.6 million DALYs are lost due to HIV/AIDS. HIV/AIDS is the seventh leading cause of death in SEAR countries.

6. List some of the effects stigma has on HIV prevention, care and support for individuals with HIV, and their families.
   Some of the effects of stigma include discrimination in the workplace and in healthcare settings, exclusion from social functions, denial of benefits, privileges and services. Stigma is a barrier to protective behaviours and testing and often results in the needs of marginalized populations being systematically ignored.

Case study

The five provinces in Country X have had different experiences with the HIV/AIDS epidemic. Examine the following data:

Table 2.1
Measures of HIV impact by province, Country X, 2002

<table>
<thead>
<tr>
<th>Province</th>
<th>Proportion of deaths in adults due to HIV (estimated)</th>
<th>Life expectancy at birth</th>
<th>Proportion of deaths among working adults due to HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samad</td>
<td>1.3</td>
<td>65.6</td>
<td>1.5</td>
</tr>
<tr>
<td>Panga</td>
<td>2.7</td>
<td>55.1</td>
<td>4.8</td>
</tr>
<tr>
<td>Bijart</td>
<td>1.7</td>
<td>67.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Topinagar</td>
<td>2.5</td>
<td>58.9</td>
<td>3.5</td>
</tr>
<tr>
<td>Jawara</td>
<td>1.5</td>
<td>55.9</td>
<td>2.1</td>
</tr>
</tbody>
</table>
a. In which province has the impact of HIV/AIDS been greatest?
   *The impact of HIV/AIDS has been the greatest in Panga province.*

b. Based on the prevalence data in the Unit 1 case study and the data above, which province would you expect to have the greatest impact of HIV/AIDS by the year 2012?
   *Panga*

**Unit 3 Answers**

**Warm-up questions**

1. Which body cells does HIV infect?
   a. respiratory cells
   b. skin cells
   c. red blood cells
   d. white blood cells

   HIV infects white blood cells, which are involved in protecting the body against infection as part of the immune system. These include lymphocytes and macrophages.

2. How many major strains of HIV exist?
   *Two; HIV-1 and HIV-2.*

3. Which of the following is NOT a method of HIV transmission?
   a. sexual intercourse
   b. *casual physical contact*
   c. blood exchange
   d. mother to foetus

   *HIV transmission is transmitted through body fluids, not through casual physical contact.*

4. What type of infectious agent is HIV?
   a. bacterium
   b. *virus*
   c. prion
   d. none of the above

   *HIV stands for human immunodeficiency virus.*

5. True or false? HIV infection and the onset of AIDS occur simultaneously. False. AIDS is characterized by clinical appearance of symptoms. It can occur years after the initial HIV infection.

6. Which region of the world has the greatest diversity of HIV subtypes, making the development of one unique treatment or vaccine difficult?
   *Sub-Saharan Africa has the greatest diversity of HIV subtypes.*

7. Which of the following is associated with increased risk of sexual transmission of HIV?
94  a. failure to use a male or female condom
  b. a greater number of sexual partners
  c. a higher viral load in an infected partner
  d. all of the above

Failure to use a condom allows the virus to pass more easily from an infected to an uninfected person. The more sexual partners an individual has, the more likely the risk of one of them being infected with HIV. A greater amount of virus in the bodily fluids increases the chances that the virus will be transmitted to the uninfected partner.

8. List the three main types of antiretroviral drugs used to treat HIV infection.
   The three main types of antiretroviral drugs are nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors and protease inhibitors.

9. True or false? The presence of existing sexually transmitted infections increases the risk of acquiring HIV during sexual intercourse.
   True. The inflammation and ulceration caused by existing STIs makes it easier for HIV to enter the body.

10. Which of the following ultimately fatal opportunistic infections commonly occurs in AIDS patients?
    a. herpes zoster
    b. fungal infections
    c. tuberculosis (TB)
    d. all of the above

    AIDS patients have weaker immune systems, making it easier for the patients to acquire these opportunistic infections.

11. True or false? A vaccine for the prevention of HIV infection is currently available.
    False. While vaccines are being researched and may be available many years in the future, currently there is no HIV vaccine.

12. True or false? Some STIs such as Chlamydia are biologically more easily acquired by young women, making them more susceptible to HIV infection.
    True. Because of their more fragile vaginal walls, young women are more likely to be infected.

Case study

Panga province in Country X has experienced rapid expansion of the HIV epidemic. Examine the data then answer the question below:
Table 3.3
Incidence of various STIs over time, Panga province, Country X.

<table>
<thead>
<tr>
<th>STI</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea*</td>
<td>2.0</td>
<td>5.4</td>
<td>10.5</td>
</tr>
<tr>
<td>Syphilis*</td>
<td>1.5</td>
<td>2.5</td>
<td>8</td>
</tr>
<tr>
<td>Reported cases of urethritis from STI clinic</td>
<td>2 987</td>
<td>3 452</td>
<td>6 784</td>
</tr>
<tr>
<td>HIV incidence (estimated)</td>
<td>0.5%</td>
<td>1.2%</td>
<td>1.6%</td>
</tr>
</tbody>
</table>

* Cases per 1,000 population 15-49 years old

a. Do you think that sexually transmitted infections (STIs) may be playing an important role in the spread of HIV infection? Why?

Yes, STIs are likely to be playing a major role in the spread of sexually transmitted HIV in this province. It is likely that STIs are important in HIV transmission because:

- rates of STIs are high and increasing
- prevalence of HIV is relatively low and incidence is rising.

b. Would an STI prevention programme be an important part of the province’s HIV control efforts?

Yes, an enhanced STI control programme may be critical to decreasing HIV incidence.

c. Given the HIV incidence in Panga province, what do you think will happen with tuberculosis rates in the next several years and why?

Tuberculosis (TB) rates will likely increase as the HIV epidemic spreads. TB is the most important opportunistic infection in South-East Asia. TB cases will involve both the appearance of active tuberculosis among persons already infected with TB and transmission of TB from HIV-infected persons to both those with and without HIV infection.
Unit 4 Answers

Warm-up questions

1. Which of the following terms indicates the number or proportion of persons in a population who have a disease at a given point in time?
   a. sensitivity
   b. prevalence
   c. negative predictive value
   d. none of the above
   Sensitivity and negative predictive value are terms used to describe a case definition, while prevalence is a measure of disease burden in a given population.

2. True or false? One-time cross-sectional surveys are valid methods of HIV/AIDS surveillance. False. Surveillance systems involve ongoing collection and analysis of data, not a one-time survey.

3. Match the following terms with their definitions:
   **Sentinel surveillance**
   surveillance system in which reports are obtained only from certain selected facilities and populations
   **Laboratory-based reporting**
   surveillance system in which the reports of cases come from clinical laboratories as opposed to healthcare practitioners or hospitals
   **Case definition**
   clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes

4. Which of the following terms indicates the number of persons who newly develop a disease within a specified time period?
   a. specificity
   b. positive predictive value
   c. incidence
   d. none of the above
   Specificity and positive predictive value are terms used to describe a case definition, while incidence is the rate at which disease burden is increasing in a particular population.

Case study

Country X has a surveillance system based on integrated disease surveillance.

- AIDS reporting has been done using the Bangui definition of AIDS, which is widely used in Africa. WHO has sponsored a pilot project in the country to examine the sensitivity, specificity and positive predictive value of the Bangui case definition.
- The Bangui case definition results were compared against a complex, laboratory-based, ultra-sensitive WHO pilot case definition, which uses both HIV testing and CD4 cell determination to say whether a patient has AIDS or not.
- One hundred patients were evaluated using the Bangui case definition and the new ultra-sensitive case definition.
Examine the comparison data in the following table.

<table>
<thead>
<tr>
<th></th>
<th>New WHO case definition</th>
<th>Bangui case definition</th>
<th>Present</th>
<th>Absent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition met</td>
<td></td>
<td></td>
<td>65</td>
<td>4</td>
<td>69</td>
</tr>
<tr>
<td>Definition not met</td>
<td></td>
<td></td>
<td>6</td>
<td>25</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>71</td>
<td>29</td>
<td>100</td>
</tr>
</tbody>
</table>

**c.** If the new WHO case definition is defined as the "gold standard," what are the sensitivity and specificity of the Bangui case definition?

\[
\text{Sensitivity} = \frac{65}{71} (92\%), \quad \text{specificity} = \frac{25}{29} (86\%)
\]

**b.** What is the positive predictive value of the Bangui case definition in patients similar to those in this study?

\[
\text{PPV} = \frac{65}{69} (94\%)
\]

**c.** What proportion of the patients in this study actually have AIDS?

*You cannot tell from these data. Case definitions are for epidemiologic, not clinical purposes. However, at least 71\% of patients (as defined by the new WHO case definition) have AIDS. The true proportion is likely to be higher.*

**d.** What did the 29 patients who did not meet the new WHO case definition have?

*You cannot say from these data. They may have had other diseases characterized by wasting (e.g. advanced tuberculosis or cancer) or they may have AIDS that was not detected by the case definition (e.g., earlier clinical stages of HIV infection).*

**Unit 5 Answers**

**Warm-up questions**

1. True or false? HIV/AIDS surveillance can be used to identify groups or geographic areas for targeted interventions. True. By providing an assessment of the distribution and prevalence of the disease, surveillance can help to identify the areas and populations that might benefit the most from interventions.

2. ______________ provides detailed, high-quality data about a more specific population by using a smaller, more reliable system.
   a. universal AIDS case reporting
   b. sentinel surveillance

*Unlike universal case reporting, sentinel surveillance allows for a more complete data set to be obtained from a smaller number of sites that are known to be more reliable at reporting cases.*
3. True or false? Prevalence and incidence data can be directly compared.

True
False

False. While prevalence measures the number or proportion of people in a given population with a particular disease or condition, incidence measures the rate at which new cases are occurring. While they cannot be compared, they help to provide a more complete picture of the epidemic. For example, while prevalence might be low at the beginning of an epidemic, incidence might be high because of a rapid rate of transmission.

4. Name two sentinel populations that can be sampled for HIV sentinel surveillance activities.

Potential sentinel populations include antenatal clinic attendees, STI patients, blood donors, etc.

5. Incidence is the rate at which new HIV infections occur in a population in a given period of time, while prevalence is a unitless proportion that measures the level of HIV infection in a population.

Incidence measures the rate of new infections, while prevalence measures the number or proportion of people in a population who are infected with HIV.

6. Which of the following are core elements of an HIV/AIDS surveillance system?
   a. AIDS case reporting
   b. HIV seroprevalence surveys in selected populations
   c. both a and b
   d. neither a nor b

Used together, these two elements of surveillance help to give a more complete picture of the epidemic. While HIV surveillance can describe the current levels and trends, AIDS case reporting gives a picture of clinical disease burden and important methods of HIV transmission.

Case study
In Inyo province, Country X’s Ministry of Health has conducted a long-term cohort study of 1 000 residents who were originally uninfected with HIV in 1997 to measure the incidence and prevalence of HIV infection.
Examine the data in the table below.

Table 5.3
HIV infections in Panga province Cohort Study, 1998-2002

<table>
<thead>
<tr>
<th></th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>New HIV infections</td>
<td>10</td>
<td>8</td>
<td>12</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td>Total HIV infections</td>
<td>55</td>
<td>53</td>
<td>22</td>
<td>35</td>
<td>50</td>
</tr>
<tr>
<td>Population at risk (non-infected)</td>
<td>1000</td>
<td>945</td>
<td>947</td>
<td>978</td>
<td>965</td>
</tr>
<tr>
<td>Total population (infected and non-infected)</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
</tr>
</tbody>
</table>

a. What is the prevalence of HIV infection in 2002?

\[
\frac{50}{1000} = 5\% 
\]

b. What is the incidence of HIV infection in 2002?

\[
\frac{16}{965} = 1.7\% \text{ or } 1.7 \text{ per 100 person-years} 
\]

c. In which year was the incidence the highest? 2002

Unit 6 Answers

Warm-up questions

1. Which of the following is the goal of second-generation HIV surveillance?
   a. better understanding of behaviours driving the epidemic
   b. surveillance more focused on subpopulations at highest risk for infection
   c. surveillance of the children of patients who acquired HIV in the first wave of infections
   d. a and b
   e. none of the above

   Second-generation surveillance is designed to collect and integrate data from a variety of sources including behavioural surveys, sentinel surveillance, STI surveillance, etc.

2. The types of elements included in second-generation surveillance vary according to the type of epidemic present. List the three possible stages of the epidemic. The three possible states of the epidemic are low-level, concentrated and generalized.

3. True or false? Second-generation surveillance is flexible and can change with the needs and state of the epidemic in a particular country. True. Second-generation surveillance has many components that can be selected for use in a country, depending on its particular circumstances.
4. Which of the following is not yet a regular element of second-generation HIV surveillance?
   a. screening of donated blood
   b. behaviour surveillance
   c. surveillance for coexisting opportunistic infections
   d. AIDS case surveillance

   As access to care improves, surveillance for opportunistic infections will become more important, but it is not yet a regular component of second-generation surveillance.

**Case study**

Country X has a generalized HIV epidemic but has yet to move beyond AIDS case surveillance, research projects and an occasional HIV prevalence survey.

There is limited funding from the World Bank to expand surveillance activities in Panga province (a district of Country X), where HIV incidence and STI rates are reported to be high.

a. How would you suggest investing these funds?

There is no exact answer. Given the limited nature of surveillance activities in Panga province, improving second-generation HIV surveillance in this province should be made a priority. Components of second-generation surveillance that could be implemented include HIV and STI serosurveillance in defined and general populations and behavioural surveillance to assess sexual and drug-injecting behaviours.

b. What is your goal, and what benefits do you expect from an investment in surveillance?

The goal of an improved second-generation surveillance programme is to provide sufficient data to guide the prevention and treatment programmes.

Since Panga province has a generalized epidemic, sentinel seroprevalence surveys should be instituted and conducted regularly. These data could then be used to estimate the spread of HIV in the province and to evaluate the impact of prevention programmes designed to limit transmission.

In addition, given the prominent role that STIs appear to play in the epidemiology of HIV in the province, improving surveillance of STIs may also be an important investment. STI surveillance is also good because STI incidence can serve as a surrogate to monitor HIV risk behaviours.

**Unit 7 Answers**

**Warm-up questions**

1. True or false? Because of the urgent need to treat and prevent HIV/AIDS, issues such as confidentiality and informed consent do not need to be addressed.
False. Because of the stigma associated with HIV and related behaviours, infected individuals are vulnerable to social, physical and legal harms. They need to have their privacy protected through measures such as confidentiality and informed consent.

2. The principle of beneficence refers to the minimization of risk to individuals in the areas of:
   a. physical risk
   b. psychological harm
   c. stigmatization
   d. all of the above

Beneficence refers to balancing the benefits and risks to individuals. This includes not only physical dangers, but psychological harm and stigmatization also.

3. True or false? Providing large monetary or in-kind incentives is a good way to ensure that more participants agree to give informed consent. False. With excessive incentives, individuals may decide to participate for purely economic reasons. This might create bias, since the sample might then include a larger number of people with high infection rates who are in greater need of money or health care.

4. True or false? In low-level epidemics, information about HIV infection in high-risk or marginalized groups should be widely publicized to prevent further spread of the disease. False. In the early stages of a low-level epidemic, the general public may react to information about HIV infection in high-risk groups by calling for restrictive and prohibitive measures, driving these groups further underground. Be careful when designing public awareness programmes during this stage.

5. The process by which potential threats to confidentiality are discussed with subjects before they decide to participate is known as informed consent. Giving subjects full information about the study and the potential risks and benefits helps them to make a more informed decision about whether to participate.

6. List three potential risks to participants in a behavioural surveillance study. Potential risks include disclosure leading to isolation, loss of employment, prosecution, etc.

7. True or false? Surveillance is an academic exercise, and investigators should not become involved as advocates in the communities in which they work. False. Investigators can become advocates for the communities they study, promoting additional treatment and prevention services.

8. List two types of programmes or services that can be developed as a result of surveillance activities. Potential services include STI clinics, voluntary testing and counselling centres, HIV prevention programmes, public awareness campaigns, etc.
9. If _______ about HIV infection is violated, subjects may suffer discrimination, stigma, or even be subject to criminal charges.
   a. privacy
   b. informed consent
   c. confidentiality
   d. beneficence

   *Confidentiality involves protecting the personal information of study participants, including their infection status. If this is violated, they may suffer physical, social or legal harms, because of stigma associated with HIV.*

10. True or false? In unlinked anonymous testing, informed consent is not obtained, although some information identifying the sample with the patient remains.
   *False. Informed consent does not need to be obtained because the survey is anonymous. That is, no personal identifying information of the patient remains on the sample.*

Case study

You are the health officer in charge of HIV/AIDS surveillance for Panga province in Country X. You have been asked to design and implement a special seroprevalence survey among male patients with acute urethritis attending the STI clinic at the provincial referral hospital.

You are weighing two choices:

- The first would entail a self-administered questionnaire and an additional blood test for HIV and syphilis.
- The second would entail a blinded survey of all patients who have blood drawn for syphilis serologies. Approximately 50% of patients who present with acute urethritis have serum samples drawn for syphilis; syphilis serologies are done at the clinician’s discretion, and there is no standard protocol for when to order these serologies.

a. For which option would you need informed patient consent?

   *You would need informed patient consent for Choice 1 because this involves procedures that would not be routinely conducted (interview and separate blood draw). If you wanted to administer a questionnaire to patients in Option 2 and link it to their HIV results, you would need an informed consent for this, as well.*

b. How likely are the two options to yield an accurate estimate of the prevalence of HIV infection in this patient population?

   *It would depend on the participation rate. If you could get most patients to participate in Option 1, that would be preferable. Because syphilis serologies, which are the basis for HIV testing in Option 2, are only drawn for 50% of the patients and are drawn at the discretion of the clinician, they are unlikely to represent a true random sample of the clinic population.*
c. In which option would patient confidentiality be better protected?

Option 2, because the patients’ names would not be linked to their HIV results. On the other hand, patients found to be HIV infected in Option 2 would not have the opportunity necessarily to seek care for HIV.

d. If you were to offer an incentive (e.g., reimbursement for transportation) to participants in Option 1, would this be considered ethical?

Incentives must be modest in order to be ethical. Reimbursing participants for out-of-pocket expenses for getting to the study site is a reasonable incentive. Buying them a cow or chickens is not.

Unit 8 Answers

Warm-up questions

1. List two demographic variables by which surveillance data can be analysed.
   Data can be analysed using variables such as age, sex, marital status, etc.

2. True or false? Compiling all the data into one comprehensive chart or graph is more effective than including many simpler diagrams.
   False. Do not include too much data in one graphic, since it makes it confusing and difficult to interpret. Creating multiple simple graphics is more effective.

3. Which of the following cannot be extracted from public health surveillance data:
   a. changes over time
   b. changes by geographic distribution
   c. differences according to subject’s sex
   d. none of the above

   If data is analysed properly, it can be used to examine all of the above issues.
4. Match the type of chart/graph with its example:

Scale line graph

% HIV Prevalence

Year 1 Year 2 Year 3 Year 4 Year 5 Year 6 Year 7 Year 8 Year 9 Year 10

Area map

Pie chart

Histogram

Number of Children (thousands)

<1 1 2 3 4 5 to 9 10 to 13

Age of Children
Case study
Examine the data below to answer questions 1-3.

Table 8.2
HIV prevalence (%) by province, among STI patients, Country X, 2000-2003

<table>
<thead>
<tr>
<th>Province</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>5.0</td>
<td>2.4</td>
<td>7.2</td>
<td>14.4</td>
</tr>
<tr>
<td>B</td>
<td>4.2</td>
<td>2.0</td>
<td>2.3</td>
<td>2.8</td>
</tr>
<tr>
<td>C</td>
<td>6.5</td>
<td>10.4</td>
<td>9.4</td>
<td>5.5</td>
</tr>
<tr>
<td>D</td>
<td>7.6</td>
<td>6.3</td>
<td>7.6</td>
<td>5.8</td>
</tr>
<tr>
<td>E</td>
<td>7.1</td>
<td>6.5</td>
<td>5.6</td>
<td>3.2</td>
</tr>
</tbody>
</table>

1. Create a graph to show prevalence trends by year in province A

2. Create a bar graph to show prevalence by province by year.

3. Using the data in Table 8.3, create a pie chart showing the number of reported cases of syphilis from five STI clinics in five provinces in Country X in 2002.
**Table 8.3**

**Reported cases of urethritis among males by province in Country X, 2002**

<table>
<thead>
<tr>
<th>Province</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>242</td>
</tr>
<tr>
<td>B</td>
<td>298</td>
</tr>
<tr>
<td>C</td>
<td>567</td>
</tr>
<tr>
<td>D</td>
<td>678</td>
</tr>
<tr>
<td>E</td>
<td>198</td>
</tr>
</tbody>
</table>

**Unit 9 Answers**

**Warm-up questions**

1. List three of the stakeholder groups that should be engaged during the evaluation of the surveillance system.

   *Potential stakeholder groups include public health practitioners, health-care providers, government officials, representatives of affected communities, non-profit and donor organizations, etc.*

2. If there is a high probability that cases identified by the surveillance system are actually cases of HIV infection, the system is said to have high:
   
   a. sensitivity
   b. representativeness
   c. acceptability
   d. positive predictive value

   *If a system has a high positive predictive value, then cases that are identified are more likely to be actual cases instead of false positives. This system is better than one that has a low positive predictive value.*

**Case study**

Panga province is in the coastal area of Country X and has the country’s major port city. An English university has been conducting studies of commercial sex workers in the port city for nearly a decade. For the last five years, they have been conducting serial seroprevalence surveys for HIV and syphilis.
You are the District Surveillance Officer for Panga province. You are asked by the Ministry to evaluate these special studies to determine if the Ministry should take over sponsorship of the studies and include them in the provincial sentinel surveillance system.

a. How would you start your evaluation?

_Get stakeholders involved by meeting:_
- representatives of the provincial health department
- community-based organizations working with HIV prevention among commercial sex workers
- representatives of the British university who have been conducting the surveys.

_You may want to invite one or two of them to become a part of the evaluation team. Before designing your evaluation, you would gather details about the surveys, that is, the particulars of data collection, the costs (personnel, other)._ 

b. What would you focus on in your evaluation?

…it would be important to understand the acceptance of the British university among the local population and how they are perceived in the community. Also, gather information about the process of data collection. Ask questions such as:
- Who collects the data?
- What type of training did they receive?
- Where do they get participants?
- Where are blood samples analysed?
- What is the quality of the lab results?
- If blood samples are sent to the UK for analysis, is there a long lag time between data collection and announcement of results?
- If the Ministry of Health were to take over the sponsorship of the studies, would the personnel need to be changed?
- Who would do the work?
- Is the expertise/capacity there? If not, how would it be built?
- What would the cost of this be?
- Where are the data analysed?
- What have the data been used for?

c. What criteria would you use to assess the performance of the system?

_The cost of the system would be an important factor to evaluate. The acceptability of the surveillance system would also be key:_

- Do individuals agree to complete the surveys?
- How representative are those that complete the surveys of the general population?
- Are others missing? How valid is the data that is collected?
- How would the data be used?
d. What would you recommend?

*It would depend on the results of the evaluation. If the British university is widely accepted in the community and is eager to assist the Ministry in a smooth and cost-effective transition it may be worth considering. But the data would need to be valid and of good predictive value to be a worthwhile investment.*

**Final Case Study**

You are the HIV Surveillance Officer for the Northern Province in the country of Serosia. Northern Province is a large province in Serosia, a country with a concentrated HIV epidemic. The Northern Province has three large cities - Indam, the capital; Mandu, a border city; and Tampang, a port city.

HIV seroprevalence surveys are conducted annually in the Northern Province in antenatal clinics. You examine data from the past five years and observe the following:

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of ANC attendees</td>
<td>6120</td>
<td>6790</td>
<td>6942</td>
<td>6671</td>
<td>6859</td>
</tr>
<tr>
<td>Median Prevalence</td>
<td>2.5%</td>
<td>2.0%</td>
<td>2.0%</td>
<td>1.5%</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

1. What trends do you see?
*The median ANC HIV prevalence has stabilized and there is an apparent decline over the last three years.*

STI clinic data for the past five years in the Northern Province shows the following trend:

Behavioral surveys have indicated that condom use among sex workers in the Northern Province is increased from 55% in 2001, to 70% in 2003, 70% and 85% in 2005.
2a. How would you present the ANC data, the STI data, and condom use data together?

2b. How would you interpret these data?

*These data show a decrease in median ANC HIV prevalence, a decrease in STI prevalence, and an increase in the percentage of condom use among CSWs. Taken together, these data seem to validate the decreasing trend in the HIV epidemic in Serosia.*

Annual seroprevalence surveys have been conducted at five antenatal clinics in the province for the past five years. The survey is conducted between June and September of each year. Evaluation of the seroprevalence surveys is one of your responsibilities. This entails assessing the data for quality and completeness. After the first two months of the current annual survey you examine the database and observe the following missing data:

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of subjects</th>
<th>Percent missing data:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Age</td>
</tr>
<tr>
<td>Site 1</td>
<td>158</td>
<td>6%</td>
</tr>
<tr>
<td>Site 2</td>
<td>165</td>
<td>5%</td>
</tr>
<tr>
<td>Site 3</td>
<td>208</td>
<td>2%</td>
</tr>
<tr>
<td>Site 4</td>
<td>287</td>
<td>4%</td>
</tr>
<tr>
<td>Site 5</td>
<td>189</td>
<td>5%</td>
</tr>
</tbody>
</table>

3a. What are your thoughts regarding the data in this table? Is there anything of concern?

20% of HIV serologic results are missing from site 4.

3b. What are some possible explanations for this finding? How would you investigate these? What steps would you take to correct the problem(s)?
There are many possible explanations, including:

- A problem with data entry. This could be investigated by examining the hard copies of the data.
- Laboratory error: testing was not done.
- Laboratory error: testing was done but not recorded.

You conduct your investigation and find that the HIV serologic results are missing on the hard copies. You then visit the laboratory and meet the director. In your discussions, you discover that reagents for HIV testing were not available for a period of time. The laboratory director indicates that there is now an ample supply of HIV reagents and that the survey can be completed without any interruptions.

Having identified the problem, how do you address it in the short term and what are some steps you can take to ensure that such a problem does not recur?

Additional training session might be needed. At a minimum, the seroprevalence coordinator should meet first with the laboratory director and then with laboratory staff to review the protocol.

- In addition, since one lapse in protocol was found, the coordinator should keep a close watch on the data from this site and should make frequent visits there to assess adherence to protocol, answer questions and stress the importance of seroprevalence surveys.
- Improving communication between the seroprevalence coordinator and the laboratory director regarding the adequacy of supplies should also be discussed.
Research or non-research classification

Public health surveillance and programme evaluation are usually not considered to be research and do not have the same requirements for informed consent as research with human subjects. There are, however, some areas where public health surveillance and programme evaluation overlap with research. In general, when knowledge acquired from surveillance activities can be applied generally or does not result in public health action, the activity is considered research. Specific criteria, suggested by the U.S. Center for Disease Control and Prevention (CDC), for classifying a study as not being research are listed below, and specific guidance is shown in Table E.1. Determining whether a surveillance system is research or not research is important because it determines whether research protections, such as institutional review board approval and informed consent are needed or not.

The CDC criteria for classifying a public health activity as non-research include:

- Intent of a study is to identify and control a health problem or improve a public health programme or service
- Intended benefits of the project are primarily or exclusively for the participants or the participants’ community.
- Data collected are needed to assess and/or improve the programme or service, the health of the participants or the participants’ community.
- Knowledge that is generated does not extend beyond the scope of the activity.
- Project activities are not experimental.

Surveillance systems may be either research or non-research.

- Surveillance systems are likely to be non-research when they involve the regular, ongoing collection and analysis of health-related data conducted to monitor the frequency of occurrence and distribution of disease or a health condition in the population.
- Data generated by these systems are used to manage public health programmes.
- These systems have in place the ability to invoke public health mechanisms to prevent or control disease or injury in response to an event.
- Thus, the primary intent of these surveillance systems is to prevent or control disease or injury in a defined population by producing information about the population from whom the data were collected.

Activities that would be classified as non-research include:

- AIDS case reporting systems;
- regular antenatal clinic (ANC) serosurveillance surveys;
- regular behavioural surveys;
- many surveys of high-risk populations that collect simple demographic, biological and behavioural data on an ongoing basis for the purposes of guiding HIV prevention and control efforts.
Surveillance systems are likely, however, to be classified as research when they involve the collection and analysis of health-related data conducted either to generate knowledge that is applicable to other populations and settings than the ones from which the data were collected or to contribute to new knowledge about the health condition.

The information gained from the data collection system may or may not be used to invoke public health mechanisms to prevent or control disease, but this is not a primary intent of the project.

Thus, the primary intent of these surveillance systems is to generate generalizable knowledge. Characteristics of surveillance systems that most likely fit into this category are:

- longitudinal data collection systems (for example, follow-up surveys and registries) that allow for hypothesis testing;
- the scope of the data is broad and includes more information than occurrence of a health-related problem;
- analytic analyses can be conducted;
- cases may be identified to be included in subsequent studies.

**Institutional review boards**

Being classified as research does not mean that ethical standards can be ignored in a study. If it has been determined that a study is a research project rather than surveillance, review and approval by a local or national ethics committee or institutional review board is necessary. Most donor agencies and countries have additional requirements regarding review and approval. External review by these committees provides the extra protection for study subjects and investigators and is helpful in anticipating problems and suggesting solutions.

In special circumstances, institutional review boards will include on their committee special advocates for the risk populations that will be participating in research. For example, when conducting surveillance or special studies among prisoners, a prisoner advocate should be included in the institutional review board and participate in all discussion regarding the study protocol. When this sort of review is needed, the study protocol should be submitted as soon as possible since the review may take several weeks.

**WHO ethical guidelines**

The World Health Organization has commissioned a set of ethical guidelines specifically directed at second-generation surveillance, available at www.who.int/hiv/pub/epidemiology/en/sgs_ethical.pdf. These guidelines provide an overview of literature in the field of medical ethics, the ethics of epidemiological research and the ethics of surveillance. Other issues addressed relate to:

- data collection in behavioural surveillance
- serosurveillance, with an emphasis on consent
- data use and dissemination with an emphasis on the obligation to disseminate data
- the right to access test results
The guidelines also take into account the ethical implications of the data collection by type of the epidemic: low level, concentrated and generalized.

Table B-1
**Guidance for classifying public health activities as research and to protect human subjects.**

<table>
<thead>
<tr>
<th></th>
<th>Research</th>
<th>Practice (non-research)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>“…systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.”</td>
<td>May use scientific methods to identify and control a health problem with benefits for the study participants or their communities.</td>
</tr>
<tr>
<td><strong>Primary Intent</strong></td>
<td>To generate new or generalizable knowledge (information that can be applied in other settings)</td>
<td>To benefit study participants or the communities from which they come</td>
</tr>
<tr>
<td><strong>Methodology</strong></td>
<td>• Scientific principles and methods used</td>
<td>• Scientific principles and methods may be used</td>
</tr>
<tr>
<td></td>
<td>• Hypothesis testing/generating</td>
<td>• Hypothesis testing/generating</td>
</tr>
<tr>
<td></td>
<td>• Knowledge is generalizable</td>
<td>• Knowledge may be generalizable</td>
</tr>
<tr>
<td><strong>Examples</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Surveillance</strong></td>
<td>• Scope of data is broad</td>
<td>Regular, ongoing collection and analyses to measure occurrence of health problem (disease registry)</td>
</tr>
<tr>
<td><strong>Projects</strong></td>
<td>• Analytical analyses</td>
<td>• Scope of data is health condition or disease, demographics, and known risk factors</td>
</tr>
<tr>
<td></td>
<td>• Hypothesis testing</td>
<td>• Invokes public health mechanisms to prevent or control disease or injury</td>
</tr>
<tr>
<td></td>
<td>• Subsequent studies using cases</td>
<td></td>
</tr>
<tr>
<td><strong>Emergency</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Response</strong></td>
<td>• Samples stored for future use</td>
<td>• Solves an immediate health problem</td>
</tr>
<tr>
<td></td>
<td>• Additional analyses performed beyond immediate problem</td>
<td>• No testing of methods or interventions</td>
</tr>
<tr>
<td></td>
<td>• Investigational drugs tested</td>
<td></td>
</tr>
<tr>
<td><strong>Programme</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
<td>• Test an intervention</td>
<td>• Assess success of established intervention</td>
</tr>
<tr>
<td></td>
<td>• Systematic comparison of standard and non-standard interventions</td>
<td>• Evaluation information used for feedback into program (management)</td>
</tr>
</tbody>
</table>

This training module presents an introduction to the HIV epidemic and gives an overview of public health surveillance measures to combat the infection. After completing this course, participants should:

- know the three HIV epidemic states and be able to characterize the HIV/AIDS epidemic in their country
- be familiar with the predominant routes of HIV transmission and the key risk factors of transmission
- be able to describe the components of an effective HIV surveillance system and the elements of second generation HIV surveillance
- understand the ethics involved in HIV surveillance and be aware of potential harm to individuals and to populations
- be able to develop a plan for evaluating their own country’s surveillance system.

This course is meant primarily for district-level surveillance officers. This module can also be used for self-study.
MODULE 2

HIV Clinical Staging and Case Reporting

World Health Organization
Regional Office for South-East Asia
2007
Module 2

HIV Clinical Staging and Case Reporting

Participant Manual

2007
Other HIV surveillance training modules of this series

*Module 1* - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual

*Module 3* - HIV serosurveillance: participant manual

*Module 4* - Surveillance for sexually transmitted infections: participant manual

*Module 5* - Surveillance of HIV risk behaviours: participant manual

*Module 6* - Surveillance of populations at high risk for HIV transmission

Facilitator training guide for HIV surveillance

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**China:** Ms Wang Lan, National Center for AIDS/STD Control and Prevention;

**Cambodia:** Dr Ly Penh Sun, Deputy Director, National Center for HIV/AIDS, Dermatology and STD;

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**Indonesia:** Ms Naning Nugrahini, Technical Officer for STI and Surveillance, Monitoring and Evaluation, Directorate of Direct Transmitted Disease Control; Dr Dicky Budiman, Sub-Directorate of AIDS & STI; Dr Dyah Erti Mustikawati, Head of Section for Evaluation and Reporting, Sub-Directorate of AIDS/STI;

**Maldives:** Mr Mohammed Rameez, Programme Coordinator, Department of Public Health;

**Myanmar:** Dr Min Thwe, National AIDS Programme Manager, Ministry of Health, Government of the Union of Myanmar; Dr Tun Myint, Divisional AIDS Officer, Mandalay AIDS/STD Prevention and Control Programme; Dr Htay Naing, Medical Officer, National AIDS Control Programme;

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**Thailand:** Ms Thanapan Fongsiri, AIDS Cluster, Bureau of AIDS, TB and STI, Department of Disease Control, Ministry of Public Health; Dr Tanarak Plipat, Medical Officer, Head
of HIV, TB and STD Surveillance Section, Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health; Mr Surasak Thanaisawanyangkoon, Health Technical Officer, Bureau of AIDS, TB and STIs, Ministry of Public Health; Mrs Mattana Herber, Health Technical Officer, Office of Disease Prevention and Control;

**Timor-Leste:** Mr Virgilio Soares, HIV/AIDS Officer, Ministry of Health;

**Vietnam:** Dr Phan Thi Thu Huong, Deputy Head of HIV/AIDS/STI Surveillance, Vietnam Administration of HIV/AIDS Control (VAAC).

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References and Further Reading Material*

APPENDIX B
Glossary and Acronyms*

APPENDIX C
Useful Links*

*Same Appendix A, B and C used for Modules 1, 2, 3 and 4.
Introduction

How to Study this Module

What you should know before the course
This module contains six units. The information provided is designed for both national-level and district-level surveillance officers. As a participant, you should have a basic medical understanding of HIV and public health surveillance before taking the course.

Module structure
The module is divided into seven units. The units are convenient blocks of material and should be studied in the order in which they are presented. In addition, there are several appendices at the end of the module. The last three appendices guide surveillance officers through the process of developing an action plan and operations manual for establishing and maintaining an HIV case-based surveillance system. Throughout the module, small group discussion questions are designed to assist in the development of the action plan and operations manual. The expected outcome from this module is an enhanced understanding of HIV case-based surveillance as well as a completed (or nearly complete) action plan and operations manual.

This module can also be used for self-study.

Because you already know quite a bit about HIV, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answer may just be a guess. Answer the questions as best you can.

You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions and you can check your work.

Appendices
More information is provided at the end of this module.

Appendix A, References and Further Reading Material*

Appendix B, Glossary and Acronyms*

Appendix C, Useful Links*

Appendix D, Answers to Warm-Up Questions and Case Studies

Appendix E, Action Plan for Implementing HIV Case Surveillance

Appendix F, Developing a Draft Operations Manual

Appendix G, Operational Manual Checklist

*Same Appendix A, B and C used for Modules 1, 2, 3 and 4.
Additions, Corrections, Suggestions

Do you have changes to this module? Is there additional information you’d like to see? Please write or email us. We’ll collect your letters and email then consider your comments in the next update to this module.

Address

HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House,
Indraprastha Estate
Mahatma Gandhi Marg
New Delhi 110 002, India
Email: hiv@searo.who.int
Fax: 91 11 23370197
Overview

What this unit is about
This unit provides an overview of the history, purpose and importance of reporting AIDS cases and the purpose and importance of HIV case reporting. It explains:

• the history of HIV and AIDS case surveillance and how changes in HIV treatment have affected surveillance recommendations and practices
• the natural history of HIV disease and the points in the course of the disease that are important to monitor for surveillance purposes
• the purpose of reporting HIV cases
• how other types of HIV programmes can provide data for surveillance purposes.

Warm-up questions
1. What are the key differences between HIV sero-surveillance and HIV case reporting?
2. True or false? HIV testing of women coming in for antenatal care is a component of HIV case reporting.
   True  False
3. Which of the following is NOT a purpose of advanced HIV infection (disease) case reporting?
   a. To determine the burden of disease attributable to advanced HIV disease in the region
   b. To assess trends in advanced HIV disease cases
   c. To provide information on the opportunistic infections associated with advanced HIV disease
   d. To measure HIV incidence.
4. List five surveillance target points in the natural history of HIV disease.
5. List three reasons for conducting HIV case reporting.

Introduction

What you will learn
By the end of this unit, you should be able to:

• describe the history of HIV and AIDS case surveillance and how changes in HIV treatments have affected surveillance recommendations and practices
• describe the stages in the natural history of HIV disease that can be useful in surveillance
• describe the primary purposes of conducting HIV case reporting
• describe the differences between HIV case reporting and HIV sero-surveillance
• list four types of HIV related programmes that can provide data for HIV surveillance.
Historical overview of HIV and AIDS case surveillance

Soon after the emergence of the AIDS epidemic in 1981, many industrialized countries moved toward reporting AIDS cases, either by name or anonymously. In the past, in developed countries, AIDS case reporting, combined with active case-finding, allowed AIDS notification and AIDS-specific mortality to be monitored. As the epidemic evolved (and given the limitation of AIDS case surveillance in assessing current transmission patterns), the focus of surveillance shifted from AIDS as an end-stage disease to HIV infection. This led to many developed countries making HIV infection reportable. Today, many of the developed countries are reporting HIV infection cases confidentially, either by name or by codes. It is generally agreed in developed countries that HIV cases should be reported, but there is still a debate regarding whether HIV cases should be reported confidentially by name or by code.

The situation is quite different in developing countries. Although AIDS case reporting was introduced in most countries in the 1980s and early 1990s (depending on the detection of the first case in the country), reporting of AIDS cases for surveillance has occurred primarily via systems that rely on passively receiving reports. This has generated incomplete and inaccurate data, because of under diagnosis, under notification and delay, hampering the utility of case reporting. The HIV case reporting system has not been introduced in most developing countries.

In South-East Asia, Thailand was the first country to introduce AIDS case reporting in 1984. In Thailand, the completeness of AIDS case reporting is estimated about 80%. Reported AIDS cases have, so far, provided useful information on trends in the incidence of the disease.

In all other South-East Asian countries, under-reporting of AIDS cases, exacerbated by a weak health infrastructure and lack of diagnostic capacity, has produced unreliable data of little use for monitoring trends or planning HIV prevention, care and treatment services. It has been difficult to estimate the level of under reporting except for some countries. Thus, most countries have relied on HIV sero-surveillance in selected populations at sentinel sites to monitor HIV trends. Additionally, the second generation surveillance system, which integrates AIDS case reporting, HIV sero-surveillance, STI surveillance and risk-behaviour surveillance, has facilitated the production of estimated numbers of people living with HIV, using epidemiological models.

Impact of ART on AIDS case reporting

The increased availability of timely and appropriate ART (Antiretroviral therapy) delivery may prevent or delay the development of AIDS as it was previously defined and reverse symptoms and CD4 count levels. The advances of ART mean, therefore, that public health surveillance of AIDS alone does not provide reliable information on the scale and magnitude of the HIV epidemic. Data on HIV infection cases are more useful for determining populations needing prevention and treatment services. Therefore, the scope of surveillance must move from AIDS case reporting to reporting a wider spectrum of HIV infection.

HIV case reporting refers to the methods used to capture individual-level information on persons with HIV infection. This means that each person with HIV infection is reported using a single case report form containing information that pertains only to that person.
This type of reporting occurs at the facility level and is forwarded to the local level as individual case reports. The local-level surveillance officers aggregate the data and forward that to the national surveillance programme.

In this module, we present updated methods for reporting of persons with HIV disease. Specifically, this module provides guidance for South-East Asian countries to replace the reporting of AIDS cases (clinical stage 4) with the reporting of advanced HIV infection (disease), reporting that corresponds with the new clinical stages 3 and 4. In addition, countries may also conduct HIV infection reporting. Because HIV infection reporting (all clinical stages) identifies information on HIV-infected persons at any stage of HIV disease, it also includes persons with advanced HIV disease (which includes persons with AIDS).

Terminology

This unit discusses the options and methods for case reporting. WHO refers to the reporting of all stages of HIV as ‘HIV infection reporting (all clinical stages)’ and to the reporting of advanced HIV (clinical stages 3 and 4 only) as ‘advanced HIV (infection or disease) reporting.’ Advanced HIV reporting includes AIDS.

The Relationship Between the Natural History of HIV and Surveillance

Natural history of HIV and target points for surveillance

HIV infection results in a chronic condition. Shortly after becoming infected, an individual may experience signs and symptoms of this initial infection (called primary HIV infection). These signs and symptoms may include fever, muscle aches and swollen glands. Often these symptoms go unnoticed by the infected person, and some people do not experience any symptoms or signs of primary HIV disease.

Following primary infection, most HIV-infected persons are without symptoms or have only mild symptoms for several years. Over time, the immune systems of infected persons weaken, resulting in the development of HIV-related illnesses. These illnesses become increasingly severe as the degree of immune weakness progresses. The clinical assessment and classification of clinical stages provides a standardized approach to describing the points in the course of the disease that correspond to increasing degrees of immune deficiency. Without specific treatment, HIV-infected persons deteriorate clinically over time. The median time of HIV progression to death, in absence of ART, has been estimated to be 11 years, although there is some evidence that serotype E may have faster progression. The end-stage of disease is called AIDS. AIDS is defined by the presence of a specific group of illnesses (called opportunistic illnesses) that are associated with late-stage HIV disease, but they are generally uncommon in persons whose immune systems are functioning normally.

- Prior to antiretroviral therapy (ART) (that is, drugs used to fight infection by retroviruses), the average time from HIV infection to onset of clinical AIDS in North American patients was 11 years and from AIDS to death was about 2.7 years.
- There is no significant difference between HIV infection and onset of AIDS in developing countries and developed countries.
The advent of effective ART has considerably reduced the time and rate of progression to AIDS and death from AIDS in areas where these drugs are available. It has also been associated with the development of fewer HIV opportunistic infections.

In order to fully understand the HIV epidemic, several key stages in the development of the disease should be counted. These are depicted in figure 1.1 and include:

- HIV incidence (that is, the number or rate of new HIV infections)
- HIV prevalence (that is, the number or rate of all persons living with HIV, regardless of how long they have been infected or whether or not they are aware of their infection)
- The incidence of advanced HIV disease
- The prevalence of advanced HIV disease
- Deaths from advanced HIV disease.

Figure 1.1
Target points for HIV surveillance within the natural history of HIV without treatment

<table>
<thead>
<tr>
<th>HIV seroconversion</th>
<th>Primary HIV infection</th>
<th>Asymptomatic HIV infection</th>
<th>Advanced HIV disease</th>
<th>Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence advanced HIV disease</td>
<td>Prevalence advanced HIV disease</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HIV prevalence (all clinical stages)

Measuring each of these points in the course of HIV disease provides for a complete HIV surveillance system and can be used for determining the need for prevention or medical interventions, and as measures of the success of such programmes. However, in resource-constrained settings, it is often difficult to include all of these target points in the surveillance system. In areas where not all of these points can be counted, efforts should be made to obtain information on as many points as possible. HIV case surveillance can provide information on some of these points.

Measurement of new HIV infections

In order to know the direction of the HIV epidemic, it is important to have information on the HIV incidence, or the number or rate of new HIV infections occurring. Effective HIV prevention programmes should result in a decrease in the number of new infections. Although only a few methods exist for measuring new HIV infections and these methods are far from perfect, there are some tests that can be done to estimate the number and rate of new HIV infections. There are several assays that have been developed to identify new HIV infections. However, some work for certain sub types only, while others have proven to overestimate results of HIV incidence.
Another, more widely used method of measuring the rate of new HIV infections has been to monitor the trends in HIV prevalence among the youngest group (15-19 or 15-24 years) of women attending antenatal clinics. This use of sentinel HIV sero-surveillance has been the most common way of estimating HIV incidence in developing countries. Though difficult to measure accurately, this method of estimating the number and rate of new HIV infections is valuable and is likely to become an increasingly important component of HIV surveillance. Moreover, HIV prevalence among 15-24 years old is an indicator for the Millennium Development Goals.

**Measurement of HIV prevalence**

HIV prevalence is the number of persons living with HIV infection. This includes persons with any stage of HIV disease (newly acquired infections, long-standing asymptomatic infections and late-stage disease, including AIDS). Prevalence includes HIV-infected persons who may not be aware of their infection. Prevalence does not include HIV-infected persons who have died. It is difficult to have a complete and accurate count of all persons infected with HIV. As a result, prevalence is often estimated. HIV prevalence estimates can be done using a variety of data sources, including HIV/AIDS case reports and results from surveys and special studies. In developing countries, sentinel sero-surveys of women attending antenatal clinics have been the most frequently used data for prevalence estimates.

**Measurement of advanced HIV disease**

Obtaining an accurate and complete count of persons with advanced HIV disease is important as a way to anticipate need for medical care and other support services, as well as to obtain a measure of the success of treatment of HIV infection at earlier stages of the disease. In countries where ART is now increasingly available, the number of persons with advanced HIV disease and mortality should decline, even in the face of ongoing HIV transmission. You can count the number of persons with advanced HIV disease through case reporting. Persons with advanced HIV disease are symptomatic and, if they seek care, can be reported from healthcare facilities.

**Measurement of HIV/AIDS mortality**

Deaths from advanced HIV disease/AIDS have dropped dramatically in countries where antiretroviral treatment has been widely used. Thus, tracking deaths from advanced HIV disease is an important measure of the success of treatment programmes. In addition, understanding the proportion of deaths from HIV and the age groups most severely affected are important measures to understand the magnitude of the problem. However, in order to accurately count and track trends in HIV-related deaths, countries must have well-functioning vital statistics registries. In developing countries, reporting of AIDS deaths is highly incomplete due to the stigma associated with the disease and very weak vital reporting systems. The use of alternative methods for mortality surveillance needs to be examined in countries where vital statistics registries are not in place or are incomplete.

**Purpose of HIV Case Surveillance**

Accurate, timely and complete information on HIV cases can be used to:

- determine the burden and impact of HIV on health services;
• provide information on the opportunistic infections associated with advanced HIV disease;
• determine the characteristics and risk factors (transmission categories) of persons with HIV infection;
• determine the burden of disease attributable to HIV in the region;
• know the distribution by age, sex and geographic location;
• assess trends in HIV incidence and prevalence, if reporting is nearly complete (>80%);
• use data from HIV surveillance for the purposes of:
  • advocacy
  • resource mobilization
  • programme planning
  • targeting
  • monitoring and evaluation.

Surveillance terminology

Surveillance is a broadly used term that refers to many types of activities employed in the systematic collection of information on the state of the HIV epidemic. As previously mentioned, South-East Asian countries have relied primarily on blinded HIV seroprevalence surveys and AIDS case reporting to measure the level and trends in HIV prevalence. Case reporting is used in tandem with HIV sero-prevalence surveys, as they provide different but complementary information. Listed below are descriptions of the surveillance terms used in this module.

Table 1.1

<table>
<thead>
<tr>
<th>Differences between HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIV sero-prevalence or HIV sero-surveillance</strong> (means the same thing)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>HIV infection reporting</strong> (all clinical stages)</td>
</tr>
<tr>
<td><strong>Advanced HIV infection (disease) reporting</strong></td>
</tr>
<tr>
<td><strong>AIDS case reporting</strong></td>
</tr>
</tbody>
</table>

Discussing the table

Looking at Table 1.1, answer the following questions:

a. How are HIV sero-surveys and HIV case reporting different?

b. Are serological survey methods used in HIV case reporting?
The need for replacing AIDS case reporting

ART has dramatically altered the natural history of HIV disease. ART delays progression from early HIV disease to the advanced stages of HIV, including AIDS, and reduces HIV-related mortality. In fact, one measure of the success of ART programmes is an increase in HIV prevalence and a decrease in AIDS incidence and HIV/AIDS-related deaths.

The current WHO recommendation is to provide ART to all persons with clinical stage 4, and to consider providing ART to persons with clinical stage 3. In addition, ART should be offered to persons with earlier stages of disease if CD4 counts are low (<200). These changes in treatment have important implications for HIV advance disease reporting. Providing ART to persons prior to the development of AIDS will result in fewer persons progressing to AIDS. Consequently, AIDS case reporting can no longer provide a stable way of monitoring the HIV epidemic. In addition, it is important to know how many people are currently in need of ART. Case reporting can provide this information. Because persons with clinical stages 3 and 4 may be offered ART, the WHO has changed its reporting recommendations to replace AIDS case reporting with either of the following:

- reporting of persons with advanced HIV infection (disease)
- reporting of persons with all clinical stages of HIV (this requires including information on the clinical stage of HIV at diagnosis).

As HIV testing in South-East Asian countries becomes more widespread, it provides the opportunity to monitor HIV infections that may occur prior to the development of AIDS. In other words, asymptomatic HIV-infected persons can also be counted. Expansion of AIDS case surveillance to include persons with HIV infection who have not yet developed late-stage HIV disease (advanced HIV disease/AIDS) may provide a more complete picture of the epidemic.

Incorporating Data Collected from HIV Programmes into Case Reporting

Programmes with information for reporting

Though HIV case reporting is a newly recommended surveillance practice, AIDS case reporting has been recommended for many years. In South-East Asia, AIDS case reporting has occurred primarily through passive reporting by healthcare providers. An additional method of collecting case reports is for surveillance officers and staff to work closely with programmes that provide care to persons with HIV infection. In this way, surveillance officers can assist more directly with the reporting process and improve the completeness of case reporting. Programmes that are likely to be good sources of HIV cases include:

- HIV care and antiretroviral treatment programmes
- tuberculosis (TB) programmes (especially those that conduct HIV testing among TB patients)
- programmes that provide ART to pregnant women (prevention of mother-to-child transmission [PMTCT] programmes)
- vital statistics registries (to identify persons who die with HIV disease).
How to use programme data for case surveillance

Data collected from programmes that provide service or care to persons with HIV infection can be used for surveillance purposes in two different ways:

• programme data can be analysed and used to supplement HIV case reporting data and data collected from HIV sentinel sero-surveillance
• programme data can be used to identify HIV-infected persons who should be reported to the surveillance programme.

You can only use programme data for HIV case reporting if:

• programmes collect and retain patient-level information
• methods are in place or developed to record cases that have been reported
• programme staff are trained on how to report cases and provided with case report forms
• surveillance officers provide guidance and technical assistance in completing case report forms.

In addition, case reporting is more likely to occur if surveillance officers:

• meet programme managers to discuss the importance of case surveillance, provide case report forms and training
• adequately assure the security and confidentiality of case data (particularly if cases are reported using patient names)
• provide regular feedback to the healthcare workers/providers regarding the results from case surveillance.

In order to ensure efficient use of time and resources, those programmes that serve the largest number of HIV-infected persons should be targeted for assistance with case reporting.

Unit 1 Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion

Get into small groups to discuss the following questions:

1. Does your country have a functional HIV case reporting system?

2. If your country is not conducting HIV case reporting, discuss why it is not.

3. If your country does not have an HIV case reporting system, discuss current limitations to HIV case reporting. What are some possible solutions for these limitations?
4. Working alone or with others from your country, region or district, complete the following tables and then discuss your responses in your small group.

Table 1.2
**HIV case reporting in your country**

<table>
<thead>
<tr>
<th>Surveillance activities</th>
<th>Is this conducted? (Tick one box)</th>
<th>If yes, how often?</th>
<th>Who is the responsible person/officer? (Name and title)</th>
<th>How can data from this activity be used and by whom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV case reporting</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case reporting for advanced HIV infection [disease]</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case surveillance for AIDS</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case surveillance of AIDS deaths</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TB surveillance: case reporting of diagnosed TB cases</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveillance of death registration</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you answered 'yes' to more than one of the above questions on case reporting for HIV or AIDS, please answer the following:

Is the surveillance system able to link case reports on one individual reported multiple times or from multiple sources? If so, explain how this is done and at what level (district, national) the linking occurs.

Table 1.3
**HIV sero-prevalence surveys in your country**

<table>
<thead>
<tr>
<th>Surveillance activities</th>
<th>Ever conducted? (Tick one box)</th>
<th>If yes, how often?</th>
<th>When was the last survey conducted? (Record year)</th>
<th>Who is the responsible person/officer? (Name and title)</th>
<th>How are data disseminated, and to whom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal clinic attendees (ANC)</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men who have sex with men</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Injection drug users</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commercial sex workers</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other populations</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specify:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please indicate in the table 1.3 which HIV sero-prevalence surveys are being conducted or have been conducted in your country.

Please indicate in the table 1.4 which of the following prevention/control programmes are conducted in your country.

### Table 1.4
**Prevention and control programmes in your country**

<table>
<thead>
<tr>
<th>Surveillance activities</th>
<th>Does this programme exist in your country?</th>
<th>When did the programme begin? (Year)</th>
<th>Who monitors the programme?</th>
<th>How often are indicators reported?</th>
<th>How are data disseminated, and to whom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of mother-to-child transmission (PMTCT)</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV care</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV treatment</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuberculosis control and prevention</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orphans and vulnerable children</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STI prevention and control Specify:</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other populations Specify:</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional questions regarding TB control programmes:

i. Are TB patients routinely tested for HIV?

ii. If so, describe the mechanism used to report these cases to the surveillance unit.
Please indicate in table 1.5 which of the following special surveys are conducted in your country.

Table 1.5

<table>
<thead>
<tr>
<th>Survey type</th>
<th>Is this conducted?</th>
<th>If so, how often?</th>
<th>When was the last survey conducted? (Record year)</th>
<th>Who is responsible? (Name and/or title)</th>
<th>How are data disseminated, and to whom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health facility survey</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of service/care survey</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service availability mapping survey</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>'PLACE' survey</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: (Specify)</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mortality surveys looking at HIV-related deaths</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioural surveys (with or without biomarkers, please indicate)</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population-based surveys (DHS, AIS)</td>
<td>Yes / No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Acronyms:

AIS - AIDS Indicator Survey  
DHS - Demographic Health Survey  
PLACE - Priorities for Local AIDS Control Efforts  
TB - Tuberculosis

Apply what you’ve learned/case study

Work on this case study independently.

1. You are the district surveillance officer for Serosia in South-East Asia. Serosia has been estimated to have one of the highest prevalence levels of HIV in the region. The national AIDS control programme is interested in expanding and improving its surveillance programme and the national surveillance officer is conducting site visits to various districts to discuss ways of improving surveillance. During your meeting with the national surveillance officer, you are asked to suggest additional surveillance activities in your district that you believe could be implemented successfully. Describe what these activities would be.
2. The national surveillance officer has indicated that there is an interest in using data collected from HIV and other care programmes for reporting of persons with advanced HIV disease. Review the worksheet you completed in your small group discussion and use this to determine the necessary steps to expand current surveillance activities. List these activities.

Unit 1 Summary

- For a full understanding of the HIV epidemic, you should monitor five key stages in the course of HIV disease: HIV incidence, HIV prevalence, incidence of advanced HIV disease, prevalence of advanced HIV disease, and deaths due to advanced HIV infection.
- HIV case reporting is conducted to obtain accurate and timely information on the burden of disease. This is necessary in order to provide and measure the impact of programmes for HIV prevention, care and treatment.
- The 2006 WHO HIV surveillance recommendations call for replacing AIDS case reporting with reporting of persons with advanced HIV infection (clinical stages 3 and 4). Countries may opt to report all persons with HIV infection, regardless of their clinical stage.
- Information collected as part of HIV-related programmes (tuberculosis control programmes, HIV care and antiretroviral treatment monitoring programmes, etc.) can be a source of identifying and reporting HIV-infected persons.
Notes
Overview

What this unit is about

This unit provides an overview of the history and purpose of HIV clinical staging and HIV/AIDS surveillance case definitions. It includes the following:

- a brief history of HIV clinical staging systems and surveillance case definitions
- a description of the 2006 WHO HIV clinical staging criteria, (the presumptive and definitive criteria) and the 2006 WHO surveillance case definitions
- case reporting options and their advantages and disadvantages
- an explanation of the link between HIV clinical staging, antiretroviral treatment recommendations and HIV case reporting.

Warm-up questions

1. True or false? In the revised (2006) adult and paediatric WHO HIV clinical staging systems, there are four clinical stages.

   True       False

2. True or false? The revised (2006) WHO HIV surveillance case definition includes the same clinical stages for adults and infants.

   True       False

3. True or false? The clinical criteria included in the revised (2006) WHO HIV surveillance case definition include only definitive diagnosis of clinical events.

   True       False

4. List four reasons why HIV clinical staging systems were developed.

5. True or false? Previous surveillance case definitions in developing countries focused only on stage 4 (AIDS).

   True       False

Introduction

What you will learn

By the end of this unit, you should be able to:

- describe the history of the HIV/AIDS clinical staging system and surveillance case definitions
- describe the 2006 WHO HIV clinical staging criteria (the presumptive and definitive
criteria) and the surveillance case definition for HIV infection, advanced HIV disease, and AIDS
• list at least one advantage and one disadvantage of HIV case surveillance, advanced HIV case surveillance, and AIDS case surveillance
• explain the link between HIV clinical staging, antiretroviral treatment recommendations, and HIV/AIDS case reporting.

Table 2.1.
Unit 2 annexes

<table>
<thead>
<tr>
<th>Annex</th>
<th>Information provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Presumptive and definitive criteria for recognizing HIV-related clinical events in adults (15 years or older) and children (younger than 15 years) with confirmed HIV infection</td>
</tr>
<tr>
<td>2.2</td>
<td>Presumptive diagnosis of severe HIV disease among HIV sero-positive and HIV-exposed children</td>
</tr>
</tbody>
</table>

History of Clinical Staging and HIV/AIDS Case Surveillance Definitions

Previous clinical staging criteria
Clinical staging criteria for HIV and AIDS were developed to:

• provide uniformity for clinical evaluation of persons with HIV infection
• provide an indicator of prognosis
• guide clinical management of patients
• help study the natural history of HIV infection.

The Walter Reed staging classification system was developed in 1986 for use among United States military personnel. This staging system included both clinical and laboratory manifestations of HIV disease. The inclusion of a laboratory component and the list of AIDS opportunistic illness in the Walter Reed staging classification system worked well in developed countries, but was not suitable for developing countries.

To provide a clinical staging system that could be used worldwide, the WHO convened a panel of experts in 1989 and developed the 1990 staging system for adults. The 1990 staging system was based primarily on clinical criteria. A paediatric staging system was adopted in 2003.

Previous surveillance case definitions
There have been several AIDS surveillance case definitions used throughout the world. The initial WHO AIDS surveillance case definition (Bangui) was developed in 1985 and formalized in 1986 for developing countries. The definition was modified in 1989 to include HIV serologic criteria for adults in areas with laboratory capacity. Additional regional surveillance case definitions were developed by the Pan American Health Organization (the Caracas definition), the European Centers for Disease Control and Prevention, and the United States Centers for Disease Control and Prevention. Each of these definitions was modified as laboratory testing became available and as additional information regarding the clinical manifestations of late-stage HIV disease became known. In addition
to modifications of the AIDS surveillance definitions, some regions developed surveillance case definitions for HIV disease not yet meeting the criteria for AIDS. The WHO had not previously developed a surveillance case definition for HIV disease alone (that is, for persons who are HIV-infected, but do not meet the surveillance case definition of AIDS).

The 2006 HIV Clinical Staging System and Surveillance Case Definitions

Updated clinical staging system

The increased availability of ART has resulted in the need for an updated HIV/AIDS clinical staging system that:

- harmonizes the 2002 three-stage paediatric staging system with the 1990 four-stage adult system
- includes stages at which prophylactic and antiretroviral therapy should be considered and recommended
- updates clinical conditions
- harmonizes the clinical staging and surveillance case definitions
- includes immunologic criteria for clinical staging and surveillance case definitions.

Anticipating greater availability of ART, WHO and CDC convened a panel of experts in 2004 to develop updated clinical staging systems for adults and children. Regional consultations were held in all WHO regions in 2004 and 2005. The clinical staging criteria and surveillance case definitions were adopted in 2006. The revisions were intended to identify the treatable nature of HIV infection in the presence of ART. Clinical staging should be done at the time of initial HIV diagnosis, upon entry into clinical care for HIV infection and at each clinical visit.

Table 2.2.

WHO clinical classification of established HIV infection

<table>
<thead>
<tr>
<th>HIV-associated symptomatology</th>
<th>WHO clinical stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>asymptomatic</td>
<td>1</td>
</tr>
<tr>
<td>mild symptoms</td>
<td>2</td>
</tr>
<tr>
<td>advanced symptoms</td>
<td>3</td>
</tr>
<tr>
<td>severe symptoms</td>
<td>4</td>
</tr>
</tbody>
</table>

The revised staging systems include:

- presumptive clinical diagnoses that can be made in the absence of sophisticated laboratory tests
- definitive clinical criteria that require confirmatory laboratory tests.

With expansion of laboratory capacity in developing countries, including those in South-East Asia, the WHO developed an immunological classification system for HIV infection. These criteria are based upon the known decline in CD4 cells with the progression of HIV disease. Listed below are the age-related values and associated degree of immunodeficiency. Note that for children under five years of age, the CD4 percent rather than absolute count should be used.
Table 2.3.
WHO-proposed immunological classification for established HIV infection

<table>
<thead>
<tr>
<th>HIV-associated immunodeficiency</th>
<th>&lt; 11 mo. (%)</th>
<th>12-35 mo. (%)</th>
<th>36-59 mo. (%)</th>
<th>≥ 5 yrs (mm/3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None/not significant</td>
<td>&gt; 35</td>
<td>&gt; 30</td>
<td>&gt; 25</td>
<td>&gt; 500</td>
</tr>
<tr>
<td>Mild</td>
<td>30-35</td>
<td>25-30</td>
<td>20-25</td>
<td>350-499</td>
</tr>
<tr>
<td>Advanced</td>
<td>25-30</td>
<td>20-25</td>
<td>15-20</td>
<td>200-349</td>
</tr>
<tr>
<td>Severe</td>
<td>&lt; 25</td>
<td>&lt; 20</td>
<td>&lt; 15</td>
<td>&lt; 200 or &lt; 15%</td>
</tr>
</tbody>
</table>

Table 2.4.
WHO clinical staging of HIV/AIDS for adults and adolescents with confirmed HIV infection

**Clinical Stage 1**
- Asymptomatic
- Persistent generalized lymphadenopathy

**Clinical Stage 2**
- Moderate unexplained weight loss (<10% of presumed or measured body weight)
- Recurrent respiratory tract infections (sinusitis, tonsillitis, bronchitis, otitis media, pharyngitis)
- Herpes zoster
- Angular cheilitis
- Recurrent oral ulceration
- Papular pruritic eruptions
- Seborrhoeic dermatitis
- Fungal nail infections

**Clinical Stage 3**
- Unexplained severe weight loss (>10% of presumed or measured body weight)
- Unexplained chronic diarrhoea for longer than one month
- Unexplained persistent fever (intermittent or constant for longer than one month)
- Persistent oral candidiasis
- Oral hairy leukoplakia
- Pulmonary tuberculosis
- Lymph node TB
- Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)
- Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
- Unexplained anaemia (<8 g/dl), neutropenia (< 0.5 x 10⁹ /L) and/or chronic thrombocytopenia (< 50 X 10⁹ /L³)

---

¹ Assessment of body weight in a pregnant woman needs to consider expected weight gain of pregnancy.

² Unexplained refers to those cases in which the condition is not explained by other conditions.

³ Some additional specific conditions can also be included in regional classifications (for example, American trypanosomiasis reactivation in Americas region).


**Clinical Stage 4**

- HIV wasting syndrome
- Pneumocystis pneumonia
- Recurrent severe bacterial pneumonia
- Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month’s duration or visceral at any site)
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Extrapulmonary tuberculosis
- Kaposi’s sarcoma
- Cytomegalovirus infection (retinitis or infection of other organs)
- Central nervous system toxoplasmosis
- HIV encephalopathy
- Extrapulmonary cryptococcosis including meningitis
- Disseminated non-tuberculous mycobacteria infection
- Progressive multifocal leukoencephalopathy
- Chronic cryptosporidiosis
- Chronic isosporiasis
- Disseminated mycosis (extrapulmonary histoplasmosis or coccidiomycosis)
- Recurrent septicaemia (including non-typhoidal Salmonella)
- Lymphoma (cerebral or B cell non-Hodgkin)
- Invasive cervical carcinoma
- Atypical disseminated leishmaniasis
- Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy

---

**Table 2.5.**

**WHO clinical staging of HIV/AIDS for children with confirmed HIV infection**

**Clinical Stage 1**

- Asymptomatic
- Persistent generalized lymphadenopathy

**Clinical Stage 2**

- Unexplained persistent hepatosplenomegaly
- Papular pruritic eruptions
- Extensive wart virus infection
- Extensive molluscum contagiosum
- Fungal nail infections
- Recurrent oral ulcerations
- Unexplained persistent Parotid enlargement
- Lineal gingival erythema
- Herpes zoster
- Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis, tonsillitis)
### Clinical Stage 3

- Moderate unexplained malnutrition not adequately responding to standard therapy
- Unexplained persistent diarrhoea (14 days or more)
- Unexplained persistent fever (above 37.5 intermittent or constant, for longer than one month)
- Persistent oral candidiasis (after first 6-8 weeks of life)
- Oral hairy leukoplakia
- Acute necrotizing ulcerative gingivitis/periodontitis
- Lymph node tuberculosis
- Pulmonary tuberculosis
- Severe recurrent bacterial pneumonia
- Symptomatic lymphoid interstitial pneumonitis
- Chronic HIV-associated lung disease including bronchiectasis
- Unexplained anaemia (< 8g/dl), neutropenia (<0.5X 10^9/L) or chronic thrombocytopenia (< 50 x 10^9/L)

### Clinical Stage 4

- Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy
- Pneumocystis pneumonia
- Recurrent severe bacterial infections (e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia)
- Chronic herpes simplex infection; (orolabial or cutaneous of more than one month’s duration or visceral at any site)
- Extrapulmonary tuberculosis
- Kaposi's sarcoma
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Central nervous system toxoplasmosis (after one month of life)
- HIV encephalopathy
- Cytomegalovirus infection retinitis or CMV infection affecting another organ, with onset at age over one month.
- Extrapulmonary cryptococcosis (including meningitis)
- Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidiomycosis, penicilliosis)
- Chronic cryptosporidiosis
- Chronic isosporiasis
- Disseminated non-tuberculous mycobacteria infection
- Cerebral or B cell non-Hodgkin lymphoma
- Progressive multifocal leukoencephalopathy
- Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy

### Updated WHO surveillance case definitions

Changes to the clinical staging of HIV infection combined with the expanded use of ART have resulted in a need to revise case surveillance recommendations. Previous case definitions have focused exclusively on reporting persons who met the Bangui or expanded AIDS case definition.

The following tables present the case definitions for HIV infection and advanced HIV disease (including AIDS).
### Table 2.6

**WHO case definition for HIV infection**

<table>
<thead>
<tr>
<th>Adults and adolescents and children &gt;18 months</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV infection is diagnosed basing on:</td>
<td></td>
</tr>
<tr>
<td>• a positive HIV antibody testing (rapid or laboratory-based enzyme immunoassay). This is usually confirmed using a second HIV antibody test (rapid or laboratory-based enzyme immunoassay) relying on different antigens or different operating characteristics than the initial test. And/or</td>
<td></td>
</tr>
<tr>
<td>• a positive virologic test for HIV or its components (HIV-RNA or HIV-DNA or ultrasensitive HIV p24 antigen) confirmed by a second virologic test obtained from a separate determination.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Children younger than 18 months</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV infection is diagnosed basing on:</td>
<td></td>
</tr>
<tr>
<td>• a positive virologic test for HIV or its components (HIV-RNA or HIV-DNA or ultrasensitive HIV p24 antigen) confirmed by a second virologic test obtained from a separate determination taken more than four weeks after birth.</td>
<td></td>
</tr>
</tbody>
</table>

### Table 2.7

**Criteria for diagnosis of advanced HIV disease (including AIDS) for reporting for adults and children.**

<table>
<thead>
<tr>
<th>Clinical criteria for a diagnosis of advanced HIV in adults and children with confirmed HIV infection</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Presumptive or definitive diagnosis of any one stage 4 condition</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Immunological criteria for diagnosing advanced HIV disease in adults and children five years or older with confirmed HIV infection</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 count less than 350 per mm³ in an adult or child</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Immunological criteria for diagnosis in a child younger than five years with confirmed HIV infection</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>%CD4 &lt; 30 among those younger than 12 months of age</td>
<td></td>
</tr>
<tr>
<td>%CD4 &lt; 25 among those aged 12-35 months</td>
<td></td>
</tr>
<tr>
<td>%CD4 &lt; 20 among those aged 35-59 months.</td>
<td></td>
</tr>
</tbody>
</table>

* AIDS in adults and children of any age is defined as: clinical diagnosis (presumptive or definitive) of any stage 4 condition with confirmed HIV infection; OR immunological criteria in adults and children with confirmed HIV infection and ≥ 5 years of age; first-ever documented % CD4 count < 200 per mm³ or % CD4 + < 15; or among children aged 12-35 months first-ever documented % CD4 + < 20; or among infants < 12 months of age first-ever documented % CD4 + < 25.

### Reporting of primary HIV infection

There is no standard case definition of primary HIV infection. However, primary HIV infection is of great importance, both because it represents recently acquired infection and because persons with primary HIV infection are highly contagious. The reporting of persons with primary HIV infection is one method of capturing the leading edge of the epidemic. Currently, in settings where persons with primary HIV infection are not likely to seek medical care (as is likely in much of South-East Asia), reporting of persons with primary HIV infection is probably of limited value and is not recommended. Rather, patients who may be diagnosed with primary HIV infection should be reported as HIV-infected.
Symptomatic primary HIV infection presents two to four weeks after HIV acquisition and may include any of the following symptoms:

- lymphadenopathy
- pharyngitis
- maculopapular rash
- orogenital ulcers
- meningoencephalitis
- lymphopaenia (including low CD4)
- opportunistic infections.

These clinical conditions should not be confused with clinical staging criteria. Primary HIV infection can be diagnosed by recent HIV sero-conversion or by identifying HIV products (HIV-RNA or HIV-DNA and/or ultrasensitive HIV p24 antigen with a negative HIV antibody test.)

**WHO HIV case surveillance recommendations**

In the light of the case definition revisions, WHO recommends that countries standardize their surveillance practices and case definitions to include the reporting of HIV-infected persons not previously reported. A case of HIV disease includes all stages of HIV infection (clinical stages 1-4).

Countries may choose to report all cases diagnosed with HIV (clinical stages 1-4). If this option is implemented, countries will report persons at any clinical stage of infection/disease, as well as reporting all persons with advanced HIV infection/disease (clinical stages 3 and 4). This means that persons who are initially diagnosed with HIV at stages 1 or 2 and later fall into advanced HIV infection/disease will be reported twice. Persons who are first diagnosed with HIV at clinical stage 3 or 4 will be reported as having advanced HIV infection/disease and will only be reported once.

However, if countries are not able to report all cases of HIV, they may choose to report cases diagnosed with advanced HIV infection/disease. If countries are reporting advanced HIV infection/disease, AIDS case reporting is not required.

The graphic on the next page illustrates what your surveillance system will yield, depending on what you report.

**Advantages and disadvantages of case reporting options**

WHO recommendations on case reporting:

1. Countries should replace AIDS case reporting (option C) with reporting of HIV advanced infection/disease (option B). While it is no longer necessary for a country to report AIDS cases if advanced HIV infection/disease case reporting has begun, countries may choose to continue to report AIDS cases for monitoring trends, particularly if the completeness of reporting of AIDS cases was 80% or more.
2. Option A is the ultimate goal and as a long-term strategy, countries should plan to report all HIV infection cases to obtain a more complete picture of the epidemic. It is recommended that countries implement pilot projects to gain experience in
implementing a system of reporting all HIV infection/disease cases. Based on these experiences, national scale HIV case reporting system can be planned.

Selecting the type of case surveillance to conduct should be based on a thorough understanding of the advantages and disadvantages of the various surveillance options, as well as the availability of resources to collect, analyse and interpret surveillance data. Regardless of the option selected, it is recommended that surveillance programmes conduct surveillance activities in a manner that provides for complete, timely and consistent reporting that can accommodate changes.

Table 2.8
HIV case surveillance, all clinical stages (1-4)

<table>
<thead>
<tr>
<th>Advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• can provide information on the current and future need for ART and prevention services</td>
</tr>
<tr>
<td>• in situations where a large proportion of the population tests regularly, HIV case reporting can estimate the level of and trends in HIV prevalence and provide information on characteristics of persons more recently infected</td>
</tr>
<tr>
<td>• provides a more complete picture of the HIV-infected population</td>
</tr>
<tr>
<td>• includes reporting of persons with advanced HIV disease.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• cannot determine the rate of newly acquired infections (incidence)</td>
</tr>
<tr>
<td>• requires frequent and widespread HIV testing among at-risk persons if data are to provide complete count of HIV-infected persons</td>
</tr>
<tr>
<td>• in countries with mature epidemics, the initial HIV case-reporting activities will result in a substantial number of persons reported with more advanced HIV disease (clinical stages 3 and 4)</td>
</tr>
<tr>
<td>• if clinical stages are not included in the HIV case reporting, it will be difficult to compare trends in countries in which AIDS case reporting has been functioning well.</td>
</tr>
</tbody>
</table>
Table 2.9
Advanced HIV infection case surveillance (includes AIDS) (clinical stages 3 and 4)

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• is likely to provide complete picture of persons with advanced HIV disease, because they seek care for symptoms, are diagnosed and can be reported by the healthcare provider</td>
<td>• cannot determine the rate of newly acquired infections (incidence)</td>
</tr>
<tr>
<td>• provides information on the number of diagnosed persons on ART and information on the number of those in need of, but not yet receiving, ART (assists with programme planning efforts)</td>
<td>• will not be useful for planning for ART, should treatment guidelines change to include the provision of ART to persons in earlier clinical stages</td>
</tr>
<tr>
<td>• allows for more complete reporting, since persons receiving ART are in care settings where surveillance officers can assist with case reporting and can train clinic staff to report cases</td>
<td>• cannot provide information on all persons diagnosed with HIV</td>
</tr>
<tr>
<td>• countries with mature epidemics and decreasing incidence, are likely to include a large proportion of the total number of cases.</td>
<td>• in areas with changing epidemics, this cannot provide information on populations newly infected and diagnosed.</td>
</tr>
</tbody>
</table>

Table 2.10
AIDS case surveillance (clinical stage 4)

<table>
<thead>
<tr>
<th>Advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• allows for monitoring trends in countries where AIDS case reporting has been complete (at least 70% complete for at least the previous five years)</td>
</tr>
<tr>
<td>• can be used to measure the success of ART programmes (number of living AIDS cases should increase and number of newly diagnosed AIDS cases should decrease)</td>
</tr>
<tr>
<td>• in countries where people wait until they are severely ill to seek care, this may be the only type of reporting that can be complete.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• does not provide adequate information for planning for ART and prevention services</td>
</tr>
<tr>
<td>• provides an incomplete picture of the number of persons diagnosed with HIV disease.</td>
</tr>
</tbody>
</table>

Linking HIV Clinical Staging, ART Use and HIV Surveillance

Initiating ART

The best time to begin antiretroviral treatment can be determined using clinical staging and CD4 counts/ percents. Current WHO treatment recommendations are divided into recommendations for use in areas in which CD4 testing is available, and areas in which such testing is not available.

WHO has specified the optimal times to initiate ART based upon clinical staging and CD4 count when available.
Table 2.11
WHO SEARO recommendations for initiating ART based on clinical staging and CD4 testing

<table>
<thead>
<tr>
<th>Clinical stage</th>
<th>CD4 available</th>
<th>CD4 not available</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Treat if CD4 &lt;200</td>
<td>Do not treat</td>
</tr>
<tr>
<td>II</td>
<td>Treat if CD4 &lt;200</td>
<td>Do not treat</td>
</tr>
<tr>
<td>III</td>
<td>Treat if CD4&lt;350</td>
<td>Treat</td>
</tr>
<tr>
<td>IV</td>
<td>Treat</td>
<td>Treat</td>
</tr>
</tbody>
</table>

ART is recommended for children and infants with clinical stages 3 and 4, regardless of the CD4 cell count or percentage. Results from CD4 testing are used to guide decisions on beginning ART in children and infants with clinical stages 1 and 2.

As described above, clinical staging is:

- used to determine the best time to begin treatment for HIV disease
- a key component of the surveillance case definitions.

The link between these is useful for surveillance purposes. HIV surveillance is generally conducted by healthcare providers, usually from hospitals and clinics that provide ART. Thus, patients who are receiving care at these facilities will have their clinical stage determined. This is particularly useful in those countries in which reporting of advanced HIV disease or AIDS is done. In those settings, persons on ART are likely to include those who should be reported to the public health authorities. In addition, ART programmes may use monitoring programmes that can easily identify persons who should be reported to the health authorities. These monitoring systems usually include all the information necessary to report these cases. The new clinical staging system, HIV treatment recommendations, and surveillance case definition and recommendations for reporting should facilitate optimal care of HIV-infected persons and improve reporting.

---

4 WHO SEARO adult and pediatric treatment guidelines
Presumptive and definitive criteria for recognizing HIV-related clinical events in adults (15 years or older) and children (younger than 15 years) with confirmed HIV infection

**Adults (15 years or older)**

<table>
<thead>
<tr>
<th>CLINICAL EVENT</th>
<th>CLINICAL DIAGNOSIS</th>
<th>DEFINITIVE DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Stage 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>No HIV-related symptoms reported and no signs on examination.</td>
<td>Not applicable.</td>
</tr>
<tr>
<td>Persistent generalized lymphadenopathy (PGL)</td>
<td>Painless enlarged lymph nodes &gt; 1 cm, in two or more non-contiguous sites (excluding inguinal), in absence of known cause &amp; persisting for &gt; 3 months.</td>
<td>Histology.</td>
</tr>
<tr>
<td>Clinical Stage 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent bacterial upper respiratory tract infections (current event plus one or more in last six-month period).</td>
<td>Symptom complex; for example, unilateral face pain with nasal discharge (sinusitis), painful inflamed eardrum (otitis media), or tonsillo-pharyngitis without features of viral infection (such as coryza, cough).</td>
<td>Laboratory studies where available; for example, culture of suitable body fluid.</td>
</tr>
<tr>
<td>Herpes zoster.</td>
<td>Painful vesicular rash in dermatomal distribution of a nerve supply that does not cross midline.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Angular cheilitis.</td>
<td>Splits or cracks at the angle of the mouth not due to iron or vitamin deficiency, and usually respond to antifungal treatment.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Recurrent oral ulcerations (two or more episodes in last six months).</td>
<td>Aphthous ulceration, typically painful with a halo of inflammation and a yellow-grey pseudo-membrane.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Seborrhoeic dermatitis.</td>
<td>Itchy scaly skin condition, particularly affecting hairy areas (scalp, axillae, upper trunk and groin).</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Fungal nail infections.</td>
<td>Paronychia (painful red and swollen nail bed) or onycholysis (separation of the nail from the nail bed) of the fingernails (white discoloration—especially involving proximal part of nail plate—with thickening and separation of nail from nail bed).</td>
<td>Fungal culture of nail/nail plate material.</td>
</tr>
<tr>
<td><strong>Clinical Stage 3</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unexplained severe weight loss (&gt; than 10% of body weight).</td>
<td>Reported unexplained weight loss (&gt; 10% of body weight) and visible thinning of face, waist and extremities, with obvious wasting or body mass index &lt; 18.5. In pregnancy weight loss may be masked.</td>
<td>Documented loss of more than 10% of body weight.</td>
</tr>
<tr>
<td>Unexplained chronic diarrhoea for longer than one month.</td>
<td>Chronic diarrhoea (loose or watery stools three or more times daily) reported for longer than one month.</td>
<td>Three or more stools observed and documented as unformed, and two or more stool tests reveal no pathogens.</td>
</tr>
<tr>
<td>Unexplained persistent fever (intermittent or constant and lasting for longer than one month).</td>
<td>Fever or night sweats for more than one month, either intermittent or constant with reported lack of response to antibiotics or anti-malaria agents, without other obvious foci of disease reported or found on examination. Malaria must be excluded in malaria areas.</td>
<td>Documented fever &gt; 37.6 °C with negative blood culture, negative Ziehl-Nielsen (ZN) stain, negative malaria slide, normal or unchanged chest X-ray and no other obvious focus of infection.</td>
</tr>
<tr>
<td>Oral candidiasis.</td>
<td>Persistent or recurring creamy white curd-like plaques which can be scraped off (pseudo-membranous), or red patches on tongue, palate or lining of mouth, usually painful or tender (erythematous form).</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Oral hairy leukoplakia.</td>
<td>Fine white small linear or corrugated lesions on lateral borders of the tongue, which do not scrape off.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
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</tr>
<tr>
<td>Pulmonary tuberculosis (current).</td>
<td>Chronic symptoms: (lasting ≥ 2-3 weeks) cough, haemoptysis, shortness of breath, chest pain, weight loss, fever, night sweats and no clinical evidence of extrapulmonary disease.</td>
<td>One or more sputum smear positive for acid-fast bacilli and/or radiographic abnormalities consistent with active tuberculosis and/or culture positive for <em>Mycobacterium</em>.</td>
</tr>
<tr>
<td>Discrete peripheral lymph node M tuberculosis infection (especially cervical) is considered a less severe form of extrapulmonary tuberculosis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One or more sputum smear positive for acid-fast bacilli and/or radiographic abnormalities consistent with active tuberculosis and/or culture positive for <em>Mycobacterium</em>.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe bacterial infection (for example, pneumonia, meningitis, empyema, pyomyositis, bone or joint infection, bacteraemia or severe pelvic inflammatory disease).</td>
<td>Fever accompanied by specific symptoms or signs that localize infection, and response to appropriate antibiotic.</td>
<td>Isolation of bacteria from appropriate clinical specimens (usually sterile sites).</td>
</tr>
<tr>
<td>Acute necrotizing ulcerative gingivitis or necrotizing ulcerative periodontitis.</td>
<td>Severe pain, ulcerated gingival papillae, loosening of teeth, spontaneous bleeding, bad odour and rapid loss of bone and/or soft tissue.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Unexplained anaemia (&lt; 8g/dL), neutropenia (&lt; 0.5 &gt;10⁹/L or chronic (more than one month) thrombocytopenia (&lt;5 0 &gt;10⁹/L).</td>
<td>Not presumptive clinical diagnosis.</td>
<td>Diagnosed on laboratory testing and not explained by other non-HIV conditions.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not responding to standard therapy with haematinics, antimalarials or anthelmintics as outlined in relevant national treatment guidelines, WHO Integrated Management of Childhood Illness guidelines or other relevant guidelines.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
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<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Clinical Stage 4</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV wasting syndrome.</td>
<td>Unexplained weight loss (&gt; 10% body weight), with obvious wasting or body mass index &lt;18.5.</td>
<td>Documented weight loss &gt; 10% of body weight; PLUS two or more unformed stools negative for pathogens; OR documented temperature of &gt; 37.6 ºC or more with no other cause of disease, negative blood culture, negative malaria slide and normal or unchanged CXR.</td>
</tr>
<tr>
<td></td>
<td>PLUS unexplained chronic diarrhoea (loose or watery stools three or more times daily) reported for longer than one month; OR reports of fever or night sweats for more than one month without other cause and lack of response to antibiotics or anti-malarials; malaria must be excluded in malaria areas.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Pneumocystis</em> pneumonia.</td>
<td>Dyspnoea on exertion or non-productive cough of recent onset (within the past three months), tachypnoea and fever AND Chest x-ray evidence of diffuse bilateral interstitial infiltrates AND No evidence of a bacterial pneumonia; bilateral crepitations on auscultation with or without reduced air entry.</td>
<td>Cytology or immunofluorescent microscopy of induced sputum or bronchoalveolar lavage, or histology of lung tissue.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent bacterial pneumonia.</td>
<td>Current episode plus one or more previous episodes in last six months; acute onset (&lt; 2 weeks) of symptoms (such as fever, cough, dyspnoea and chest pain) PLUS New consolidation on clinical examination or CXR; response to antibiotics</td>
<td>Positive culture or antigen test of a compatible organism.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------------------------------------------</td>
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</tr>
<tr>
<td>Chronic herpes simplex virus (HSV) infection</td>
<td>Painful, progressive anogenital or orolabial ulceration; lesions caused by recurrent</td>
<td>Positive culture or DNA (by polymerase chain reaction) of herpes simplex virus or</td>
</tr>
<tr>
<td>(orolabial, visceral of any duration)</td>
<td>herpes simplex virus infection and reported for more than one month; history of</td>
<td>compatible cytology/histology.</td>
</tr>
<tr>
<td></td>
<td>previous episodes.</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Visceral herpes simplex virus requires definitive diagnosis.</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Oesophageal candidiasis.</td>
<td>Recent onset of retrosternal pain or difficulty in swallowing (food and fluids)</td>
<td>Macroscopic appearance at endoscopy or bronchoscopy, or by microscopy/histology.</td>
</tr>
<tr>
<td></td>
<td>together with Oral <em>Candida</em>.</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Extrapulmonary tuberculosis.</td>
<td>Systemic illness (such as fever, night sweats, weakness and weight loss).</td>
<td><em>M. tuberculosis</em> isolation or compatible histology from appropriate site</td>
</tr>
<tr>
<td></td>
<td>Other evidence for extrapulmonary or disseminated TB varies by site, such as</td>
<td>or radiological evidence of military TB (diffuse, uniformly distributed small</td>
</tr>
<tr>
<td></td>
<td>pleural, pericardial, peritoneal involvement, meningitis, mediastinum or abdominal.</td>
<td>military shadows or micronodules on CXR).</td>
</tr>
<tr>
<td></td>
<td>Discrete peripheral <em>Mycobacterium tuberculosis</em> infection (especially cervical) is</td>
<td></td>
</tr>
<tr>
<td></td>
<td>usually considered a less severe form of extrapulmonary tuberculosis.</td>
<td></td>
</tr>
<tr>
<td>Kaposi’s sarcoma.</td>
<td>Typical appearance in skin or oropharynx of persistent, initially flat, patches</td>
<td>Macroscopic appearance at endoscopy or bronchoscopy, or by histology.</td>
</tr>
<tr>
<td></td>
<td>with a pink or violaceaous colour, skin lesions that usually develop into plaques</td>
<td></td>
</tr>
<tr>
<td></td>
<td>or nodules.</td>
<td></td>
</tr>
<tr>
<td>Cytomegalovirus disease (other than liver, spleen</td>
<td>Retinitis only: may be diagnosed by experienced clinicians. Typical eye lesions</td>
<td>Retinitis only: may be diagnosed by experienced clinicians. Typical eye lesions</td>
</tr>
<tr>
<td>or lymph node).</td>
<td>on fundoscopic examination: discrete patches of retinal whitening with distinct</td>
<td>on fundoscopic examination: discrete patches of retinal whitening with distinct</td>
</tr>
<tr>
<td></td>
<td>borders, spreading centrifugally, often following blood vessels, associated with</td>
<td>borders, spreading centrifugally, often following blood vessels, associated with</td>
</tr>
<tr>
<td></td>
<td>retinal vasculitis, haemorrhage and necrosis.</td>
<td>retinal vasculitis, haemorrhage and necrosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Central nervous system toxoplasmosis.</td>
<td>Recent onset of a focal nervous system abnormality consistent with intracranial disease or reduced level of consciousness AND response within ten days to specific therapy.</td>
<td>Positive serum toxoplasma antibody AND (if available) single/multiple intracranial mass lesion on neuro-imaging (computed tomography or magnetic resonance imaging).</td>
</tr>
<tr>
<td>HIV encephalopathy.</td>
<td>Disabling cognitive and/or motor dysfunction interfering with activities of daily living, progressing over weeks or months in the absence of a concurrent illness or condition other than HIV infection which might explain the findings.</td>
<td>Diagnosis of exclusion: and (if available) neuro-imaging (computed tomography or magnetic resonance imaging).</td>
</tr>
<tr>
<td>Extrapulmonary cryptococcosis (including meningitis).</td>
<td>Meningitis: usually subacute, fever with increasing severe headache, meningism, confusion, behavioural changes that respond to cryptococcal therapy.</td>
<td>Isolation of <em>Cryptococcus neoformans</em> from extrapulmonary site or positive cryptococcal antigen test on cerebrospinal fluid or blood.</td>
</tr>
<tr>
<td>Disseminated non-tuberculous mycobacteria infection.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Diagnosed by finding atypical mycobacterial species from stool, blood, body fluid or other body tissue, excluding lung.</td>
</tr>
<tr>
<td>Progressive multi focal leukoencephalopathy (PML).</td>
<td>No presumptive clinical diagnosis.</td>
<td>Progressive neurological disorder (cognitive dysfunction, gait/speech disorder, visual loss, limb weakness and cranial nerve palsies) together with hypodense white matter lesions on neuro-imaging or positive polyomavirus JC polymerase chain reaction on cerebrospinal fluid.</td>
</tr>
<tr>
<td>Cryptosporidiosis (with diarrhoea lasting more than one month).</td>
<td>No presumptive clinical diagnosis.</td>
<td>Cysts identified on modified Ziehl-Nielsen microscopic examination of unformed stool.</td>
</tr>
<tr>
<td>Chronic isosporiasis.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Identification of <em>Isospora</em>.</td>
</tr>
<tr>
<td>Disseminated mycosis (coccidiomycosis, histoplasmosis, penicilliosis).</td>
<td>No presumptive clinical diagnosis.</td>
<td>Histology, antigen detection or culture from clinical specimen or blood culture.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>---------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Lymphoma (cerebral or B cell non-Hodgkin).</td>
<td>No presumptive clinical diagnosis.</td>
<td>Histology of relevant specimen or culture from any appropriate clinical specimen.</td>
</tr>
<tr>
<td>Invasive cervical carcinoma.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Histology or cytology.</td>
</tr>
<tr>
<td>Visceral leishmaniasis.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Diagnosed by histology (amastigotes visualized) or culture from any appropriate clinical specimen.</td>
</tr>
</tbody>
</table>

**Children (younger than 15 years)**

<table>
<thead>
<tr>
<th>Clinical Stage 1</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Asymptomatic.</td>
<td>No HIV related symptoms reported and no signs on examination.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Persistent generalized lymphadenopathy.</td>
<td>Persistent swollen or enlarged lymph nodes &gt;1 cm at two or more non-contiguous sites (excluding inguinal), without known cause.</td>
<td>Clinical diagnosis.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Stage 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unexplained persistent Hepatosplenomegaly.</td>
<td>Enlarged liver and spleen without an obvious cause.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Papular pruritic eruptions.</td>
<td>Papular pruritic vesicular lesions, scabies and insect bites should be excluded.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Extensive wart virus infection.</td>
<td>Characteristic warty skin lesions; small fleshy grainy bumps, often rough, flat on sole of feet (plantar warts); facial, more than 5% of body area or disfiguring.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Extensive molluscum contagiosum infection.</td>
<td>Characteristic skin lesions: small flesh-coloured, pearly or pink, dome-shaped or umbilicated growths, may be inflamed or red; facial, more than 5% of body area or disfiguring. Giant molluscum may indicate more advanced immunodeficiency.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Fungal nail infections.</td>
<td>Fungal paronychia (painful, red and swollen nail bed) or onycholysis (painless separation of the nail from the nail bed). Proximal white subungual onchomycosis is uncommon without immunodeficiency.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Recurrent oral ulceration.</td>
<td>Current event plus at least one previous episode in past six months. Aphthous ulceration, typically with a halo of inflammation and yellow-grey psuedomembrane.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Unexplained persistent parotid enlargement.</td>
<td>Asymptomatic bilateral swelling that may spontaneously resolve and recur, in absence of other known cause, usually painless.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Lineal gingival erythema.</td>
<td>Erythematous band that follows the contour of the free gingival line; may be associated with spontaneous bleeding.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Herpes zoster.</td>
<td>Painful rash with fluid-filled blisters, dermatomal distribution, can be haemorrhagic on erythematous background, and can become large and confluent. Does not cross the midlines.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------</td>
<td>-------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Recurrent upper respiratory tract infection (URTI).</td>
<td>Current event with at least one episode in past six months. Symptom complex; fever with unilateral face pain and nasal discharge (sinusitis) or painful swollen eardrum (otitis media), sore throat with productive cough (bronchitis), sore throat (pharyngitis) and barking croup-like cough (laryngeotracheal bronchitis). Persistent or recurrent ear discharge.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Unexplained moderate malnutrition.</td>
<td>Weight loss: low weight-for-age, up to −2 standard deviations from the mean, not explained by poor or inadequate feeding and or other infections, and not adequately responding to standard management.</td>
<td>Documented loss of body weight of −2 standard deviations from the mean, failure to gain weight on standard management and no other cause identified during investigation.</td>
</tr>
<tr>
<td>Unexplained persistent diarrhoea.</td>
<td>Unexplained persistent (14 days or more) diarrhoea (loose or watery stool, three or more times daily), not responding to standard treatment.</td>
<td>Stools observed and documented as unformed. Culture and microscopy reveal no pathogens.</td>
</tr>
<tr>
<td>Unexplained persistent fever &gt;37.5°C intermittent or constant, for longer than one month).</td>
<td>Reports of fever or night sweats for longer than one month, either intermittent or constant, with reported lack of response to antibiotics or antimalarial agents. No other obvious foci of disease reported or found on examination. Malaria must be excluded in malarious areas.</td>
<td>Documented fever of &gt;37.5 °C with negative blood culture, negative malaria slide and normal or unchanged chest X-ray, and no other obvious foci of disease.</td>
</tr>
<tr>
<td>Oral candidiasis (after first 6-8 weeks of life).</td>
<td>Persistent or recurring creamy white to yellow soft small plaques which can be scraped off (pseudomembranous), or red patches on tongue, palate or lining of mouth, usually painful or tender (erythematous form).</td>
<td>Microscopy or culture.</td>
</tr>
<tr>
<td>Oral hairy leukoplakia.</td>
<td>Fine small linear patches on lateral borders of tongue, generally bilaterally, which do not scrape off.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
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</tr>
<tr>
<td>Acute necrotizing ulcerative gingivitis or stomatitis, or acute necrotizing ulcerative periodontitis.</td>
<td>Severe pain, ulcerated gingival papillae, loosening of teeth, spontaneous bleeding, bad odour, and rapid loss of bone and/or soft tissue.</td>
<td>Clinical diagnosis.</td>
</tr>
<tr>
<td>Lymph node tuberculosis.</td>
<td>Non acute, painless “cold” enlargement of peripheral lymph odes. Response to standard anti-tuberculosis treatment in one month.</td>
<td>Histology or fine needle aspirate for Ziehl-Nielsen stain or culture.</td>
</tr>
<tr>
<td>Pulmonary tuberculosis.</td>
<td>Nonspecific symptoms, e.g. chronic cough, fever, night sweats, anorexia and weight loss. In the older child also productive cough and haemoptysis. History of contact with adult with smear positive pulmonary tuberculosis. No response to standard broad spectrum antibiotic treatment.</td>
<td>One or more sputum smear positive for acid-fast bacilli and/or radiographic abnormalities consistent with active tuberculosis and/or culture-positive for <em>Mycobacterium</em>.</td>
</tr>
<tr>
<td>Severe recurrent bacterial pneumonia.</td>
<td>Cough with fast breathing, chest in drawing, nasal flaring, wheezing, and grunting. Crackles or consolidation on auscultation. Responds to course of antibiotics. Current episode plus one or more in previous six months.</td>
<td>Isolation of bacteria from appropriate clinical specimens (induced sputum, bronchoaveolar lavage, and lung aspirate).</td>
</tr>
<tr>
<td>Symptomatic lymphocytic interstitial pneumonia.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Chest X-ray: bilateral reticulonodular interstitial pulmonary infiltrates present for more than two months with no response to antibiotic treatment and no other pathogen found. Oxygen saturation persistently &lt;90%. Cor pulmonale and increased exercise-induced fatigue. Characteristic histology.</td>
</tr>
<tr>
<td>Chronic HIV-associated lung disease (including bronchiectasis)</td>
<td>History of cough productive of copious amounts of purulent sputum (bronchiectasis only), with or without clubbing, halitosis, and crepitations and/or wheezes on auscultation;</td>
<td>Chest X-ray may show honeycomb appearance (small cysts) and/or persistent areas of opacification and/or widespread lung destruction, with fibrosis and loss of volume.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
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</tr>
<tr>
<td>Unexplained anaemia (&lt;8g/dl), neutropenia (&lt;0.5 X 10^9/L) or chronic thrombocytopenia (&lt;50 x 10^9/L)</td>
<td>No presumptive clinical diagnosis.</td>
<td>Laboratory testing, not explained by other non-HIV conditions, not responding to standard therapy with haematinics, antimalarial agents or anthelmintics as outlined in WHO Integrated Management of Childhood Illnesses guidelines.</td>
</tr>
<tr>
<td><strong>Clinical Stage 4</strong></td>
<td>Persistent weight loss not explained by poor or inadequate feeding, other infections and not adequately responding in two weeks to standard therapy. Visible severe wasting of muscles, with or without oedema of both feet, and/or weight-for-height of -3 standard deviations from the mean, as defined by WHO Integrated Management of Childhood Illnesses guidelines.</td>
<td>Documented weight loss of -3 standard deviations from the mean with or without oedema.</td>
</tr>
<tr>
<td>Pneumocystis pneumonia</td>
<td>Dry cough, progressive difficulty in breathing, cyanosis, tachypnoea and fever; chest indrawing or stridor. (Severe or very severe pneumonia as in WHO Integrated Management of Childhood Illnesses guidelines. Rapid onset especially in infants younger than six months of age. Response to high-dose co-trimoxazole with or without prednisolone. Chest X-ray typical bilateral perihilar diffuse infiltrates.</td>
<td>Cytology or immunofluorescent microscopy of induced sputum or bronchoalveolar lavage, or histology of lung tissue.</td>
</tr>
<tr>
<td>Recurrent severe bacterial infection, e.g. empyema, pyomyositis, bone or joint infection, meningitis but excluding pneumonia</td>
<td>Fever accompanied by specific symptoms or signs that localize infection. Responds to antibiotics. Current episode plus one or more in previous six months.</td>
<td>Culture of appropriate clinical specimen.</td>
</tr>
<tr>
<td>Chronic herpes simplex infection; (orolabial or cutaneous of more than one month’s duration or visceral at any site)</td>
<td>Severe and progressive painful orolabial, genital, or anorectal lesions caused by herpes simplex virus infection present for more than one month.</td>
<td>Culture and/or histology.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Oesophageal candidiasis (or candida of trachea, bronchi or lungs).</td>
<td>Difficulty in swallowing, or pain on swallowing (food and fluids). In young children, suspect particularly if oral Candida observed and food refusal occurs and/or difficulties/crying when feeding.</td>
<td>Macroscopic appearance at endoscopy, microscopy of specimen from tissue or macroscopic appearance at bronchoscopy or histology.</td>
</tr>
<tr>
<td>Extrapulmonary / disseminated tuberculosis</td>
<td>Systemic illness usually with prolonged fever, night sweats, weight loss. Clinical features of organs involved, e.g. sterile pyuria, pericarditis, ascites, pleural effusion, meningitis, arthritis, orchitis., pericardial or abdominal.</td>
<td>Positive microscopy showing acid-fast bacilli or culture of Mycobacterium tuberculosis from blood or other relevant specimen except sputum or bronchoaveolar lavage. Biopsy and histology.</td>
</tr>
</tbody>
</table>
| Kaposi’s sarcoma                                   | Typical appearance in skin or oropharynx of persistent, initially flat, patches with a pink or blood-bruise colour, skin lesions that usually develop into nodules.                                                   | Not required but may be confirmed by:  
  - typical red-purple lesions seen on bronchoscopy or endoscopy;  
  - dense masses in lymph nodes, viscera or lungs by palpation or radiology;  
  - histology.                                                                                                                                               |
<p>| Cytomegalovirus retinitis or cytomegalovirus infection affecting another organ, with onset at age over one month. | Retinitis only.                                                                                                                                                                                                     | Definitive diagnosis required for other sites. Histology. cerebrospinal fluid polymerase chain reaction.                                                                                                             |
| Central nervous system toxoplasmosis onset after age over one month. | Fever, headache, focal neurological signs, convulsions. Usually responds within ten days to specific therapy.                                                                                                     | Computed tomography scan (or other neuroimaging) showing single/multiple lesions with mass effect/ enhancing with contrast.                                                                                     |
| Extrapulmonary cryptococcosis (including meningitis). | Meningitis: usually sub acute, fever with increasing severe headache, meningism, confusion, behavioural changes that responds to cryptococcal therapy.                                                           | Cerebrospinal fluid microscopy (India ink or Gram stain), serum or cerebrospinal fluid cryptococcal antigen test or culture.                                                                                  |</p>
<table>
<thead>
<tr>
<th>CLINICAL EVENT</th>
<th>CLINICAL DIAGNOSIS</th>
<th>DEFINITIVE DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV encephalopathy.</td>
<td>At least one of the following, progressing over at least two months in the absence of another illness: • failure to attain, or loss of, developmental milestones, loss of intellectual ability; or • progressive impaired brain growth demonstrated by stagnation of head circumference; or • acquired symmetric motor deficit accompanied by two or more of the following: paresis, pathological reflexes, ataxia, gait disturbances.</td>
<td>Neuroimaging demonstrating atrophy and basal ganglia calcification and excluding other causes.</td>
</tr>
<tr>
<td>Disseminated mycosis (coccidiomycosis, histoplasmosis, penicilliosis)</td>
<td>No presumptive clinical diagnosis.</td>
<td>Histology: usually granuloma formation. Isolation: antigen detection from affected tissue; culture or microscopy from clinical specimen or blood culture.</td>
</tr>
<tr>
<td>Disseminated mycobacteriosis, other than TB.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Nonspecific clinical symptoms including progressive weight loss, fever, anaemia, night sweats, fatigue or diarrhoea; plus culture of atypical mycobacteria species from stool, blood, body fluid or other body tissue, excluding lung.</td>
</tr>
<tr>
<td>Chronic cryptosporidiosis</td>
<td>No presumptive clinical diagnosis.</td>
<td>Cysts identified on modified Ziehl-Nielsen microscopic examination of unformed stool.</td>
</tr>
<tr>
<td>Chronic <em>Isospora</em></td>
<td>No presumptive clinical diagnosis.</td>
<td>Identification of <em>Isospora</em> spp.</td>
</tr>
<tr>
<td>Cerebral or B cell non-Hodgkin lymphoma.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Diagnosed by central nervous system neuroimaging; histology of relevant specimen.</td>
</tr>
<tr>
<td>CLINICAL EVENT</td>
<td>CLINICAL DIAGNOSIS</td>
<td>DEFINITIVE DIAGNOSIS</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Progressive multi-focal leukoencephalopathy.</td>
<td>No presumptive clinical diagnosis.</td>
<td>Progression nervous system disorder (cognitive dysfunction, gait or speech disorder, visual loss, limb weakness and cranial nerve palsies) together with hypodense white matter lesions on neuroimaging or positive chain reaction on cerebrospinal fluid.</td>
</tr>
</tbody>
</table>
Annex 2.2

Presumptive diagnosis of severe HIV disease among HIV-sero-positive and HIV-exposed children

Clinical criteria for presumptive diagnosis of severe HIV disease among infants and children under 18 months in situations where virological testing is not available.

A presumptive diagnosis of severe HIV disease should be made if:
- the infant is confirmed as being HIV-antibody-positive  
  AND
- diagnosis of any AIDS-indicator conditions can be made  
  OR
- the infant is symptomatic with two or more of the following:
  - oral thrush
  - severe pneumonia
  - severe sepsis.

Other factors that support the diagnosis of severe HIV disease in an HIV-sero-positive infant include:
- Recent HIV-related maternal death or advanced HIV disease in the mother
- CD4 <20%.

Note: confirmation of the diagnosis of HIV-infection should be sought as soon as possible.

Unit 2 Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion

Get into small groups to discuss the following questions.

1. Which AIDS case definition has been used in your country? (Tick the appropriate answer).

<table>
<thead>
<tr>
<th>Bangui definition</th>
<th>Yes / No / Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO expanded case definition</td>
<td>Yes / No / Not sure</td>
</tr>
<tr>
<td>CDC case definition</td>
<td>Yes / No / Not sure</td>
</tr>
<tr>
<td>Some other definition</td>
<td>Yes / No / Not sure</td>
</tr>
</tbody>
</table>

If yes, specify:

2. Have there been any changes made to the case definitions used in your country in the past? If so, when and why?
3. Describe and develop a figure to represent the data flow from the reporting facility on up to the national surveillance programme.

4. Although there is no standard case definition for primary HIV infection, what can be learned from reports of persons with primary HIV infection?

Apply what you’ve learned/case study

Work on this case study independently.

As an HIV surveillance officer for Serosia, you are charged with standardizing the practice of the country’s HIV reporting. What processes would you implement to ensure that HIV case surveillance is standardized?

Serosia recently began providing free antiretroviral therapy to HIV-infected individuals. Serosia uses the WHO recommendations for antiretroviral treatment to determine the best time to begin antiretroviral therapy.

a. CD4 testing is available in the northern district of Serosia. What are the WHO recommendations as to when adults and adolescents should begin ART?

b. CD4 testing is not available in the western district of Serosia. What are the WHO recommendations as to when adults and adolescents should begin ART?

Unit 2 Summary

- The increased use of ART resulted in the need for WHO to update its HIV clinical staging criteria, linking them to recommendations for initiation of ART.
- The 2006 WHO clinical staging criteria harmonize the adult and paediatric clinical staging criteria into four stages and provide for inclusive immunological criteria.
- The 2006 WHO clinical staging criteria are used in the surveillance case definitions.
- WHO recommends that countries standardize their surveillance practices and case definitions.
- The 2006 WHO surveillance case definitions include:
  - HIV disease (stages 1-4)
  - advanced HIV infection/disease (clinical stages 3 and 4 and/or CD4 count <350)
  - AIDS (clinical stage 4 and/or CD4 count <200).
- WHO recommends that ART be initiated for persons with clinical stage 4 or CD4 stage 3 and <350 or any stage with CD4 count <200. Linking the treatment recommendations to clinical staging and surveillance case definitions should facilitate HIV surveillance.
Overview

What this unit is about

This unit provides an overview of the purpose and importance of HIV case surveillance. It explains:

- the purpose of HIV case surveillance
- methods of conducting HIV surveillance
- reporting sources for HIV surveillance.

Warm-up questions

1. Which of the following is NOT a purpose of advanced HIV disease case surveillance?
   a. To assess trends in advanced HIV disease cases
   b. To provide information on the opportunistic infections associated with advanced HIV disease
   c. To measure HIV incidence
   d. To determine the burden of disease attributable to advanced HIV disease in the region.

2. Which of the following describes case-based HIV surveillance?
   a. All HIV cases reported in a given time period are summarized into a single case report form
   b. A method to estimate the HIV prevalence among women attending antenatal clinics
   c. Each person diagnosed with HIV has a care report form that includes information specific to that person
   d. A system that measures the rate of HIV transmission in selected risk groups.

3. Which of the following variables is not necessary on an HIV case report form?
   a. Clinical stage of HIV at the time of HIV diagnosis
   b. History of sexually transmitted diseases
   c. Name of facility completing the case report form
   d. Mode of transmission (probable risk category).

4. List three potential sources for HIV case reports.

Introduction

What you will learn

By the end of this section, you should be able to:

- list reportable events in HIV case surveillance system
- describe the differences between aggregate and case-based HIV reporting
- list potential HIV reporting sources
- list key variables to include on a HIV case report form.
Defining Reportable Events for HIV Case Surveillance Systems

HIV surveillance programme functions

The primary functions of HIV surveillance programmes are to:

- monitor the HIV epidemic by providing information on the characteristics of persons with HIV infection (all clinical stages) and advanced HIV infection over time
- identify the number of persons currently in need of treatment
- estimate the number of persons who will need treatment in the near future
- provide data for developing and monitoring the impact of prevention programmes.

HIV case surveillance activities can be designed to monitor the full spectrum of HIV disease. The ability of the surveillance programme to monitor the clinical events during the course of HIV infection depends on the extent of clinical care that is routinely provided to persons with HIV infection. Figure 3.1 shows events that surveillance programmes may wish to monitor. Monitoring each of these events will provide data to assist in planning prevention programmes and care and treatment programmes.

Figure 3.1
Monitoring the spectrum of HIV disease
Countries should standardize HIV case definitions for surveillance purposes. All persons meeting the case definition should be reported to the sub-national/national surveillance programme authority. To understand the epidemic and to effectively plan for providing antiretroviral therapy and prophylaxis, it is important to include information on the clinical stage of the patient at the time of diagnosis. Reporting persons with all stages of HIV disease will provide the most comprehensive picture of the epidemic.

Terminology
This unit discusses the options and methods for case reporting. WHO refers to:

- the reporting of all stages of HIV as ‘HIV infection’ reporting
- the reporting of advanced HIV (clinical stages 3 and 4 only) as ‘advanced HIV (infection or disease)’ reporting. This includes AIDS.

HIV infection case reporting
In HIV infection case surveillance, all persons, regardless of their clinical stage, should be reported to the surveillance programme. This includes:

- anyone who is newly diagnosed with HIV at any clinical stage
- anyone who was previously diagnosed with HIV but not previously reported to the surveillance unit
- anyone who was previously diagnosed and reported with clinical stage 1 or 2 who has progressed to clinical stage 3 or 4 is reported again as having advanced HIV infection/disease.

Thus, all persons who have been diagnosed with HIV disease will be reported and their clinical stages and CD4 counts (if available) at the time of diagnosis or closest to diagnosis should be reported as well.

HIV case reporting includes reporting persons with advanced HIV infection/disease. This means that HIV-infected persons who are first diagnosed with HIV at clinical stage 3 or 4 (or CD4 count <350 cells/mm³) will be reported once (as advanced HIV infection). If a person is initially diagnosed with HIV infection at stage 1 or 2, the person will be reported as having HIV infection. If this person deteriorates to clinical stage 3 (or CD4 count <350 cells/mm³), the person will be reported again as having advanced HIV infection. All case reports of persons with HIV infection, including advanced HIV infection, should include the patient’s clinical stage at the time of diagnosis (of HIV infection or advanced HIV infection).

Reporting of all HIV infection cases, regardless of the clinical stage, will be challenging to implement and conduct in developing countries because of various infrastructural constraints and weak information systems. However, this is the goal standard, and in the long term, countries should see themselves moving towards this goal. It is important to begin thinking and planning and to gain experience by undertaking small-scale pilot projects that can eventually be taken to national scale.
Advanced HIV infection/disease reporting (including AIDS)
With advanced HIV disease case surveillance, all persons with a documented HIV-positive test and who have a clinical stage 3 or 4 diagnosis or CD4 count <350 cells/mm$^3$ should be reported to the surveillance system. Persons with clinical stages 1 or 2 or CD4 counts ≥350 cells/mm$^3$ will not be reported to the surveillance system until they reach clinical stage 3 or 4 or have a decline in their CD4 count to 350 cells/mm$^3$. AIDS cases do not need to be reported separately, as they are reported as cases of advanced HIV disease.

AIDS case reporting
AIDS case reporting has been in place in South-East Asia for many years. It has been relatively complete in a few countries, but in most others, few of the AIDS cases have been reported.

For countries in which AIDS case reporting has been relatively complete, (80% or more) continuing AIDS case reporting (that is, clinical stage 4) should be considered. The merit in continuing with AIDS case reporting is that it will permit the tracking of trends.

However, in those countries in which few of the AIDS cases have been reported, countries should switch to reporting of advanced HIV infection (disease), as this option already includes AIDS cases (clinical stage 4) and data on AIDS cases can be easily analysed.

Planning for HIV case surveillance
Although WHO has developed new HIV surveillance case definitions, these will need to be adopted by countries. Countries should:

- identify dedicated staff at the national level (and sub-national, if applicable) who will establish and monitor the HIV case surveillance system
- adopt standardized HIV surveillance case definitions
- conduct rapid assessment/evaluation to determine the current status of the AIDS case reporting system
- work with appropriate staff to incorporate the elements of the case definitions into the country’s notifiable disease list
- determine who is responsible for reporting (such as healthcare providers, counsellors at voluntary counselling and testing sites and laboratories)
- determine reportable laboratory and clinical events (such as positive HIV EIA, rapid tests, western blots, or CD4 tests)
- determine if only newly diagnosed persons (that is, newly diagnosed HIV disease and newly diagnosed advanced HIV disease) should be reported, or if all persons with HIV disease are to be reported (meaning prospective and retrospective case reporting)
- adopt a case report form that is either case-based or designed for aggregate reporting
- develop a model operations manual for case reporting that can be modified at the sub-national level
- Start in a small scale, perhaps in major health centers or urban hospitals to roll out the system, before expanding. ART clinics may be a good starting point as these clinics attract HIV-infected individuals.
Data Collection

Identifying reporting sources

Surveillance programmes should establish or be aware of any laws that mandate reporting and who should report cases. Using this information, surveillance programmes should identify reporting sources where HIV diagnosis, care and treatment occur. The following are some examples of reporting sources:

- healthcare clinics (health centers)
- ART treatment clinics
- tuberculosis (TB) clinics
- voluntary HIV counselling and testing (VCT) sites
- hospice (for advanced HIV disease)
- hospitals
- prevention of mother-to-child transmission programmes
- vital statistics registries (for persons diagnosed with HIV only at death, but they can also be used to provide information on the number of and trends in HIV-related deaths).

These are useful sources for identifying cases because these are places where HIV-infected people can be found. Although all of these sources should be included as places from which cases will be reported, some are more likely to yield a larger number of cases than others. In general, sites at which ongoing care of HIV-infected persons is provided will be the most useful sites to identify cases. This is because these programmes can identify HIV cases, provide information on the clinical stage of disease (and therefore which case definition applies), and provide most, if not all, of the information needed to complete a case report form.

Surveillance officers should contact individuals within these programmes or facilities to discuss case reporting, provide case report forms and promote timely and complete reporting from staff at these sites.

Ways to identify cases

New cases of HIV infection are found mainly by passive surveillance. In a passive surveillance system, healthcare providers identify individuals who seek care at a facility and report those who meet the case surveillance definitions. The data are then forwarded to the next level in the surveillance system. The ability of a passive reporting system to identify and report all individuals who meet the surveillance case definition depends on how many HIV-infected individuals have access to HIV testing, get tested, obtain care at a health facility, and then get reported. In other words, the completeness of reporting (that is, the sensitivity of the surveillance system) depends both on individual behaviour (seeking testing and care) and the extent to which healthcare providers complete and forward case reports. The sensitivity of the surveillance system can be improved by increasing access to testing—providing HIV testing facilities at primary healthcare centers, using rapid tests, providing confidential and high-quality counselling and testing services, taking steps to reduce HIV-associated stigma, and ensuring that health staff are well trained in HIV surveillance.
Case Reporting Methods

Case-based and aggregate case reporting

In many developing countries, information at individual level is collected at health facilities using a single form for each individual or a line register where each line is dedicated to one individual. Each facility sends the forms/line register to the next level—that is, to the district or province. At the district/province level, the data are aggregated (that is, a single form summarizes all of the patients who were diagnosed with the condition at all the health facilities in the district in a given time period). The data are aggregated by demographic characteristics, risk profile, clinical characteristics, etc. (See Annex 3.1 for example.) Such an approach is called aggregate case reporting and is often simpler than case-based reporting. However, it is not as flexible, as it does not allow data to be analysed in ways that are not pre-determined.

In contrast, in a case-based reporting system, each person diagnosed with the condition is reported using a separate case report form. In this way, information that pertains to that patient specifically is collected and forwarded to the health authorities all the way up to a level where data are computerized. (See Annex 3.2. for example.) Case-
Based reporting allows for analysis of surveillance data in a variety of ways. As countries adopt patient-level monitoring of ART, HIV case-based surveillance systems should also be scaled up.

**Educating providers**

Surveillance officers and their staff should educate providers regarding:

- the importance of HIV case reporting
- reporting requirements, laws and regulations
- case definitions
- how to complete and forward a case report form
- the timeframe in which to report cases (newly diagnosed only, or previously diagnosed as well as newly diagnosed).

At each of the reporting sites, you should identify a liaison. This is the person who will be responsible for case reporting and will be the contact person for the surveillance programme.

The surveillance programme should provide the reporting sites with the following:

- case report forms
- instructions for completing the forms
- information on who and how to contact the surveillance officer if questions arise.

**Laboratory-initiated reporting**

*Laboratory reporting* is a method in which the laboratories notify surveillance programmes of patients who should be reported. Laboratory reporting is an important component of HIV reporting, although it is not currently practiced in SEAR countries. In most SEAR countries, all public-sector laboratories reporting HIV EIA/Western blot are attached to VCT centers. CD4 testing is done at only a few public-sector laboratories attached to centers where HIV care/ART is provided. Information for surveillance purposes is collected through the VCT or healthcare/ART centers attached to the laboratories.

Laboratory-initiated reporting differs from provider-initiated reporting. Laboratories do not diagnose patients and do not, in general, have enough information to actually report individual cases. However, they are an important source of information for surveillance programmes. The feasibility of setting up a laboratory-initiated system in the private sector can be explored to increase the completeness of reporting.

When laboratories notify surveillance programmes of persons who are likely to have HIV infection, care must be taken to include such information that would facilitate surveillance programme officers follow up with the healthcare provider and to report the case.

The following information should be provided by the laboratory to the surveillance programme officers so that the surveillance programme can follow up cases:

- patient’s name or code
- sex
- date of birth
• laboratory identifier
• date of test
• test result
• requester/provider name and telephone number.

**When to report cases**

If you have an HIV case reporting system (Option A), a case should be reported when:

- the person is diagnosed with HIV infection, regardless of clinical status
- when a person previously diagnosed and reported with HIV clinical stage 1 or 2 deteriorates to advanced HIV disease
- an HIV-infected person dies.

If you have an advanced HIV case reporting system (Option B), a case should be reported when:

- an HIV patient is diagnosed with clinical stage 3 or 4 or CD4 count <350 cells/mm³ (note the need to consider CD4% in children <18 months)
- an HIV-infected person dies.

Countries are not required to report AIDS cases if they are reporting advanced HIV infection cases. If countries wish to continue reporting AIDS cases (feasible only in countries that have a well-functioning AIDS case surveillance system in which completeness of reporting has been at least 80% over the past several years), a case should be reported when:

- an HIV patient is diagnosed with clinical stage 4 or CD4 count <200 cells/mm³ (note the need to consider CD4% in children <five years)
- a person with AIDS dies.

Surveillance staff should work with healthcare providers and others who will be responsible for completing case report forms to ensure that case reports are submitted at appropriate times. Consider Table 3.2:

**Table 3.2**

**Clinical stages and immunologic criteria to report cases for HIV case surveillance options**

<table>
<thead>
<tr>
<th>HIV case surveillance options</th>
<th>Clinical stage and immunologic criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 or 2 or CD4 count &gt;350 cells/mm³</td>
</tr>
<tr>
<td>HIV case surveillance</td>
<td>Submit case report form</td>
</tr>
<tr>
<td>Advanced HIV infection/disease surveillance</td>
<td>3 or 4 or CD4 count &lt;350 cells/mm³</td>
</tr>
<tr>
<td></td>
<td>Submit case report form</td>
</tr>
<tr>
<td>AIDS case surveillance*</td>
<td>4 or CD4 count &lt;200 cells/mm³</td>
</tr>
<tr>
<td></td>
<td>Submit case report form</td>
</tr>
</tbody>
</table>

*Note that a single patient who is initially diagnosed with HIV clinical stages 1 or 2 and later deteriorates to clinical stage 3 or 4 should be reported again as a case of advanced HIV disease.
**Mandatory variables for counting cases**

A minimum amount of information must be available at the surveillance office in order to count a patient as an HIV case. This information is submitted using the case report form. Only those cases that meet the WHO HIV or advanced HIV disease case definitions should be reported.

The mandatory variables required on the case report form for the surveillance programme to count a reportable case are:

- case identifier (name or code)
- sex
- date of birth
- date of diagnosis by laboratory or healthcare provider (use the earliest date)
- clinical stage
- date of death (or number of deaths if using aggregate reporting).

**Updating and un-duplicating cases**

Countries that adopt case-based surveillance systems will have *longitudinal computerized databases*.

Longitudinal databases will permit:

- the addition of new information into the existing case record
- the ability to capture the time at which the patient was diagnosed and reported with stage 1 or 2 HIV disease deteriorates to advanced HIV disease
- inclusion of information on date of death (and possibly cause of death)
- adding start dates for care, ART and prophylaxis.

For countries that adopt a case-based surveillance system, HIV cases may be reported more than once. This is because individuals/patients may get tested at more than one site or may change the place that they receive healthcare. When that happens, both the original and the new healthcare provider will report that patient.

The surveillance system should be able to correctly distinguish newly reported persons from persons previously reported. Problems related to inaccurate linking include the following:

- over-counting cases if cases were not properly linked (that is, two reports that are submitted for the same person are thought to represent two different people and are counted as two cases rather than one).
- under-counting cases if cases were incorrectly linked (that is, two reports for two different people are thought to be two reports for the same person and are counted as only one case).

To avoid an inaccurate count of cases, the surveillance programmes at which case-level data are maintained should routinely un-duplicate their cases. The simplest way to do this is to determine the case variables that will be used to un-duplicate the cases. At a minimum, these should include the patient identifier (name or
code) and the date of birth. Additional information that is likely to be unique to that individual (for example, address) can also be included as the variables used for un-duplicating cases.

As individual cases are reported, the surveillance staff should compare the name/code and date of birth (plus any other unique variables) with previously reported cases. In general, if there is a correct match on the name and date of birth, it is highly probable that it represents a duplicate case report. Un-duplicating cases when a code, rather than a name, is used is more problematic, unless the code includes at least some parts of the patient’s name. At a minimum, surveillance programmes should standardize the methods used for un-duplicating cases so that all staff responsible for un-duplicating case records do so using the same standardized method.

Although un-duplicating cases is important for gathering an accurate case count, there will be situations in which the information necessary to un-duplicate cases is either not available or in which two or more case reports from the same individual are not properly matched. This situation results in over-counting cases and occurs more frequently in settings where cases are identified with codes rather than names.

**Forwarding case reports**

Each country must determine the reporting chain for HIV case reports. This may involve forwarding report forms from healthcare providers to a sub-national level, but ultimately, HIV case reports should be sent to the national surveillance unit where a complete database should be maintained. An example of a three-tier reporting structure is given below:

Figure 3.2

**Three-tier reporting structure**

Roles and responsibilities

For case reporting to be successful, a clear understanding of the roles and responsibilities of national and sub-national surveillance programmes should be delineated and communicated to all parties involved in case reporting. Ongoing communication regarding roles and responsibilities should produce a spirit of cooperation and lead to quality surveillance data.
### Table 3.3
**Responsibilities of the national HIV surveillance programme**

- develop operational guidelines on HIV surveillance
- train and assist surveillance programmes at the sub-national level
- maintain a complete and accurate HIV surveillance database that is secure and has limited access by authorized personnel only
- analyse, interpret and disseminate HIV surveillance data
- critically assess the performance of the surveillance programmes through ongoing monitoring of surveillance activity
- provide overall guidance and training of sub-national surveillance programmes.

### Table 3.4
**Responsibilities of the sub-national HIV surveillance programme**

- solicit, receive, review and file HIV case reports on a timely basis
- ensure that case reports are filled out completely, accurately and clearly
- evaluate each case report to determine if it meets the criteria for HIV diagnosis
- evaluate each case report to determine if it contains enough information for determination of clinical stage (that is, documentation of the clinical stage, clinical information that can be used to determine clinical stage or immunological information such as CD4 count/percent)
- ensure that minimum data elements are documented (that is, demographic characteristics, geographic region, risk information, diagnosis date and report date)
- conduct follow-up investigations on cases of epidemiologic importance
- maintain a complete and accurate HIV surveillance database that is secure and has limited access by authorized personnel only
- identify reporting sources, provide an active liaison with physicians and institutions who are reporting cases, abstract medical records to generate case reports when necessary, and supply routine feedback to providers in cases reported.

### Table 3.5
**Responsibilities of healthcare providers**

- complete HIV reporting forms for each person newly diagnosed with HIV infection
- complete HIV reporting forms for persons with a change in clinical status (for example, clinical diagnosis of advanced HIV disease or AIDS, CD4 count <350, etc.)
- complete HIV reporting forms upon death of HIV-infected persons (and include cause of death, if available)
- submit forms to sub-national or national-level surveillance unit, as per reporting chain for the country (under confidential cover, see Unit 5)
- record each instance of case reporting to the surveillance unit on patient’s clinical record.
Case Report Form

Purpose of an HIV case report form

The purpose of the case report form is to standardize the collection of information that is obtained on all reported HIV cases.

An HIV case report form is designed to:

- collect information that promotes understanding of HIV infection, morbidity and mortality
- facilitate reporting an HIV case (person diagnosed with HIV)
- standardize the collection of variables.

Elements of a case report form

A comprehensive case report form should include:

- Administrative information:
  - name and address of facility completing report (reporting source)
  - date form completed
  - report status (new or update)
- Demographic information:
  - patient identifier (name or code)
  - date of birth
  - sex
  - race/ethnicity (if applicable)
  - current status (alive, dead, unknown)
  - country of residence
- Information on the patient’s HIV-related risk behaviour:
  - sex with male
  - sex with female
  - injected non-prescription drugs
  - perinatal/mother-to-child transmission
  - blood transmission-related variables
  - occupational exposure
- Diagnosis information:
  - date of HIV diagnosis
  - facility of diagnosis
- Clinical stage:
  - date of first clinical stage
  - clinical stage
  - date of first clinical stage 3 diagnosis
  - date of first clinical stage 4 diagnosis
- Immunologic status:
  - date of first CD4 test
  - result of first CD4 test (count and/or percent)
  - date of first CD4 count <350 cells/mm³
  - date of first CD4 count <200 cells/mm³
• Care and treatment:
  • use of ART
  • date first used ART
  • use of prophylaxis against *Pneumocystis carinii* pneumonia

• Vital status:
  • date of death
  • cause of death

Countries should carefully consider which elements to include in the case report form. The form should only include information that is readily available to the person completing the form and information that can be collected from most of the reporting facilities. In addition, the case report form should not be overly burdensome to those who need to complete it.

Surveillance programmes should determine the types of personnel who are responsible for completing the case report form. Issues of patient confidentiality should be carefully considered when making this determination. For example, physicians may report cases, but careful thought should determine whether support staff, such as clerical staff at voluntary counselling and testing sites, should be permitted to report cases. All persons involved in reporting patients with HIV disease should be provided with information on the need for and methods to protect patient privacy.

**Modifying and piloting the case report form**

A generic HIV case report form is shown in Annex 3.3. This form can be modified to meet country-specific issues and be tailored to ensure that the terminology used is easy to understand. Providing education and instructions on how to complete the reporting form is essential in order to achieve accurate and standardized case reporting. Prior to adopting a new case report form, the form should be pilot-tested at a selected number of reporting sites and modified on the basis of the results from the pilot testing.

**Monitoring Mortality in HIV Surveillance**

**Why monitor HIV deaths**

Monitoring mortality is an integral part of an effective HIV case surveillance system. Information on HIV-related deaths is a useful method of:

- measuring the impact of HIV-related care and treatment
- assisting countries in estimating the need for future care of HIV-infected patients with HIV disease
- estimating the size of the workforce
- demonstrating the relative impact of HIV-related mortality as compared to other causes of death
- estimating the number of years of productive life lost
- measuring the number of orphans resulting from HIV deaths in parents.

**Interpreting trends in HIV deaths**

As the number of HIV-infected persons receiving ART increases, the number of deaths attributable to HIV should decline. This can provide a good marker for the impact that
ART has on HIV-related mortality. If the vital statistics programme collects causes of death, analysis of the death registry data alone can be used to determine the magnitude of HIV-related deaths relative to other causes.

As HIV-related deaths decline, the number of persons living with HIV infection (that is, the prevalence of HIV) will increase. It is important not to mistake this increase in prevalence as an indication that the epidemic is worsening. Use of HIV sero-surveys among women attending antenatal clinics should be monitored, with special attention to trends in the HIV prevalence among the youngest women as an estimate of trends in HIV incidence. In addition, if additional methods to estimate HIV incidence are used in the country, the results from these activities should be considered as well.

ART monitoring programmes often collect ongoing information on patients. Collecting annual data on persons previously reported with HIV can be used to determine if the patient is still alive. At times, a death will be known to the ART monitoring staff. This information can also be provided annually to the surveillance programme, where it can be used to update the case record. If the data are reasonably complete, they can be used in the same manner as death data obtained from vital records.

**Identifying patient-level deaths**

Individual data on deaths can be obtained in three ways:

- through matching case-based HIV reports with vital statistics programmes
- through periodic follow-up reviews of patient records in ART-monitoring programmes
- through HIV case report forms submitted when an HIV-infected person dies (regardless of the cause of death).

Some countries have well-functioning vital statistics programmes. If these countries conduct name-based HIV case surveillance, matching of the two registries can provide case-level information on HIV cases who have died, regardless of the cause of death. If HIV testing rates are high (so that most HIV-infected persons are diagnosed), and HIV case surveillance and death registries are complete, then adding the date of death into the HIV case registry provides a reasonably good estimate of the number of persons living with HIV. This information can be used to estimate the number of persons who are currently, or will soon be in need of care and treatment.

**Additional methods of monitoring HIV deaths**

In developing counties where vital registries are not comprehensive, alternative methods have been used to determine the number and causes of deaths. Two examples of methods to obtain the number of deaths are:

- the Sample Registration System
- demographic sentinel surveillance.

Both these systems involve sampling a section of the population and monitoring this sample for vital events including births, deaths and migration out of the area.
Although these systems are not as complete as well-functioning vital statistics systems, they are useful methods of determining estimates of vital events.

To provide the causes of deaths in these sampled populations, verbal autopsies can be used. Verbal autopsies are a way of assigning cause of death to persons who have died outside of hospital (where causes of deaths are usually recorded). Once a death has occurred in one of the sampled sites, a health worker conducts an interview with a relative of the deceased.

This interview uses a standardized form to:

- gather information on the signs and symptoms the decedent experienced shortly prior to death
- collect additional information about each of these deaths that can be used to determine the probable causes of deaths.

The information obtained from the interview is reviewed by a physician, who assigns a probable cause of death using the International Statistical Classification of Diseases and Related Health Problems.

Unit 3 Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups to discuss these questions.

1. Which of the following are notifiable in your country?

   - HIV infection □ Yes / □ No
   - Advanced HIV disease □ Yes / □ No
   - AIDS □ Yes / □ No
   - HIV/AIDS □ Yes / □ No
   - HIV antibody test □ Yes / □ No
   - CD4 counts □ Yes / □ No
   - If yes, what level/count is reportable? □ all □ <200 □ <350
   - Viral load □ Yes / □ No
   - Others, specify:

2. If your country conducts case-based reporting, what sort of information is recorded on the form that could be useful for determining the clinical stage of disease?

   - Case reporting is not done in my country
   - Clinical presentation (HIV/AIDS indicator conditions)
   - Clinical staging is recorded by provider
• CD4 counts
• No information is recorded that can be used for clinical staging.

Comment:

3. With the WHO revisions presented earlier, will the surveillance case definitions for HIV infection have to be changed in your country?
   □ Yes / □ No

If yes: Specify what aspects will have to be changed, and explain what changes will be needed in the following:

• notifiable diseases list:
• case definitions:
• case reporting forms:
• detailed case investigation forms:
• reporting sources:
• data flow
• others-

4. Describe the form that is used to report cases with HIV infection in your country. Is it specific to HIV and/or AIDS or it is used for reporting all cases of notifiable diseases?

5. Is there a separate form for investigation of HIV or AIDS cases? List the forms and describe their use.

6. Review your country’s HIV case report form (or AIDS case report form if HIV reporting is not currently done in your country). Does this form include the minimum variables necessary to report a case? If not, what variables are missing?

7. If your country conducts case-based surveillance at any level, complete the table below.

<table>
<thead>
<tr>
<th>Reporting Levels</th>
<th>Patient’s Name</th>
<th>Coded Identifier</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public health facility to sub-national level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public health facility to national level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory to care providers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory to national level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, specify:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Apply what you’ve learned/case study

Work on this case study independently.

You are the district surveillance officer for an urban district in Serosia, a mid-sized country in South-East Asia with a concentrated HIV epidemic. In Serosia, AIDS case reporting has been conducted for many years, but is incomplete. Serosia has opted to conduct reporting of advanced HIV infection (disease) and has implemented a case-based
reporting system from health facilities to the sub-national level. From the sub-national level to the national level, cases are reported in aggregate.

1. List the responsibilities of the surveillance officer at the sub-national and national levels.
2. Identify the methods used and key issues to consider when un-duplicating cases.

**Unit 3 Summary**

- HIV surveillance is used to provide information on the number and characteristics of persons with HIV disease and advanced HIV disease, to determine the current and future need for ART and also prevention programmes; and finally to assess the impact of these programmes.
- HIV case surveillance includes reporting of persons newly diagnosed with HIV, persons previously diagnosed but not reported and persons previously reported with clinical stages 1 and 2 who have now deteriorated to advanced HIV disease (clinical stages 3 and 4).
- Advanced HIV infection (disease) reporting includes reporting of persons with clinical stages 3 and/or 4 and persons with CD4 counts <350, regardless of their clinical stage.
- AIDS case reporting includes reporting of persons with clinical stage 4 and persons with CD4 counts <200, regardless of their clinical stage. AIDS case reporting is not necessary if countries are reporting persons with advanced HIV disease.
- Countries should begin HIV case reporting by identifying staff and resources, adopting the surveillance case definition, determining who will be responsible for case reporting, adopting a case report form (using a case-based or aggregate form) and developing an operations manual.
- Surveillance officers should identify likely sources for cases, such as laboratories, healthcare facilities, HIV and tuberculosis treatment programmes and HIV counselling and testing sites.
- Surveillance officers should work closely with key staff at these sites to integrate surveillance into their programmes.
- HIV surveillance can be conducted using active surveillance methods (in which surveillance officers identify and report cases directly) or through passive surveillance (in which health care providers report cases to the surveillance programme organizers).
- Countries should adopt either a case-based surveillance system (in which each individual will be reported using one case report form per case) or an aggregate surveillance system (in which sub-national surveillance programmes submit one surveillance form that includes the total number of cases and demographic characteristics in aggregate form). Case-based surveillance provides the greatest flexibility for data analysis, but may be too burdensome for healthcare providers and surveillance programmes.
- Monitoring HIV-related deaths can provide useful information. This can, however, be difficult in countries with weak vital statistics systems. Alternative methods of monitoring deaths can involve identifying HIV-related deaths from ART treatment programmes or ART cohorts. In some countries, selected areas use Sample Registration Systems or conduct demographic sentinel surveillance, which identifies vital events in the selected areas. Causes of deaths that are identified in these areas can be determined using verbal autopsy methods.
Overview

What this unit is about
The periodic evaluation of surveillance systems is needed in order to maintain:

- a responsive and relevant system of monitoring shifting disease trends
- effective disease control and management interventions.

Close monitoring of a newly established surveillance system is needed in order to identify and fix incorrect reporting practices.

This unit discusses how to:

- monitor the establishment of the HIV surveillance system
- conduct an effective evaluation, with emphasis on evaluating the completeness, timeliness and validity (or accuracy) of the data collected in the surveillance system.

Warm-up questions
1. List three aspects of a disease under surveillance that an effective surveillance system should monitor.

2. List two methods to measure completeness of case reporting.

3. List two methods to report the timeliness of case reporting.

Introduction

What you will learn
By the end of this unit you should be able to:

- describe how to monitor the establishment of the HIV surveillance system
- describe three elements of a disease under surveillance that a surveillance system should monitor
- describe methods to measure the completeness, timeliness and accuracy of your surveillance system.

Purpose of public health surveillance
Public health surveillance is conducted to describe the extent of and trends in a disease that is determined to be of public health importance. Surveillance is conducted to guide public health interventions (such as prevention, treatment and control).

Why evaluate?
Once you’ve set up an HIV/AIDS surveillance system, you will want to make sure that it remains effective as the epidemic shifts over time. If your system is not accurately capturing information, surveillance and other public health programmes:
will not have the right information to control HIV
• cannot appropriately plan for treatment and prevention
• will not effectively monitor the impact of treatment and prevention efforts.

Ensuring accurate collection of surveillance data
A number of factors contribute to the accuracy and completeness of information collected on persons diagnosed with HIV. These include:

• the clarity of surveillance forms
• the quality of training and supervision of persons who complete surveillance forms
• the care exercised in data management.

Evaluating Surveillance Systems

Purpose of evaluation
Comprehensive guidelines have been developed to address the methods used to evaluate surveillance systems\(^5\). The purpose of evaluating public health surveillance systems is to ensure that problems of public health importance are being monitored effectively. Surveillance systems should be evaluated periodically, and the evaluation should include recommendations for improving quality, efficiency and usefulness. Evaluation of a public health surveillance system focuses on how well the system operates to meet its purpose and objectives. System evaluation provides information to improve services and delivery. Specific objectives of ongoing evaluations of surveillance system may include the following:

• appraising and prioritizing the events to be kept under surveillance
• evaluating the quality of the epidemiologic information produced
• assessing how surveillance results affect disease control and policy
• identifying the elements of the system that can be enhanced in order to improve the quality of information.

The direction and process of the evaluation must be focused to ensure that time and resources are used as efficiently as possible. Focusing the evaluation design for a public health surveillance system involves:

• determining the specific purpose of the evaluation (for example, to assess training needs)
• identifying stakeholders who will receive the findings and recommendations of the evaluation (that is, the intended users)
• considering what will be done with the information generated from the evaluation (that is, the intended uses)
• specifying the questions that will be answered by the evaluation
• determining the standards for assessing the performance of the system.

\(^5\) Centers for Disease Control and Prevention. Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. MMWR 2001;50 (No. RR-13):[inclusive page numbers].
Monitoring and evaluating your HIV surveillance system can help determine:

- if reporting sources are sending case report forms as soon as cases are identified
- the completeness of the variables included on the case report forms
- the number and proportion of facilities reporting cases
- facilities that are not reporting cases.

The methods described below pertain to surveillance programmes that use a case-based system. The ability to evaluate a surveillance system is another benefit of using a case-based reporting system.

Different attributes of a surveillance system can be monitored. Following are examples:

- Is the system flexible?
- Is the information accurate?
- Is the system simple?
- Is the system acceptable?
- Are the data complete?

Three attributes of the surveillance system should be reported at least annually. These are:

- completeness of case reporting
- timeliness of case reporting
- validity (accuracy) of data reported.

**Measuring Completeness of Reporting**

**Measuring the true frequency of HIV infection/disease**

Completeness of reporting measures the proportion of all true cases that are reported to the surveillance system. This definition of completeness should not be confused with measuring the completeness of information that is collected on a case report form. Surveillance programmes should strive to have reporting as complete as possible. As surveillance systems improve, completeness should increase.
One aspect that will improve completeness of reporting is to periodically evaluate the number of facilities that are reporting cases. Surveillance units should identify the specific healthcare facilities that should be reporting and determine the number of cases reported from these sites.

**Methods to measure completeness**

You should evaluate completeness of reporting for a specified time period, such as one year. To calculate the completeness of reporting, divide the number of reported cases during a given time period (such as one year) by the total number of expected cases for the same period. The expected number of cases can be obtained as part of the estimation process using the Workbook/Spectrum models. Completeness is usually presented as a percent.

Table 4.1

**Calculating completeness of reporting**

<table>
<thead>
<tr>
<th>Number of reported cases during the time period</th>
<th>Total number of expected cases during the time period</th>
</tr>
</thead>
</table>

Expansion of case finding is likely to result in the identification of cases that were not reported. Once these cases have been identified, they should be reported and the source of report should indicate that cases were identified during the evaluation of the completeness of case reporting.

**Measuring Timelines of Reporting**

**Measuring timeliness**

Timeliness refers to how soon after diagnosis the case was reported to the authorities (for example, national surveillance officers or Ministries of Health). Timeliness is to be measured at each level. For example, at the sub-national level, surveillance officers will determine the timeliness of reporting from the health facilities to the sub-national level. In order that surveillance data are useful for implementing effective prevention and control measures and in planning care and treatment for infected persons, health officials must know about diseases in a timely fashion.

Timeliness can be measured as one of the following:

- median time between diagnosis of HIV or AIDS and receipt of the case report form
- the proportion of cases that are received within a specified time period, from diagnosis to receipt of report (for example, within three, six or 12 months of diagnosis).

**Standard for timeliness**

Countries should adopt realistic and useful standards for the timeliness of case reporting in their countries. The following are gold standards to strive to achieve:

- 70% of cases should be reported within six months of diagnosis
- 85% of cases should be reported within a year of diagnosis.
How to measure timeliness

Two variables are needed to measure timeliness:

- the date the case was diagnosed
- the date the case was reported.

Table 4.2 demonstrates a four-step process for determining the timeliness of case reporting.

Table 4.2

Determine the timeliness of case reporting

<table>
<thead>
<tr>
<th>Step</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Calculate completeness of reporting at 12 months after the diagnosis year. If completeness is ≥ 85%, then go to Step 2. (A high rate of completeness is necessary, because when reporting is not 100%, timeliness will be overestimated.)</td>
</tr>
<tr>
<td>2</td>
<td>Calculate time (number of months) from diagnosis to report: (report date) - (diagnosis date) OR [(year of report)<em>12 + month] - [(year of diagnosis)<em>12 + month] For example, the report date is May 2004 and the diagnosis date is November 2003. The time interval (in months) is: [(2004</em>12) + 5] - [(2003</em>12) + 11] = 6 months</td>
</tr>
<tr>
<td>3</td>
<td>Determine the number of cases with a time to report ≤ 6 months.</td>
</tr>
<tr>
<td>4</td>
<td>Calculate timeliness of case reporting: Number of cases diagnosed within a year and reported within six months of diagnosis Number of cases diagnosed and reported for that diagnosis year</td>
</tr>
</tbody>
</table>

Timeliness can also be calculated as the median time between the date of diagnosis and the date of report. In this calculation, completeness of reporting should be at least 85%. The timeliness should be calculated for a specified time period, as described in calculating the proportion of cases reported within six or 12 months.

Measuring Validity

Validity measures the extent to which the information on the case report form matches information in the patient record at the health facility. Validity can be considered a measure of the 'truth,' assuming that the patient’s record at the healthcare facility is correct.

You can measure the validity of information collected in the case report forms by re-abstracting data on previously reported cases and comparing the information contained in the original and re-abstracted forms. Table 4.3, below, gives top-level steps for re-abstractation.
Table 4.3

Re-abstraction study steps

<table>
<thead>
<tr>
<th>Step</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Choose a person not previously involved with the data or site to do the re-abstraction check. This person should work for the national surveillance programme and should be familiar with the case report forms and methods for reviewing clinic records, abstracting data and completing the case report form.</td>
</tr>
<tr>
<td>2</td>
<td>Randomly choose a sample of cases at a site.</td>
</tr>
<tr>
<td>3</td>
<td>At the site, go back to patient records (using the unique identification number) for those persons chosen as the sample.</td>
</tr>
<tr>
<td>4</td>
<td>Compare the information (variables) in the record with MOH records.</td>
</tr>
<tr>
<td>5</td>
<td>Record the accuracy of the variables on your national form.</td>
</tr>
</tbody>
</table>

Scheduling re-abstraction studies

For re-abstraction studies, you will need to match case surveillance information to medical record information. The timeframe for re-abstraction should be one day to six months after the initial case report. The timeframe chosen will vary depending on the nature of a country’s record keeping. Because of the difficulty in retrieving medical records using a code-based system, re-abstraction of records reported in code-based systems should be performed soon after the original report is received at the surveillance programme.

Sampling may also be based on an earlier report year, but it may be difficult to obtain medical records for cases diagnosed several years earlier.

Avoid re-abstracting on the same day as the original abstraction, because bias may be introduced if staff members know re-abstraction is immediately to follow. Because archive data may not be available in the future, re-abstraction should be done in a timely manner.

Once a re-abstraction programme is established, all programmes should routinely re-abstract demographic, risk factor, laboratory and clinical data from a representative sample of records once a year to assess the quality and validity of national information.

Sampling strategy

You should use a simple or stratified random sample. You may use stratification if re-abstraction is to occur at several distinct facilities. Ideally, you will include in the sample all health facilities from which case reports were submitted.

Sample size is calculated once before the beginning of the re-abstraction study, using the prior year’s reported case count as a proxy for the expected reported case count. Sampling of cases may occur throughout the year to accommodate the intended sampling frame and stay within the re-abstracting period of one to six months after original abstraction. The size of the sample should take into consideration the number of case report forms to re-review, as well as time and resource constraints. While a sample of 5%-10% is usually adequate, in countries with fewer than 100 cases, it is recommended to include all cases.
Data collection

The re-abstracted data are collected on hard copy or electronic case report forms that indicate the data elements to be abstracted. Re-abstracted forms must be clearly marked as duplicates.

Staff conducting the re-abstraction:

- should be aware of the case records that need to be abstracted, but should not review the original case report form
- should work backward from the date when the initial case report form was completed and re-abstract the data
- should make certain that the case identification number/code is included in the form used for the re-abstraction.

In some situations, the person who is re-abstracting data may come across new information to add to the case report form. Generally, this would be something new in the patient’s clinic record. For example, the patient may have started antiretroviral therapy since the time the initial case report form was completed. The new information can (and should) be collected and added to the document-based surveillance data base. In order to keep the new information separate from the evaluation of the validity of reporting, collect the new information on a separate case report form (which must include the patient’s name or unique identification number/code.)

Unit 4 Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. Has there been a formal evaluation of the HIV (or AIDS, if only AIDS surveillance has been conducted so far) surveillance system in your country? If so, which parts of the surveillance system were evaluated?

2. What was the result of the evaluation? What problems were identified?

3. How were the results shared with district/provincial surveillance staff and clinics?

4. How was the surveillance system modified as a result of the evaluation?

Apply what you’ve learned/case study

Try this case study. We will discuss your answers in class.

Serosia implemented HIV case surveillance two years ago. Samoy is a large province in the coastal area of Serosia and has the country’s major port city. The surveillance
officers of Serosia and Samoy have met to discuss developing an evaluation of HIV case surveillance in Samoy.

a. What should the surveillance officers focus their evaluation on?

b. What criteria should be used to assess the performance of the system?

c. How should the information obtained in the evaluation be used?

Unit 4 Summary

- The accuracy of surveillance data depends on the clarity of case report forms, the quality of training and the supervision of those who complete the forms, and the quality of data management.
- Monitoring surveillance systems can help you determine whether reporting is complete, timely and accurate.
- You can measure the completeness of reporting (that is, whether all of the diagnosed cases are reported to surveillance) by using estimation models to compare the number of reported cases with the number of expected cases.
- The timeliness of reporting refers to how soon a diagnosed case is reported to surveillance, and can be expressed as the median reporting delay or as the proportion of cases reported in a set time period (such as six months).
- The validity of surveillance data measures the accuracy of the information collected on the report forms. Validity can be measured by re-abstracting information for a sample of reported cases and comparing the originally reported information to the information collected upon re-abstraction. Re-abstracting is used to determine the number and types of errors and to correct errors.
Overview

What this unit is about

Persons with HIV infection, and those at increased risk for HIV, are vulnerable to a number of social, legal and physical harms. Because of this, all programmes involved in HIV case surveillance must address a unique set of issues. This unit discusses those issues and provides guidance on methods to ensure that HIV case surveillance data protect patient confidentiality.

Warm-up questions

1. True or false? Because of the urgent need to treat and prevent HIV infection, the issue of confidentiality does not need to be addressed.

   True       False

2. List one reason why case reports from case-based surveillance must include patient identification.

3. Fill in the blank with the most appropriate word.

   If _______________ about HIV infection is violated, subjects may suffer discrimination and stigmatization. They may even be subject to following criminal charges:
   a. privacy
   b. informed consent
   c. confidentiality
   d. beneficence.

4. List three qualities that are necessary to have in a case identifier.
   a.
   b.
   c.

5. True or false? Because healthcare providers are responsible for submitting case reports, they do not need to receive information regarding patient confidentiality or surveillance data from the surveillance officer.

   True       False

Introduction

What you will learn

By the end of this unit, you should be able to:

- identify potential harms caused by the release of information regarding persons reported with HIV
• describe issues of confidentiality and how they relate to HIV surveillance
• describe the purpose of including a patient identifier on HIV surveillance case reports.

Addressing Ethical Issues

Ethical considerations

People and groups at increased risk for HIV infection are vulnerable to a number of social, legal and physical harms. Because of this vulnerability and the stigma (mark of disgrace or shame) attached to the disease, the surveillance system needs to address a unique set of ethical issues. Infected persons in the general population and in high-risk groups have a legitimate fear of societal discrimination and the ways it may affect them.

Groups at increased risk may include:

• sex workers
• injection drug users
• prisoners
• mobile populations
• men who have sex with men
• sex partners of high-risk persons, including those with known HIV infection.

If people fear that information about their behaviour or their HIV status will be used against them, they may avoid HIV testing or provide inaccurate personal information. Successful surveillance in marginalized populations depends on assuring the at-risk and infected communities that information about them will be held in strict confidence and used only for designated surveillance purposes.

An effective surveillance system requires that at-risk populations and populations with known elevated incidence or prevalence of HIV are identified and accessible for:

• HIV testing
• ascertainment and monitoring of behaviour
• care, treatment, social and prevention services
• reporting to the HIV surveillance programme.

In concentrated epidemics, HIV-related public health efforts focus on identification of high-risk and infected persons. In generalized epidemics, public health efforts should focus on both these risk populations and the broader population.

Experience has shown that the general public may respond to information about HIV infection in high-risk populations by calling for restrictive and prohibitive measures. Such measures simply drive risk behaviour further invisible, thus making HIV testing, prevention and care programmes more difficult and encouraging the spread of the virus.
Table 5.1
Potential harms that may occur from HIV surveillance

<table>
<thead>
<tr>
<th>Type of harm</th>
<th>Result</th>
</tr>
</thead>
</table>
| Physical     | • public attack  
               • spousal/partner abuse  
               • domestic violence |
| Legal        | • arrest  
               • prosecution (especially with high-risk populations) |
| Social       | • undesired disclosure to family or peers  
               • workplace discrimination  
               • loss of employment  
               • isolation  
               • loss of healthcare services  
               • exclusion from social environment/network. |

Discussing the table
Examine Table 5.1 and answer the following questions:

a. What are two types of social harm that HIV surveillance may accidentally cause?

b. Arrest is classified as which type of harm?

Confidentiality and data security
HIV surveillance is the joint responsibility of many participants in the healthcare system. Participants include the following:

- national and sub-national surveillance programme organizers
- public and private institutions providing clinical, counselling and laboratory services
- individual healthcare providers
- persons at risk for HIV infection
- HIV-infected persons.

The ability of surveillance programmes to collect, store, use and transmit sensitive HIV case information in a secure and confidential manner is central to the programme’s acceptability and success.

The dynamic nature of information technology is a critical consideration in developing security policies and procedures that will be used to meet the requirements and standards described here. The HIV surveillance system was created before the development of technologies such as laptops, portable external storage devices, and the internet, all of which can be potential sources for security breaches. Now, all Ministries of Health should routinely assess the changing world of technology and adjust security policies and procedures to have adequate safeguards against potential new risks.
Case Identifiers

Why case surveillance requires unique case identifiers

HIV case-based surveillance is unique among infectious disease surveillance systems because of the following factors:

- an individual can only acquire HIV once
- for surveillance purposes, an HIV-infected person is diagnosed and reported with advanced HIV disease only once.

Note that for clinical purposes, someone may be at clinical stage 3 but, following clinical improvement from treatment, respond to treatment and meet the criteria for clinical stage 2. Patient monitoring systems are used to follow these responses to treatment, but for surveillance purposes, case reports should be submitted only for:

- initial diagnosis of stage 1 or 2 disease
- initial diagnosis of stage 3 or 4 disease.

Surveillance programmes need an accurate count of persons with HIV infection and advanced HIV disease. Since patients may move and receive care at multiple facilities, patients may be reported more than once. To have an accurate count of cases, surveillance programmes need a mechanism that can identify duplicate cases and remove the most recently reported duplicate case(s) from the record. The reason to remove the later report is to maintain the earliest date of diagnosis.

If feasible, surveillance programmes may wish to establish longitudinal surveillance data bases. A longitudinal database can:

- follow reported cases over time
- identify when a patient deteriorates from HIV clinical stages 1 and 2 to advanced HIV disease
- permit updating a patient record when additional data are obtained.

In countries that have patient monitoring systems, a longitudinal case-based surveillance system can be developed using information from the patient monitoring system.

Selecting a case identifier

Implementing a case-based surveillance system requires that countries determine the method by which cases will be identified. They must decide whether such systems should employ names or unique identifiers (codes). The UNAIDS guidelines for public health and HIV surveillance ask surveillance programme organizers to consider the following questions:

- Who will be required to report? What clinical information and personal identifiers will they report? To whom will they report?
- How will the proposed system contribute to a more accurate characterization of the HIV epidemic?
- What is known about the completeness of reporting for other notifiable conditions, including those that bear some stigma? How can such experience be used to
anticipate the willingness to cooperate on the part of those who will be required to report?

Surveillance programmes must determine the most effective method of reporting cases that will allow for identifying duplicate case reports and permit longitudinal databases (if these are used).

Surveillance programmes should carefully consider the type of identifier used for case reporting. The case identifier must:

- be unique to the individual
- not change over time (for example, date of birth) or be able to readily determine when a change has occurred (for example, change of name with marriage or divorce)
- be easy to identify from a clinical record
- be something that is, or is derived from, information that is routinely collected.

The most effective method that allows for all of these factors is the use of patient names for HIV case surveillance. Many countries have concerns that use of patient names will discourage at-risk persons from HIV testing and HIV-infected persons from obtaining care. For this reason, surveillance programmes must develop and maintain methods that ensure that surveillance information is kept confidential and secure.

Although patient names are the best method to identify and report cases, countries may choose to develop a code to use for reporting cases. Developing the code should take into account the code’s ability to:

- distinguish and identify duplicate reports for the same person
- distinguish cases with the same code who are different persons
- allow for obtaining follow-up information from the surveillance programme and healthcare provider
- be available without interviewing the patient (that is, should not be created by the patient)
- be evaluated
- allow evaluation of the performance of the surveillance system (that is, permit the determination of the completeness and timeliness of reporting and the validity of the data submitted on case report forms).

Confidentiality and Security Considerations

Why confidentiality is important
Confidentiality protects subjects from adverse consequences that may arise if their personal information is known, such as their:

- HIV infection status
- sexual preference.
If confidentiality about HIV infection is violated, subjects may suffer discrimination, stigma or arrest. Public health officers must maintain the confidentiality of each individual’s records to guard against inadvertent disclosure.

Confidentiality and data security guidelines

Case-based (that is, individual patient-level) surveillance data, whether they contain a name or a code, represent confidential information. It is essential that patient confidentiality is protected. As such, surveillance programme organizers should carefully review their surveillance practices to ensure that surveillance data are held securely. Sub-national and national-level surveillance programmes should develop written policies that address security and confidentiality of reportable data. The following areas should be taken into consideration for the development of such policies and procedures.

- Surveillance data must be maintained in a physically secure environment. Consider the following:
  - make certain that data are in a secure building that cannot easily be accessed to by non-authorized staff
  - consider how to store both paper and electronic data
  - restrict access to authorized staff only
  - develop a data-release policy
  - ensure that any off-site storage (such as a backup system of the data) is secure.
- Data must be transferred in a secure manner.
  - This includes submitting reports from healthcare facilities to the sub-national level and from the sub-national level on to the national level.
  - Specific methods of transmitting surveillance data should consider that data might be transmitted by any/each of the following methods:
    - telephone
    - facsimile
    - email
    - postal service
    - computer file transfer
- Computers that hold surveillance data (even temporarily) must be secure.
  - Surveillance programmes must safeguard the security of:
    - desktop computers
    - laptop computers
    - servers/local area networks.
- Surveillance staff should receive training regarding the security and confidentiality policies and procedures at the time of hire; and periodically thereafter (such as annually).
- A breach in security or confidentiality should be thoroughly investigated to determine the source of the breach. Corrective measures, including additional staff training, should be undertaken to ensure that such a breach does not recur.
Unit 5 Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups by country, region or province to discuss these questions.

1. Think about the staff you work with. How well do you believe that these staff members can maintain patient confidentiality, particularly for patients with HIV infection?

2. What are your concerns for determining a case identifier?

3. What do you think are the current gaps in protecting patient confidentiality in your surveillance programme? You may discuss gaps in the healthcare system in general as well.

4. Are other communicable diseases in your country reported using a case-based system? How are these cases identified? (For example, are these reported using a code or name?)

5. What do you think are the existing barriers to implementing HIV case-based surveillance in which cases are reported by name?

6. Does your country have existing laws that protect public health information?

Apply what you’ve learned/case study
Try this case study. We will discuss the answers in class.

You are the health officer in charge of HIV surveillance for Inyo Province in Serosia. A prominent newspaper in this province recently published a list of names of persons in the province who have been diagnosed with HIV. What steps would you take to investigate this situation?

In the course of your investigation, you learn that a newspaper reporter thought that publishing the list of HIV-infected persons would make an interesting article and bring him fame and promotion. To obtain this list, he called the clerk for the prevention of mother-to-child transmission (PMTCT) programme and simply asked for the list. The clerk was not aware of any problems that might arise by providing the reporter with this list. What corrective action would you recommend?
Unit 5 Summary

- Persons with or at risk for HIV may be stigmatized and made vulnerable to social, legal and physical abuse.
- Fears of stigmatization and harm may result in persons avoiding HIV testing or care.
- Surveillance programmes must develop, maintain and communicate their policies and procedures for ensuring the privacy of reported persons.
- Surveillance programmes should follow established guidelines for protecting patient privacy.
- Surveillance programmes that use a case-based reporting system must determine a unique case-identifier with which to report cases. Options for case identifiers include codes and names.
- Surveillance programmes should balance the benefits of name-based reporting systems (in terms of un-duplicating and following up on reported cases) with the possible negative impact that reporting names might have on testing and care patterns among at-risk and infected persons.
- Surveillance programme organizers should be aware of guiding ethical principles for the conduct of surveillance and ensure that data collected are maintained securely so that confidentiality of reported persons is not breached.
- Published guidelines for security and confidentiality of surveillance data should be reviewed and adopted as needed for in-country use.
Overview

What this unit is about

This unit describes how HIV surveillance data can be analysed, summarized, interpreted and disseminated. It describes the different methods of analysis that can be performed from HIV case surveillance data and the types of reports that should be generated and disseminated. It also outlines the elements of an annual HIV surveillance report.

Warm-up questions

1. List three elements of an HIV surveillance report:
   a. 
   b. 
   c. 

2. True or false? Changes in reporting practices may result in a false increase or decrease in AIDS incidence.
   True  False

3. When describing the HIV epidemic, why is it preferable to perform analysis based on date of diagnosis versus date of report?

4. True or false? Increases in the number of persons receiving ART can result in a decrease in AIDS incidence (new diagnoses of HIV clinical stage 4 disease) regardless of the number of new HIV infections occurring.
   True  False

5. Which of the following are potential target audiences for surveillance reports on HIV?
   a. people who contribute to collecting the surveillance data
   b. healthcare workers
   c. public health officials at the district, provincial, national and international levels
   d. all of the above.

Introduction

What you will learn

By the end of this unit, you should be able to:

• summarize data obtained from HIV surveillance activities
• interpret HIV case surveillance data
• describe the basic elements of an annual HIV surveillance report.
Value of surveillance data

Decisions regarding public health are dependent on quality data. Accurate HIV surveillance data are central to:

- the effective monitoring of trends in HIV infection
- characterization of the populations affected
- identifying the number of persons eligible for ART
- determining the number of persons receiving ART
- the successful development and evaluation of HIV intervention and prevention programmes.

It is also important that surveillance data are presented in a manner that facilitates their use for public health action. Therefore, it is essential that HIV surveillance data meet certain criteria for quality before being analysed and disseminated.

Analysing HIV Case Surveillance Data

Newly established HIV case surveillance

Interpretation of HIV case reporting data should begin only after HIV case reporting has been in place long enough for previously diagnosed cases to have been reported. This may take several years, but it is necessary to be sure that the data, especially trend data, are not misinterpreted. For example, as reporting begins, there may be a bias in case reports, particularly if only selected geographic areas or facilities are being reported. Countries should continue to use data from HIV sero-prevalence surveys to estimate the overall prevalence of infection until HIV case surveillance is determined to be sufficiently complete and can provide a reasonably accurate estimate of the HIV prevalence.

HIV disease is usually asymptomatic for many years. Consequently, HIV-infected persons may not be diagnosed until they seek care for symptoms. As HIV testing becomes more widely available, persons who are at risk for HIV may be tested prior to developing symptoms of disease. This will lead to a more complete count of HIV-infected persons. If HIV testing is not occurring frequently in high-risk populations, HIV case surveillance is unlikely to provide a complete count of infected persons. If your country’s HIV case surveillance report forms include information on the clinical stage of disease, you will be able to determine whether persons in early stages of disease are being tested and reported.

Many countries have not had complete AIDS case reporting. In those countries, initiating HIV case reporting (all clinical stages) along with reporting of advanced HIV disease/AIDS should not affect the interpretation of data. This is because previous AIDS case reporting was not likely to be complete enough to use in a meaningful way.

There are special studies and serologic tests that can be done to estimate HIV incidence. For trends in HIV incidence, countries have traditionally relied on examination of trends in HIV prevalence in the youngest group of women tested as part of the blinded sero-prevalence surveys among women attending antenatal clinics. These data sources, rather than HIV case surveillance data, should be used to estimate the level of and trends in HIV incidence.
Analyses using HIV surveillance data

The term "HIV" in the context of surveillance refers to five categories of cases:

1. new diagnosis of HIV infection cases only
2. new diagnosis of HIV infection cases with later diagnosis of advanced HIV disease
3. concurrent diagnosis of HIV infection and advanced HIV disease
4. diagnosis of new HIV infection with later diagnosis of AIDS
5. concurrent diagnosis of HIV infection and AIDS.

HIV, advanced HIV disease and AIDS case data should be examined to answer the following questions.

- Are new diagnoses of HIV, advanced HIV disease and AIDS increasing, decreasing or remaining stable?
- Which geographic areas (for example, urban versus rural areas) have the highest number of new diagnoses HIV, advanced HIV disease and AIDS?
- What are the demographic and risk characteristics of new diagnosis of HIV, advanced HIV disease and AIDS, and have these changed over time?
- What proportion of persons with advanced HIV disease and AIDS are receiving ART?
- Are there demographic or geographic differences in persons receiving ART?
- What are the most frequent HIV-related opportunistic illnesses and are these changing over time? (This is relevant only for programmes that collect information on specific opportunistic illnesses.)

Interpreting and using surveillance data

Using surveillance data to answer the types of questions outlined above will lead to a better understanding of the HIV epidemic. Surveillance data should be used to describe the epidemic in terms of:

- person
- place
- time.

Data should be used to describe characteristics of people who are currently already infected, those who are newly infected, and how these populations differ. Knowing the infected populations can help treatment and prevention efforts to be directed to those most in need. For example, if a large proportion of HIV-infected persons are commercial sex workers:

- HIV testing programmes can be targeted to commercial sex workers
- linkage programmes to refer infected persons to care and treatment facilities can be made available
- prevention programmes directed specifically at this population can be implemented
- sero-prevalence and behavioural surveillance surveys can be implemented to obtain additional information that cannot be obtained from case surveillance.
HIV disease is usually not evenly distributed within a country. Often there are particular
areas where the disease is concentrated, such as large urban areas or coastal areas. Case surveillance data should be used to locate the areas within a country that are most severely affected. This allows for developing, implementing and evaluating treatment and prevention programmes.

Surveillance data can provide information on how diagnosis of HIV, advanced HIV
disease and AIDS change over time. Keep in mind that case surveillance data reflect
diagnosis of HIV, and may not provide any information on the number and rate of new
HIV infections.

**HIV-related mortality**

Most South-East Asian countries do not have complete death registries. The hope is
that these will be developed over a time. If information on the number and causes of
death is available, surveillance programmes should include the number of and trends in HIV-related deaths.

If countries conduct case-based HIV surveillance that can be linked directly to death
registries, the number of persons living with HIV can be determined. In some countries,
collection of mortality data has improved through wider use of demographic census and
verbal autopsies. If HIV-related mortality data are available, surveillance programmes
should use these data in surveillance reports.

**Misinterpreting surveillance data**

Increases and decreases in HIV, advanced HIV disease and AIDS cases may be due to
factors other than a true decrease or increase in the number of infections and deaths occurring. Consider factors that may influence the interpretation of surveillance data, such as the following:

- Increases or decreases in the size of the population will affect both the number of
  infections and the incidence and prevalence levels.
- Increases in HIV testing—such as expanded voluntary counselling and testing sites
  or changes in HIV testing practices among healthcare providers—may lead to more
diagnoses, but do not necessarily reflect changes in the epidemic.
- Adoption of a new case definition, particularly one that is broader, will result in an
  increase in cases.
- The use of ART delays the progression of HIV disease to advanced HIV disease and
  AIDS, thereby reducing the incidence of these diseases.
- Changes in case reporting practices, such as efforts to increase reporting from
  private providers, should increase the number of cases reported.
- Increases or decreases in the number of healthcare facilities or other factors that
  affect the use of healthcare services can impact diagnoses and reporting of HIV. For
  example, implementing or increasing a user fee may result in fewer people seeking
care, which may reduce HIV diagnoses and care reports.
- Duplicate case reports (more than one report provided for one individual) may lead
to counting one person twice.
A number of factors may affect the true incidence of advanced HIV disease and AIDS, including the following:

- past HIV incidence (keeping in mind the time it takes to develop advanced HIV disease or AIDS after HIV infection)
- ART impact on delaying the progression of HIV to advanced HIV disease or AIDS
- past HIV prevalence (that is, whether the epidemic is mature or new).

Factors that may affect the true prevalence of advanced HIV disease and AIDS cases are:

- changes in HIV-related mortality
- changes in the incidence of HIV (though this is unlikely to impact trends in advanced HIV disease until many years later)
- changes in advanced HIV disease/AIDS incidence that may occur as persons deteriorate from earlier clinical stages to clinical stages 3 and 4 and reflect HIV infection that may have occurred years earlier.

Displaying and Interpreting Surveillance Data

Analysis of the surveillance data should be done with a specific purpose in mind. That is, the surveillance officers/data analysts should know what the data are to be used for. For example, the data may be used by the national AIDS control programmes to assess the direction of the epidemic. In this situation, trends in HIV case reporting, along with trends in data obtained from sero-prevalence surveys, would be used.

Surveillance data may be used with ART monitoring data to measure the proportion of persons eligible for ART who are receiving it. Trend analysis allows programmes to monitor how well ART is reaching those in need of treatment.

Figure 6.1
Reported HIV infections, AIDS cases, and AIDS deaths, Vietnam, by year of report, 1990 through 1999

Listed on the next few pages are examples of some of the ways that data can be displayed.

**Discussing the figure**
Look at figure 6.1 and answer the following questions:

1. What factors may explain the discrepancy in the trends in the number of HIV and AIDS cases between 1992 and 1994 (that is, high numbers of HIV cases, but relatively low number of AIDS cases)?

2. What would you expect to happen to the number of AIDS cases and deaths in the absence of ART in 2004?

**Discussing the figure**
Look at figure 6.2 and answer the following questions:

![Figure 6.2](image)

1. Describe the trends in the number of ART centers and how this relates to the number of persons on ART and the number of persons alive and on ART.

2. Why are the trend lines for the number of patients on ART and the number of patients alive and on ART the same?

**Discussing the figure**
Look at figure 6.3 and answer the following questions:

1. Describe the trends in the number of patients who are eligible for ART. Explain what this means in terms of what the national AIDS control programme should consider when planning for the number of persons who might need ART in 2007.

2. What are some possible explanations for why are there more patients in HIV care than those receiving ART?
Presenting HIV Surveillance Data

Target audiences for surveillance reports

Surveillance reports need to be disseminated to those who are responsible for decision-making. HIV/AIDS surveillance reports are one of the primary means of communication with colleagues, co-workers and other stakeholders in the HIV/AIDS epidemic.

Potential target audiences for surveillance reports on HIV/AIDS include:

- those who contribute to the collection of the surveillance data
- healthcare workers
- public health officials at the district, provincial, national and international levels
- government officials, policy-makers and planners
- journalists/professional writers
- the general public.

Figure 6.4

Frequency distribution of AIDS opportunistic illnesses
Meeting minimum performance standards

Before analysis, HIV/AIDS surveillance data should meet the minimum quality standards for timeliness and completeness. Additionally, any report or presentation of the data should include a discussion of the quality and limitations of the data.

For example, many South-East Asian countries have had AIDS case reporting only from selected healthcare facilities that provide care for HIV disease. Reporting from these facilities may be complete, but this does not mean that reporting for the country is complete. Analysis of surveillance data should always consider the extent to which reporting is incomplete. When using surveillance data, incomplete reporting should be mentioned as a limitation. When possible, you should use methods to estimate the proportion of missing cases.

Preserving patient privacy

To reduce the risk of inadvertent identification of individuals, it is essential that data be presented in a way that preserves the confidentiality of persons in the HIV/AIDS database. Countries should establish data-release policies that are described in writing and are available for anyone who has access to case surveillance data. Policies for data release should:

- be guided by knowledge of the overall population characteristics and distribution, and of the HIV-infected population
- maintain confidentiality
- permit use of surveillance data for public health purposes
- specify who can receive case surveillance data and in what format.

The data-release policy should address reports from the surveillance programmes, as well as the release of surveillance data for any other purposes.

How data should be presented

Data can be presented in graphical/tabular format and narrative format. There are important considerations for presenting data. Below are some minimum standards for graphical/tabular formats.

All figures must include:

- clear titles including time period
- labelled axis
- data source
- footnotes
- interpretation (including limitations of data).

Additionally, when presenting HIV/AIDS data, you should follow local confidentiality procedures for displaying small cell sizes (5).

Presenting trend data

To assess trends in HIV cases, deaths or prevalence, it is preferable to analyse and present the data by year of diagnosis. Analyses by year of diagnosis will more closely reflect the reality of the HIV trends. Presenting data using the date of the case report inserts an artefact of reporting delays.
Formats for Disseminating Results from HIV Surveillance

Communicating surveillance results

A variety of modalities can be used to disseminate the results from analysis of surveillance data. The format used should be tailored to the audience.

Different audiences require different information and presentation styles, based on:

- their familiarity with the terminology and concepts of surveillance
- the action they will take based on the information, perhaps determined by their position in the HIV/AIDS public health structure
- whether their interest is in specific information or a comprehensive overview
- their motivation to review the data critically
- their needs or expectations.

The more organized the report, the more effective it will be in meeting the objectives.

HIV surveillance report

An HIV surveillance report should be published on a regular basis (annually, at a minimum) The HIV surveillance report will present descriptive statistics to those who report the data, to other units of the Ministry of Health, to national AIDS programmes that use HIV surveillance data to target or prioritize services for HIV prevention and patient care, and to the public. The report should include observed trends of the HIV epidemic, observed risk patterns, transmission categories, age, sex and geographic distributions.

Annual epidemiological report

The purpose of this report is to use the strategic information available in the country to publicize about the HIV epidemic to all concerned. The report provides data from all HIV/STI surveillance activities (HIV case reporting, HIV sentinel site reports, HIV sero-prevalence surveys, STI syndromic/aetiology surveillance, etc.) as well as other related programme areas (such as tuberculosis control programmes, prevention of mother-to-child transmission programmes, and care and treatment programmes). Ideally, this report can summarize the state of the HIV epidemic.

Fact sheets

Fact sheets are brief descriptions focused on a specific subject. They are written in simple language and are formatted to convey basic information on a single topic or subject area. In areas where multiple languages are spoken, some fact sheets may need to be translated into other languages. Fact sheets will often include contact information for follow-up when more in-depth information is desired. They can also be tailored to address local populations of interest. Examples of these populations include:

- gender
- risk category
- age groups (paediatric, adolescents, 50+)
- populations of special interest (sex workers, homeless, migrant populations, etc.).
Recommended analyses include:

- annual number of cases, percentages
- case rates per 1,00,000 population.

**Slide sets and presentations**

Visual presentations of surveillance data are useful for conveying information to the Ministry of Health staff, the National AIDS Programme staff, community-based organizations (CBO), community-planning groups, the general public, international donors and policy-makers. Graphic presentations can add interest and impact to numeric data of comparisons, trends, etc. Slides prepared in Power Point (or similar programmes) can be used for electronic presentations, embedded with text in printed reports or printed as posters/displays. Slide sets can address similar topics to the fact sheets and should be updated annually. Examples of information included in these slides are below:

- summary data
- geographic distribution
- trends (five or 10 years)
- proportions by demographic factors (race/ethnicity, sex, risk).

Recommended analyses include:

- annual number of cases, percentages (5-10 years)
- annual case rates per 1,00,000 population over time (5-10 years).

**HIV Surveillance Report**

As mentioned before, an HIV surveillance report should be published on a regular basis (annually, at a minimum) to present descriptive statistics to those who report the data, to other units of the Ministry of Health and National AIDS Programmes that use HIV surveillance data to target or prioritize services for HIV prevention and patient care, and to the public. The report should include observed trends of the HIV epidemic, the risk patterns observed, transmission categories, age and sex distributions and geographic distributions.

In addition to the annual report, medium and high morbidity areas should also consider publishing summary data on a quarterly or semi-annual basis. Producing and distributing a routine report will decrease the number of individual requests for data.

The report can be developed including the following components:

**Title or cover page**

A title or cover page announces what is to follow. It extends an invitation to the reader.

- The title should describe the content of the report, including the time period covered.
- The title page should also include information on where the data come from (for instance, HIV case-based surveillance for Serosia, the staff who contributed to the report, etc.).
Executive summary
An executive summary abstracts the entire report in approximately one page. This is particularly useful for busy officials who may not have time to read the whole report. Include the salient points in this, especially any recommendations.

Introduction
The introduction includes a statement of objectives/purpose of the report dates and contents of previous reports.

Body of the report
The body of the report includes the methodology of how the data were collected and managed, and the results. This includes the following information:

- definitions of terms used in the surveillance report
- discussion of the quality and limitations of the data (such as timeliness and completeness)
- narrative interpretation of the data presented
- a presentation of the data in a logical sequence (for instance, beginning with the summary or general data and progressing to more specific display of data)
- data presented separately for HIV cases, advanced HIV disease, and AIDS or as combined HIV/advanced HIV/AIDS.

The following analyses should be included in the report for HIV, advanced disease, and/or AIDS. The title of each table or figure should clearly describe the type of data displayed and the time period covered.

- HIV, advanced HIV disease and/or AIDS cases diagnosed in most recent calendar year(s)

- number and percentage of HIV, advanced HIV disease and/or AIDS cases diagnosed in the most recent calendar year, presented by:
  - age group and sex
  - transmission category and sex
  - transmission category for each race/ethnicity/sex group (may not be applicable for all areas, depending on morbidity).

- number, percentage and rates of HIV, advanced HIV disease and/or AIDS cases diagnosed by race/ethnicity in most recent calendar year (if applicable)

- information on trends in new diagnoses of HIV, advanced HIV disease and/or AIDS stratified by age and sex and transmission mode.

In those areas where case-based reports can be linked to death registries, calculation of living cases can and should be conducted. These include:

- the number and percentage of persons living with HIV (including all stages and CD4 counts):
• sex
• age groups and sex
• mode of exposure/sex.

• the number and percentage of persons living with advanced HIV disease (clinical stage 3 or 4 or CD4 count <350, including AIDS):
  • sex
  • age groups and sex
  • mode of exposure/sex.

• The number of persons living with AIDS (clinical stage 4 or CD4 count <200):
  • sex
  • age groups and sex
  • mode of exposure/sex.

Discussion
The discussion section interprets the data and explains the epidemic and how it has changed from previous years. It should also address any biases or limitations to the data. In particular, it should be noted if the data presented are not complete.

Conclusion
The conclusion re-emphasizes pertinent findings and integrates these findings into a comprehensive statement on the state of the epidemic.

Unit 6 Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion
Get into small groups to discuss these questions.

1. Who is responsible for data analysis and reporting at each level, and what kinds of reports are generated?

2. Describe the types of reports that are routinely produced using surveillance data in your country.

3. What do you think will be the effect of HIV case surveillance on the existing trends for your country?

Apply what you’ve learned/case study
Work on this case study independently.

You work in the surveillance unit of Serosia and are responsible for developing the annual HIV surveillance report. You have data from AIDS case reporting nationwide and from a single cohort of patients who received ART in a large urban clinic. Use this information to answer the following questions.
1. What data will you include in your report? Describe some of the ways you might display the data according to the source of the data.

2. The following table shows the AIDS case incidence rates over seven years. The rates are per 1,000 population. Use this information to develop a figure that will represent what you think are the most important aspects of these data.

Table 6.1
AIDS incidence (per 1,000), 1999-2005, Serosia

<table>
<thead>
<tr>
<th>Year</th>
<th>Age group (years)</th>
<th>15-19</th>
<th>20-24</th>
<th>≥25</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>15-19</td>
<td>60</td>
<td>150</td>
<td>103</td>
</tr>
<tr>
<td>2000</td>
<td>15-19</td>
<td>75</td>
<td>160</td>
<td>118</td>
</tr>
<tr>
<td>2001</td>
<td>15-19</td>
<td>20</td>
<td>29</td>
<td>18</td>
</tr>
<tr>
<td>2002</td>
<td>15-19</td>
<td>90</td>
<td>155</td>
<td>120</td>
</tr>
<tr>
<td>2003</td>
<td>15-19</td>
<td>60</td>
<td>162</td>
<td>125</td>
</tr>
<tr>
<td>2004</td>
<td>15-19</td>
<td>50</td>
<td>140</td>
<td>120</td>
</tr>
<tr>
<td>2005</td>
<td>15-19</td>
<td>30</td>
<td>88</td>
<td>100</td>
</tr>
</tbody>
</table>

3. What would you write in your report about these data? (That is, what is your interpretation of these data?)

4. The following table shows information from a clinic that has been providing ART to patients for a few years. Develop a figure that displays the data and provide explanatory text to accompany the figure.

Table: 6.2
Number of persons on ART, 2003-2005

<table>
<thead>
<tr>
<th>% on ART</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>25%</td>
<td>35%</td>
<td>35%</td>
</tr>
<tr>
<td>Women</td>
<td>30%</td>
<td>50%</td>
<td>60%</td>
</tr>
</tbody>
</table>

Unit 6 Summary
- Surveillance data should be analysed and disseminated so that they can be used for public health action.
- Surveillance programmes should be evaluated prior to analysis and dissemination to be sure that reporting is complete. In particular, programmes that have recently adopted HIV (or advanced HIV disease) surveillance should wait until the reporting of cases that were diagnosed in the past is complete.
- When interpreting surveillance data, it is important to consider factors that may falsely indicate increases or decreases in prevalence, such as changes in the size of the population, reporting practices or case definitions.
- Reports that summarize surveillance data should be disseminated to the people who contributed to collecting the data, including healthcare workers, public health officials, government officials and policy-makers, as well as the general public.
- Before analysing and disseminating surveillance data, the surveillance system should be evaluated to make sure that it meets the minimum standards for completeness, timeliness and accuracy.
• Surveillance programmes must take care to ensure that any reports that use surveillance data do so in a way that protects confidentiality.

• Surveillance data can be presented in tables and figures and may have text that explains and interprets the data alongside the tables and figures.

• It is important to present trend data using the date of diagnosis rather than the date of report in order to accurately describe the epidemic without bias from reporting practices.

• Surveillance data may be presented as periodic (at least annual) surveillance reports, annual epidemiologic reports (that include surveillance data as well as additional strategic information), fact sheets, and presentations to specific audiences, such as the staff in the Ministry of Health.
Overview

What this unit is about
This unit provides guidelines for developing an HIV case reporting operational manual and for preparing an action plan to implement HIV case reporting system in a country.

Warm-up questions
1. List the key sections of an operational manual.

2. Which of the following are elements in an implementation plan to initiate reporting of HIV or advanced HIV disease?
   a. timeline
   b. key activities
   c. responsible person
   d. all of the above.

3. True or false? Case definitions for reporting HIV and AIDS cases should be applicable nationally.
   True    False

Introduction

What you will learn
At the end of this unit, you will be able to:

• design an operational manual for HIV case reporting in your country
• develop an action plan for implementing an HIV case reporting system in your country.

To begin action on the HIV and AIDS case reporting system in your country, you will need to:

• develop a country-specific operational manual for HIV case reporting (or modify an existing operational manual used in AIDS case reporting)
• develop country-specific implementation work plans
• outline the steps necessary for implementing case reporting in your country and how this fits within guidelines and operations for regional case reporting.

Operational Manual

What is an operational manual?
An operational manual is a written document that spells out the national policy and procedures on various aspects of HIV infection and AIDS case reporting, including case definitions, sources of data, reporting procedures, data confidentiality and
dissemination. An operational manual should serve the needs of the national AIDS programme and must be consistent with international guidelines on HIV surveillance and case reporting.

Additionally, an operational manual can serve other purposes, like:

- as a reference tool for healthcare workers and surveillance staff
- as a training tool to conduct initial and refresher training on case reporting
- as a tool for monitoring the quality of the case reporting system.

In general, guidelines for surveillance are applicable nationally. Hence, a central agency, such as the surveillance unit in the national AIDS programme, should be responsible for preparing and distributing the operational manual.

**Key sections of an operational manual**

Key sections of an operational manual are briefly described below. (Refer to Appendix E and F)

1. **Purpose of the HIV case reporting system**

   This section should detail the expected purpose that the case reporting system will serve and how the information generated from the HIV case reporting system will contribute to HIV prevention and control activities in the country.

   For example:
   The national HIV case reporting system will be used to plan for the treatment and care needs of HIV-infected persons; in particular, these data will help in planning for procurement of drugs for prophylaxis and treatment of opportunistic infections, and for antiretroviral therapy. Data on demographic and risk behaviours of HIV-infected individuals will assist in characterizing transmission patterns in communities and help in targeting prevention efforts to vulnerable population sub-groups. In areas where completeness of data is adequate, HIV case reporting will assist in assessing and monitoring trends in HIV incidence and prevalence and in ascertaining the burden of disease attributable to HIV in the region. HIV case reporting data will also be used for advocacy and resource mobilization. Finally, HIV case reporting will add to our understanding of the progression of HIV disease and the impact of ART, and in refining epidemiologic assumptions for estimating and projecting the impact of the HIV epidemic.

2. **Reportable events and case definitions**

   This section lists selected events in the spectrum of HIV disease that should be emphasized in the HIV case reporting system. The case definitions of these reportable events will also be provided in this section.

   Each country should decide on the reportable events that will be emphasized in the national HIV case reporting system. All countries in SEAR have an existing AIDS case reporting system, although the reporting of AIDS cases is highly incomplete (except in Thailand). In countries where AIDS case reporting is more than 80%, an AIDS case reporting system may be continued in order to monitor trends using historical data.
In countries where completeness of reporting is very low, AIDS case reporting does not serve much purpose. It is recommended that all such countries implement a new system to start reporting cases of advanced HIV infection (which includes AIDS).

In addition, it is recommended that countries should also consider reporting early HIV infection cases that have not yet progressed to clinical stage 3 or 4. From a perspective of HIV prevention and care, it is undoubtedly of utmost importance to identify HIV infection cases early in order to prevent further spread of infection, as well as to provide the required care, counselling and psychosocial support to the infected individuals. From a surveillance perspective, a comprehensive system that detects HIV infection early is more useful, as it provides a better understanding of the HIV disease and a more complete picture of the HIV epidemic. Ultimately, all countries should aim to move toward the goal of identifying all HIV infections in the surveillance system. Currently, case reporting systems are very weak in most countries because of limitations in the overall public health infrastructure. Hence, countries should use a step-by-step approach in order to reach the ultimate goal of reporting all HIV infections. It is recommended that each country assess the feasibility of implementing a comprehensive HIV infection case reporting system by undertaking pilot studies in a few geographical areas. Based on the experience gained, further strategies of implementing a nationwide HIV case reporting system can be considered.

With regard to case definitions, it is recommended that all countries use the 2006 WHO case definitions for surveillance among adults and children.

3. Reporting sources
This section describes the types of facilities that will be included in the HIV case reporting system. The scope of reporting may include the public sector, NGOs and the private-sector facilities. Reporting of advanced HIV infection (including AIDS) requires clinical staging and (or) CD4 testing, so it should be done from a facility where physicians are available. Examples of reporting sources in the public sector include health facilities where HIV care and treatment are provided, such as primary health centers, district hospitals, PMTCT centers, TB clinics, medical colleges, hospitals, etc. A complete list of such facilities should be created in every geographical area.

4. Variables and data collection forms
The central surveillance unit should identify a minimal set of variables that each reporting unit will be required to report on. Standard data collection forms should be developed and provided to all reporting units by the central surveillance unit. In selecting the variables, ensure that every variable that is collected serves a purpose and will be used for generating information to contribute to HIV prevention and control efforts. Filling out data forms takes time of health workers at the expense of another programme activity. Therefore, case reporting forms should be carefully designed to avoid collecting non-essential information. The case reporting forms may be designed either as individual forms (one for each individual) or in the line-list register format, with one row dedicated to each HIV case.

This section of the manual should also provide instructions on how to complete the case reporting form, as well as definitions of the variables.
Refer to Unit 3 for samples set of variables and sample case reporting forms.

5. Data transmission and reporting procedures
This section outlines how to report, who should report, to whom they should report, and when they should report. This section also describes the levels through which the data should flow from the collection source to the central level of analysis and dissemination.

For example, in a large country like India, a four-tier system may be used for data transmission. In this system, data are collected at the first level in a community health center (a health facility for a population of 1,00,000). Data are then forwarded to the second level—that is, the district surveillance unit—and then to the state surveillance unit, where data are entered in a computerized database. After data entry and removal of duplicate records, the electronic files are sent to the fourth level, which is the central surveillance unit.

On the other hand, in a small country such as Maldives, where few HIV cases are reported each year, HIV case reporting forms may be directly faxed to the national AIDS programme. As much as possible, data transmission should follow and build on the existing data transmission systems for HIV and other diseases.

The flow of data should be schematically presented and should describe how the case reporting forms will be forwarded from the healthcare providers to the surveillance units at the district/state/province level to the national level and back (the dissemination feedback loop).

6. Data management and analyses
This section should describe how data will be managed at different levels of the system. For example, at the source of data collection, a country may collect data on a paper form. Then, at some level, data will get computerized. Systems for paper-based and computerized data management should be described clearly, including the hardware, networks and software used at different levels. This section should also contain information on who is responsible for entering, maintaining, cleaning and analysing the surveillance data.

7. Data security and confidentiality procedures
This section details the data security and confidentiality procedures that support the HIV case reporting system. It describes how case information should be reported, transported and stored. It also describes the actions taken if there is a breach in confidentiality.

8. Roles and responsibilities for programmes and personnel involved in HIV surveillance
This section details the roles and responsibilities for all persons involved with HIV case reporting. This includes roles for reporting sources (such as healthcare providers), sub-national surveillance staff (district/province/state level) and national surveillance staff. The roles and responsibilities should complement the data flow diagram and data reporting procedures.
Refer to Unit 3 for a sample list of roles and responsibilities.

9. Training of staff in data collection, management and analyses
This section outlines a training plan for implementing the HIV case reporting system. A training plan should include who will be trained, in what topics, for how many days, and when the training will occur.

To prepare a training plan, list all staff who are likely to be involved in HIV case reporting system. List the tasks each staff member is required to accomplish. Based on a task analysis, create a list of competencies that each staff must have in order to fulfil his/her role in the HIV case reporting system. Using this list, prepare a teaching curriculum and teaching materials, including handouts/training manual. The training curriculum should differ for staff working at different levels. For example, at the source of reporting, healthcare providers need to know how to fill out case reporting forms correctly, what constitutes a reportable event, how to report (case report form), and what to report (the variables on the case report form). Pay close attention to ensuring that providers understand all the variables on the case report form. Obtaining risk information is always challenging; developing posters or other instructional material that is easy to review can assist providers in accurately collecting this critical information.

The state-level surveillance staff must understand how to enter the data, how to identify duplicate records and how to clean the data. The national staff must be trained in data analysis, interpretation and report-writing. Additionally, all personnel involved in HIV surveillance (MOH and reporting sources/healthcare providers) must attend an annual confidentiality training (See Unit 3).

The training materials should be of high quality and preferably pilot-tested and revised if necessary. The approach to training may differ based on the size of the country. In a large country, a cascade training approach may be required—that is, master trainers should be trained in each state/province. These trainers will, in turn, train other staff in the state/province, who, in turn, will train healthcare providers at the district level.

A single training session is not necessarily adequate. The training needs should be reviewed annually. As you monitor the data submitted by the reporting sources, you may discover a need to train the staff more often if you find that the case reports are incomplete or not filled out correctly. MOH staff outside of the surveillance unit should also be apprised of the changes in the surveillance system.

10. Data dissemination
This section details all the external and internal HIV reports and publications the surveillance unit produces, and when these reports/publications should be available. The purpose of collecting HIV surveillance data is to use it for programme planning. The surveillance unit should work with stakeholders, including other programmes in the MoH, National AIDS Programmes, and National AIDS Committees, to determine their data needs and incorporate them in the reports. You should also consider the following information:

- the type of statistical software programmes that should be used
- which analyses should be conducted monthly, quarterly and/or annually.
11. Standards and monitoring

This section explains how the surveillance system will be monitored in your country. There are general monitoring principles that should be adapted to your setting, such as completeness of reporting, timeliness of reporting and accuracy of data. Details on these topics are provided in Unit 5.

Apply what you have learned

Work with your country team members to discuss each of the following sections of the HIV case reporting operations manual for your country.

1. Articulate the purpose of HIV case reporting system.
2. Identify reportable events.
3. Specify the minimum variables required to report a case.
4. Identify sources of data collection.
5. List variables to be collected.
6. Schematically present data flow (flow chart).
7. Identify training approach.
8. List key elements of data confidentiality.

Implementation plan

Purpose of an action plan

A well-developed action plan allows you to:

• establish clear objectives and outputs
• present your ideas to achieve consensus among all persons involved
• establish a realistic budget
• ensure that the appropriate staff in each facility are trained on surveillance
• determine activities
• determine responsible persons
• establish a deadline for completion of activities.

National Action Plan Worksheet

List of activities

• Identify stakeholders; debrief MoH and NAP.
• Finalize operational procedures manual.
• Finalize and pilot test forms.
• Conduct training of staff at reporting units (go through case report forms, data flow, roles and responsibilities within one month of finalizing forms and operational manual).
• Adapt state/provincial/national database to match the data collection forms
• Train data-entry persons.

You will want to consider other important areas, and may add any of these activities to your action plan:
• determining budget
• determining final training dates
• selecting the appropriate audience for training
• adapting the training curriculum from existing materials
• organizing the training(s) (facility, audiovisual equipment, supplies, etc.)
• evaluating the training
• conducting follow-up activities and site visits after the training in order to reinforce learning.

Timeline
Adding a deadline to an action plan helps you establish a realistic schedule. The sequence of events in planning a deadline is as follows:

• List your activities
• Put the activities in the order you (or your team) will do them
• Add timeline to the action plan.

Why establish a deadline?
Having deadlines:

• provides the overall picture for planning your programme
• helps keep your project on schedule
• avoids assigning too many things to one person
• helps you to meet your programme goals and objectives
• helps you to remember critical steps so nothing is forgotten in the planning process.

How to choose a timeline
When you are developing due dates, think about the following.

• the order of activities
• which activities are dependent on earlier activities
• the overall timeframe for completing the entire activity
• what factors might cause someone to miss a deadline, such as existing schedules, commitments, holidays, vacation schedules or any other sources of delay.

It is important to remember to include the people who will be involved and who will be responsible for meeting the deadlines. If the team is involved in the decision-making process about key issues like deadlines, they will be more likely to meet those deadlines. Everyone involved should receive a copy of the agreed-upon action plan.

Apply what you have learned
Work with your country team members and, using the template provided on the next page, prepare an action plan for implementing HIV case reporting system in your country. You may modify the template as you deem necessary. You may change the order of the activities or add additional activities. Check your calendar to assign realistic deadlines for each activity. Some suggested timeframes have been added to the activities. You may change those if you wish.
### Worksheet for developing action PLAN

**Worksheet 1**

1. What is the name of your country?

2. Who are the stakeholders who will review your plan? Please provide names, if possible.
   - MoH:
   - NGOs:
   - International agencies/donors:
   - Others:

3. List key persons who will be working to complete the actions in the action plan and their position.

   - Develop a contact list with the name, address, phone number, fax number, e-mail address and role of each person.

   - Finalize operational procedures manual:
   - Finalize test forms:
   - Co-ordinate training (logistics, materials):
   - Instructors:

4. List facilities in need of training.

5. List staff in need of training at each facility (community health nurses, family welfare educators, data managers, data-entry clerks, etc.)

6. What is the estimated number of people in need of training? (Multiply the number of facilities by the estimated number of persons at each facility in need of training).

7. What are the best dates to conduct trainings? List conflicting meetings/holidays during which the trainings cannot be held.

8. Are you aware of any sites where training can be conducted? If yes, please list the name and type of facilities in each and how many people each can accommodate at one time.

9. Challenges in implementing your action plans can include:
   - few or no designated trainers
   - lack of or conflicting policies
   - lack of necessary materials
   - scheduling conflicts
   - lack of funds
   - inadequate staff

   List your possible challenges in the column to the right.

10. List resources that you may be short of.

11. How can SEARO and partner organizations help you to implement your plan?
<table>
<thead>
<tr>
<th>Activities</th>
<th>Responsible Person</th>
<th>Resources Needed</th>
<th>Challenges/ Solutions</th>
<th>Target Due Date</th>
<th>Actual Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Debrief MoH and NAP (within one month).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Finalize operational procedures manual (within two months).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Finalize test forms (within two months).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Conduct training of providers and labs (within one month of finalizing forms and operational manual).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Talk with statistics office to obtain death records (within two months).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Check national database to make sure it is set up appropriately.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Train data-entry persons and back-up staff.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Answers are provided in *italics* for each unit’s warm-up questions and case studies.

Answers to the questions within the unit are not included. Questions on tables and figures are designed to stimulate small group discussion among participants in the workshop or class.

**Unit 1 Answers**

**Warm-up questions**

1. What are the key differences between HIV sero-surveillance and HIV/AIDS case reporting?

   HIV sero-surveillance *measures the prevalence of HIV infection using serological survey methods and does not report on individual patients.*

   HIV/AIDS case reporting *refers to reporting of individual patients with HIV disease, advanced HIV disease (clinical stages 3 and 4) and AIDS (clinical stage 4).*

2. True or false? HIV testing of women coming in for antenatal care is a component of HIV case surveillance.

   **True**

   False. *Sero-surveys are conducted in a blinded fashion and cases are not reported.*

3. Which of the following is NOT a purpose of advanced HIV disease/AIDS case reporting?

   a. To determine the burden of disease attributable to advanced HIV disease in the region
   b. To assess trends in advanced HIV disease cases
   c. To provide information on the opportunistic infections associated with advanced HIV disease
   d. To measure HIV incidence.

4. List five surveillance target points in the natural history of HIV disease.

   HIV incidence *(that is, the number or rate of new HIV infections)*; HIV prevalence *(that is, the number or rate of all persons living with HIV, regardless of how long they have been infected or whether or not they are aware of their infection)*; The incidence of advanced HIV disease *(or AIDS)*; The prevalence of advanced HIV disease *(or AIDS)*; Deaths from advanced HIV disease *(or AIDS).*
5. List three reasons for conducting HIV case reporting.

1. to capture the leading edge of the epidemic.
2. to provide a complete count or estimate of the number of persons with HIV infection, because AIDS case reporting does not include asymptomatic HIV-infected persons.
3. to measure the effectiveness of treatment programmes and other interventions.

Case study

Work on this case study independently.

1. You are the district surveillance officer in Serosia in South-East Asia. Serosia has been estimated to have one of the highest prevalence levels of HIV in the region. The National AIDS Control Programme is interested in expanding and improving its surveillance programme and the national surveillance officer is conducting site visits to various districts to discuss ways of improving surveillance. During your meeting with the national surveillance officer, you are asked to suggest additional surveillance activities in your district that you believe could be implemented successfully. Describe what these activities would be.

Ideally, surveillance would be able to measure the following:

- HIV incidence (or recently acquired HIV infections)
- HIV prevalence
- Advanced HIV disease/AIDS incidence (clinical stages 3 and 4)
- Advanced HIV disease/AIDS prevalence
- HIV/AIDS mortality

Developing methods of measuring each of these points in HIV disease may be very difficult. At the minimum, reporting of advanced HIV disease (clinical stages 3 and 4) should be developed. This would require the development of a standardized case report form, training surveillance staff to use the form, locating clinics where HIV-infected persons receive care, and working closely with the staff at the clinics to ensure that reporting is done properly and completely.

2. The national surveillance officer has indicated that there is interest in using data collected from HIV and other care programmes for HIV/AIDS case reporting. What programmes would you suggest using?

- treatment programmes;
- tuberculosis (TB) programmes (especially those that conduct HIV testing among TB patients);
- voluntary HIV counselling and testing programmes;
- programmes that provide for pregnant women (prevention of mother-to-child transmission [PMTCT] programmes);
- vital statistics registries.
Unit 2 Answers

Warm-up questions

1. True or false? In the revised (2006) adult and paediatric WHO AIDS clinical staging systems, there are four clinical stages.

   True  False

   True. Both the adult and paediatric clinical staging systems include four stages.

2. True or false? The revised (2006) WHO AIDS surveillance case definition includes the same clinical stages for adults and infants.

   True  False

   False. Adults and infants may have different clinical manifestations of AIDS and serologic evidence of immunosuppression differs between adults and infants. These differences are reflected in the two case definitions.

For adults the AIDS case definition is:

   A positive HIV antibody test
   AND EITHER
   Any clinical stage 3 or stage 4 disease
   OR
   Where CD4 testing is available, any clinical stage and CD4 count <350 cells/mm³

For infant, the AIDS case definition is:

   The presence of HIV infection
   AND EITHER
   Any clinical stage 3 or stage 4 disease
   OR
   Where CD4 testing is available, any clinical stage with:
   • CD4 <20% TLC in children aged 12-59 months
   • CD4 <25% total lymphocyte count (TLC) in children under 12 months
   • CD4 count <350 cells/mm³ in children aged 5 years and above

3. True or false? The clinical criteria included in the revised (2006) WHO AIDS surveillance case definition only include definitive diagnosis of clinical events.

   True  False

   False. Presumptive criteria may also be used. This is to assist areas in which access to laboratories is limited.

4. List four reasons why HIV clinical staging systems were developed.

   a. provide uniformity for clinical evaluation of persons with HIV infection
   b. as an indicator of prognosis
c. to guide clinical management of patients

d. to help study the natural history of HIV infection.

5. True or false? Previous surveillance case definitions in developing countries focused only on stage 4 (AIDS).

True False

True. Current recommendations for reporting have been expanded to include reporting of advanced HIV disease (clinical stages 3 and 4) as well as reporting of persons with HIV infection at any stage (clinical stages 1-4).

Case study

1. As an HIV Surveillance officer for Serosia, you are charged with standardizing the country’s HIV/AIDS reporting practices. What processes would you implement to insure that HIV/AIDS reporting is standardized?

A surveillance case definition should be adopted. Once it is adopted, all district and provincial surveillance officers should identify persons who diagnose and care for HIV-infected persons to inform them of reporting requirements. Any of the following surveillance case definitions may be adopted.

- All HIV cases (clinical stages 1-4) should be reported.
- All persons with advanced HIV disease should be reported (clinical stages 3 and 4).
- Additionally, all diagnosed HIV cases that have not been previously reported should be reported, using a standard case definition such as the WHO case definition of HIV for reporting.

2. Serosia recently began providing free antiretroviral therapy to HIV-infected individuals. Serosia uses the WHO antiretroviral treatment recommendations to determine the best time to begin antiretroviral therapy.

a. CD4 testing is available in the northern district of Serosia. What are the WHO recommendations for adults and adolescents to begin ART?

If CD4 testing is available, WHO ART recommendations for adults and adolescents call for beginning ART for persons at:

- WHO clinical stage 4 (AIDS) regardless of their CD4 count
- WHO clinical stage 3 whose CD4 count is <350 cells/mm$^3$
- WHO clinical stage 1 or 2 whose CD4 count is ≤200 cells/mm$^3$.

b. CD4 testing is not available in the western district of Serosia. What are the WHO recommendations for adults and adolescents to begin ART?

If CD4 testing is not available, a total lymphocyte count ≤1200 cells/mm$^3$ can be used as an indication of immunodeficiency that is severe enough to begin ART. In the absence of CD4 testing, WHO antiretroviral treatment recommendations for adults...
and adolescents call for beginning ART for persons at:

- WHO clinical stage 4 (AIDS) regardless of total lymphocyte count
- WHO clinical stage 3 regardless of total lymphocyte count
- WHO clinical stage 2 with a total lymphocyte count ≤ 1200 cells/mm$^3$

Unit 3 Answers

Warm-up questions

1. Which of the following is NOT a purpose of advanced HIV disease case surveillance?
   a. To assess trends in advanced HIV disease cases
   b. To provide information on the opportunistic infections associated with advanced HIV disease
   c. To measure HIV incidence
   d. To determine the burden of disease attributable to advanced HIV disease in the region.

2. Which of the following describes case-based HIV surveillance?
   a. All HIV cases reported in a given time period are summarized into a single case report form.
   b. A method to estimate the HIV prevalence among women attending antenatal clinics.
   c. Case surveillance in which each person diagnosed with HIV has a care report form that includes information specific to that person.
   d. A system that measures the rate of HIV transmission in selected risk groups.

3. Which of the following variables is not necessary on a HIV case report form?
   a. Clinical stage of HIV at the time of HIV diagnosis
   b. History of sexually transmitted diseases
   c. Name of facility completing the case report form
   d. Mode of transmission (probable risk category).

4. List three potential sources for HIV case reports.

   Any of the following:
   - laboratories
   - healthcare clinics (health centers)
   - ART treatment clinics
   - tuberculosis (TB) clinics
   - voluntary HIV counselling and testing (VCT) sites
   - hospice (for advanced HIV disease)
   - hospitals
   - blood banks
   - prevention of mother-to-child transmission programmes
   - vital statistics registries (for persons diagnosed with HIV only at death, but they can also be used to provide information on the number of and trends in HIV-related deaths).
Case study

Work on this case study independently.

You are the district surveillance officer for an urban district in Serosia, a mid-sized country in South-East Asia with a concentrated HIV epidemic. In Serosia, AIDS case reporting has been conducted for many years, but is incomplete. Serosia has opted to conduct reporting of advanced HIV infection (disease) and has implemented a case-based reporting system from health facilities to the sub-national level. From the sub-national level to the national level, cases are reported in aggregate.

1. List the responsibilities of the surveillance officer at the sub-national and national levels.

   Answer.

2. Identify the methods used and key issues to consider when un-duplicating cases.

   Answer.
Unit 4 Answers

Warm-up questions

1. List three aspects of a disease under surveillance that an effective surveillance system should monitor.

   - completeness
   - timeliness
   - validity (accuracy of the data).

2. List two methods to measure completeness of case reporting.

   - capture-recapture method
   - expanded case-finding.

3. List two methods to report the timeliness of case reporting.

   - The median time between diagnosis of HIV or AIDS and receipt of the case report form
   - The proportion of cases that are received within a specified time period from diagnosis to receipt of report (for example, within three, six or twelve months of diagnosis).

Case study

Try this case study. We will discuss your answers in class.

Serosia implemented HIV case surveillance two years ago. Samoy is a large province in the coastal area of Serosia and has the country’s major port city. The surveillance officers of Serosia and Samoy have met to discuss developing an evaluation of HIV case surveillance in Samoy.

a. What should the surveillance officers focus their evaluation on?

   Completeness, timeliness and validity. If performance standards are not met, corrective action (such as additional training) should be undertaken.

b. What criteria should be used to assess the performance of the system?

   Performance standards should be developed by the national surveillance programme.

   Surveillance programmes should strive to have reporting at least 85% complete.

   The following are reasonable standards for timeliness:
   - 66% of cases should be reported within six months of diagnosis
   - 85% of cases should be reported within a year of diagnosis.

   c. How should the information obtained in the evaluation be used?
Information obtained from the evaluation should be used to correct discrepancies (when errors are found when conducting an evaluation of validity) and to develop corrective action. The evaluation may identify systematic errors, and correcting these should result in marked improvement in the performance of the surveillance system.

Unit 5 Answers

Warm-up questions

1. True or false? Because of the urgent need to treat and prevent HIV infection, confidentiality does not need to be addressed.

   True  False

False: People and groups with increased risk for HIV infection are vulnerable to a number of social, legal and physical harms, including domestic violence, loss of employment and even arrest. Maintaining confidentiality is very important.

2. List one reason why case reports from case-based surveillance must include patient identification.

   Case reports in case-based surveillance must include patient identification so the programmes have an accurate count of persons with HIV infection and advanced HIV disease. Since some patients receive care at multiple facilities, surveillance programmes need a mechanism that can identify duplicate cases.

3. Fill in the blank with the most appropriate word. If _____________ about HIV infection is violated, subjects may suffer discrimination and stigmatization. They may even be subject to criminal charges.

   a. privacy  
   b. informed consent  
   c. confidentiality  
   d. beneficence

4. List three qualities that are necessary to have in a case identifier.

   a. It must be unique to the individual.  
   b. It must not change over time.  
   c. It must be easy to identify from a clinical record.

5. True or false? Because healthcare providers are responsible for submitting case reports, they do not need to receive information regarding patient confidentiality or surveillance data from the surveillance officer.

   True  False

False: Healthcare providers should be kept informed about the policies regarding patient confidentiality, so they can be certain that information regarding their patients is kept secure. Healthcare providers can reassure their patients that surveillance data are secure and private.
Case study

Try this case study. We will discuss the answers in class.

You are the health officer in charge of HIV surveillance for Inyo Province in Serosia. A prominent newspaper in this province recently published a list of names of persons in that province who have been diagnosed with HIV. What steps would you take to investigate this situation?

A first step is to meet each of the surveillance staff who have access to the data and could have provided it to the newspaper. If this does not yield any information, it would be reasonable to speak with other surveillance staff to determine what they know about the incident and to follow up with the newspaper reporter. You should discuss this incident with your supervisors, such as the director in the Ministry of Health.

In the course of your investigation you learn that a newspaper reporter thought that publishing the list of HIV-infected persons would make an interesting article and bring him fame and promotion. To obtain this list, he called the clerk for the prevention of mother-to-child transmission (PMTCT) programme and simply asked for the list. The clerk was not aware of any problem that might arise by providing the reporter with this list. What corrective action would you recommend?

This breach occurred outside of the surveillance programme and, as such, is not directly under your jurisdiction. However, incidents such as these may cause great harm not only to the individuals whose privacy was breached, but to the surveillance programme as well. Healthcare providers, infected and at-risk persons and the community at large are likely to lose confidence in the ability of surveillance programme, as well as the HIV care, treatment, and prevention programmes' ability to protect patient confidentiality.

This breach provides an opportunity for the Ministry of Health and directors of all programmes in which the identity of HIV-infected persons is known to review existing security and confidentiality policies and procedures. If there are no policies and procedures regarding confidentiality and security, they must be developed. These policies must include a data-release policy that specifies what data can be released, the format (including restrictions) that the data need to be in for release, to whom data can be released and the circumstances that permit release. An appropriate response to the reporter's request might be to provide the number of women who used PMTCT.

As part of the process of developing these policies, you should conduct a review of the country's laws regarding release of public health records (particularly those that pertain to HIV), recommendations from other public health programmes in the country, from the US Centers for Disease Control and Prevention, and from the WHO.

1. Surveillance staff should be trained on all aspects of security and confidentiality, including the data-release policy. Staff should be made aware of relevant laws and punitive actions for breaches of confidentiality and the impact that such breaches may have on the patients involved. If previous training has taken place, staff should be retrained following this incident and receive annual updates in this training. The incident itself should be discussed frankly.
2. Healthcare providers should be informed of the surveillance security and confidentiality policies and procedures so they can be confident that information concerning their patients is protected. Also, you may need to address information to the community in order to reassure the public.

3. If the release of information happened despite existing policies that forbade such release, disciplinary action should be imposed on the staff person who released the information.

Unit 6 Answers

Warm-up questions

1. List three elements of an HIV surveillance report.

   The following elements can be included in surveillance reports:

   1. Title or cover page
   2. Executive summary
   3. Introduction
   4. Body of the report -
   5. The following should be the minimum information included in the report:
      a. number of cases reported during the period (universal reporting)
      b. incidence and prevalence levels (universal reporting)
      c. age and gender of cases (universal reporting)
      d. transmission mode (sentinel AIDS case surveillance only).
   6. Discussion
   7. Conclusion

2. True or false? The conclusion section of an HIV surveillance report is an optional element.

   False. The conclusion should be included and should re-emphasize pertinent findings in the report and integrate these findings into a comprehensive statement on the state of the epidemic.

3. True or false? Changes in reporting practices may result in a false increase or decrease in AIDS incidence.

   True. Changes in reporting practices can change the number of cases reported, but this change is an artefact of reporting and not an indication of a true change in the epidemic. For this reason, it is important to pay attention to reporting practices and to investigate any change in the number of reported cases that seems unlikely to be true.

4. When describing the HIV epidemic, why is it preferable to perform analysis based on date of diagnosis versus date of report?

   Using the date of diagnosis provides information on what is truly happening with HIV diagnoses trends. Using the date of report inserts a bias associated with reporting practices, such as reporting delays. The date of report should be used to evaluate timeliness of case reporting.
5. True or false? Increases in the number of persons receiving ART can result in a decrease in AIDS incidence (new diagnoses of HIV clinical stage 4 disease) regardless of the number of new HIV infections occurring. 

True. ART can delay the clinical progression of HIV disease, which means that HIV-infected persons on ART may not develop AIDS, or if they do, it may take longer than it would have if they were not treated.

6. Which of the following are potential target audiences for surveillance reports on HIV/AIDS?
   a. people who contribute to collecting the surveillance data
   b. healthcare workers
   c. public health officials at the district, provincial, national and international levels
   d. all of the above.

Apply what you’ve learned/case study

Work on this case study independently.

You work in the surveillance unit of Serosia and are responsible for developing the annual HIV surveillance report. You have data from AIDS case reporting nationwide and from a single cohort of patients who received ART in a large urban clinic. Use this information to answer the following questions.

1. What data will you include in your report? Describe some of the ways you might display the data according to the source of the data.

   The case definitions used will affect the type of data displayed. If HIV case reporting is conducted, there will be reports of all persons with HIV disease, as well as those with advanced HIV disease. It is possible that AIDS case reporting will continue (if AIDS case reporting was relatively complete prior to the change in the WHO surveillance case definitions in 2006).

   The characteristics of all persons with HIV (that is, after combining all reports of persons with HIV and advanced HIV disease) should be used to show the characteristics of reported cases as well as trends. The data can be stratified by geographic region, age, gender, transmission category (mother-to-child, injection drug use, homosexual/bisexual, blood or blood products, heterosexual). These same analyses can be done for HIV cases and for advanced HIV disease separately. In addition, the report can list the type(s) of opportunistic illnesses and the proportion of persons with advanced HIV disease who are using antiretroviral therapy.

2. The following table shows the AIDS case incidence rates from universal case reporting over seven years. The rates are per 1,000 population. Use this information to develop a figure that will represent what you think are the most important aspects of these data.
AIDS Incidence (per 1000), 1999-2005, Serosia

<table>
<thead>
<tr>
<th>Year</th>
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<th>20-24</th>
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<tr>
<td>1999</td>
<td>60</td>
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<td>160</td>
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<td>140</td>
<td>120</td>
</tr>
<tr>
<td>2005</td>
<td>30</td>
<td>88</td>
<td>100</td>
</tr>
</tbody>
</table>

Trends in AIDS incidence by age group by age group, 1999-2005

3. What would you write in your report about these data (that is, what is your interpretation of these data)?

_AIDS incidence is lowest in the 15-19 year old group and highest in the oldest group. In 2001, all age groups had markedly lower incidence, suggesting a reporting (or surveillance) artefact. If that year is ignored, it appears that AIDS incidence peaked in 2003 for the two older groups and peaked in 2002 for the 15-to-19-year-olds, and has started to decline in all groups. Depending on when prophylactic and antiretroviral therapies became available, the decline may be due to improved medical care. It is also possible that these declines are due to earlier changes in the HIV epidemic, which may have declined in the earlier years. It is also possible that both of these factors are contributing to these changes._
4. The following table provides information from a clinic that has been providing ART to patients for a few years. Develop a figure that displays the data and provide explanatory text to accompany the figure.

<table>
<thead>
<tr>
<th></th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>% on ART</td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>2003</td>
<td>25%</td>
<td>30%</td>
<td>35%</td>
</tr>
</tbody>
</table>

**Proportion of men and women receiving ART, 2003-2005**

*Between 2003 and 2005, the proportion of both men and women receiving ART increased. Overall, a greater proportion of women received ART than men. The proportion of men on ART increased from 25% in 2003 to 35% in 2005, while for women this proportion increased from 30% in 2003 to 60% in 2005.*

**Unit 7 Answers**

**Warm-up questions**

1. List the key sections of an operational manual.

   The key sections of an operational manual are:
   1. Purpose of the HIV case reporting system
   2. Reportable events and case definitions
   3. Reporting sources
   4. Variables and data collection forms
   5. Data transmission and reporting procedures
   6. Data management and analyses
   7. Data security and confidentiality procedures
   8. Roles and responsibilities for programmes and personnel involved in HIV surveillance
   9. Training of staff in data collection, management and analyses
   10. Data dissemination
   11. Standards and monitoring
2. Which of the following are elements in an implementation plan to initiate reporting of HIV or advanced HIV disease?
   a. timeline
   b. key activities
   c. responsible person
   d. all of the above

   The answer is d. All these are elements in an implementation plan.

3. True or false? Case definitions for reporting HIV and AIDS cases should be applicable nationally.

   True.
Appendix E

Developing a Draft Operations Manual

Approaches to completing your operational manual

Discuss each of the steps in developing the operations manual with your work group and fill in the appropriate sections of the operations manual. Instructions and examples for specific sections of the operations manual are presented in italics. You should delete these instructions and examples after you have completed each of the sections of the operations manual. Note that some parts of the operations manual may require additional investigation to complete. Just leave these sections blank until additional information has been located.

Your country:
Add full title of manual:

E.g. ‘Draft Operational Manual for HIV Case Surveillance’

Add information your stakeholders/reviewers will expect to see on the cover (based on recent documents produced by your Ministry); for example:

Name of your programme:

Address or office location:

Country map, seal, logos:

Date of submission of this draft:

Other:

Acknowledgments

Add name, organization of people who worked on or reviewed the manual.

Follow the lead of other documents developed and released by your Ministry.

Table of Contents

Add/generate here. If the Table of Contents is only one page, keep the next page blank to make the first page of the manual start on a right-hand page.
Figure 8.2. Make the first page of every section start on a right hand page.

If this is an open book...

<table>
<thead>
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<th>Top</th>
<th>This is a left-hand page (even-numbered page); end every section here or leave it blank.</th>
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</thead>
<tbody>
<tr>
<td>Bottom</td>
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</tr>
</tbody>
</table>

**Mission Statement**

Use your department’s mission statement or a new one based on the SEARO mission statement.

**Organizational Chart**

This section outlines the organizational structure of the Ministry of Health. It includes the surveillance unit and other programme units. It’s important for surveillance staff to liaise with programme staff, because HIV prevention and control cuts across several programme areas in the Ministry of Health, including TB control, HIV care and treatment, and maternal and child health.

The organizational structure is often easiest to understand if it is presented as a figure.

```
+-----------------+                  +-----------------+                  +-----------------+
| Director        |                  | Tuberculosis    |                  | Clinical Services|
| MoH             |                  | Control Programme|                  | Health Workers   |
|                 | Disease Control  |                  | Medical Director |                  |
| Disease         | (Surveillance)   |                  | Health Workers   |                  |
| Control         |                  |                  | Pharmacist       |                  |
| Tuberculosis    |                  |                  |                  |                  |
| Control Programme|                |                  |                  |                  |
|                  | Disease Control  |                  |                  |                  |
| Surveillance    |                  |                  |                  |                  |
|                  | Disease Control  |                  |                  |                  |
| Surveillance    |                  |                  |                  |                  |
|                  | Disease Control  |                  |                  |                  |
| Surveillance    |                  |                  |                  |                  |
```

**Description of Geographic Area and Governance**

This section details the geographic jurisdiction for which the surveillance unit has responsibility, including both sub-national and national surveillance programmes. The multi-island nations need to outline who has responsibility for soliciting, receiving, reviewing and filing, analysing and disseminating HIV surveillance data for each of the islands. If there are surveillance programmes on these islands, this should also be reflected in the organizational chart.
### List of Key Contacts

The section lists all the persons at the surveillance programme(s) who should be contacted at the regional or national level if there are questions about HIV surveillance. Information to be included for each key contact:

- name and position of key contact
- areas of expertise
- address
- telephone number
- fax number
- email address.

### List of Reporting Sources

This section details the reporting sources in your geographic area. It is advisable to give each reporting facility a code number that will be recorded on each case reporting form that they submit. Facility/source codes are useful for the following functions:

- monitoring sources/facilities that are reporting cases versus those that are not
- identifying the sources/facility-written facility/source names can differ on forms submitted by different people; source/facility names can change over time
- identifying the sources/facility on the contact list
- preserving patient confidentiality, especially in areas with small populations where the combination of a patient’s name and the facility name may be enough to identify the person definitively.

Information to be included for each reporting source in this section:

- name of clinic/laboratory/provider
- name of primary contact
- name of back-up contact
- address
- telephone number
- fax number
- email address (if available).

<table>
<thead>
<tr>
<th>Facility Code</th>
<th>Facility Name</th>
<th>Facility Type</th>
<th>Contact Officer’s Position</th>
<th>Name &amp; Address</th>
<th>Telephone Fax Email Address</th>
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<tr>
<td>Chief Technologist</td>
<td>Jane Brown-Smith National Public Health Laboratories</td>
<td>1 King Street St. James Serosia</td>
<td></td>
<td>123-456-6789 (ph) 123-456-7890 (fax) Email: <a href="mailto:brown-smith@serosia.net">brown-smith@serosia.net</a></td>
<td></td>
</tr>
</tbody>
</table>
Staff Training

This section outlines the training schedule for MoH staff and reporting sources.

MOH staff will need to be trained on the revised reporting system. Persons should be cross-trained to ensure continuity of the programme. There may be special training needs for staff, such as software and database management training. The needs should be reviewed annually and budgeted appropriately.

MOH staff outside of the surveillance unit should also be apprised of the changes in the surveillance system.

Staff at reporting sources should be trained on what constitutes a reportable event, how to report (case report form) and what to report (the variables on the case report form). Pay close attention to ensuring the providers understand all the variables on the case report form. Obtaining risk information is always challenging, developing posters or other instructional material that is easy to review can assist providers to accurately collect this critical piece of information. This should be conducted annually. As you monitor the data submitted from reporting sources, there may be a need to train the staff more often if you find the case reports are incomplete or not filled out correctly.

Additionally, all personnel involved in HIV surveillance (MoH and reporting sources/healthcare providers) must attend an annual confidentiality training (See Unit 7).

Roles and Responsibilities for Programmes and Personnel Involved in HIV Surveillance

a. This section details the roles and responsibilities are for all persons involved with HIV surveillance. This includes roles for reporting sources (such as laboratory personnel and healthcare providers), sub-national surveillance staff (if applicable) and national surveillance staff. The roles and responsibilities should complement the data flow diagram and data reporting procedures.

b. Below is a list of the functions that a national surveillance programmes should perform. Identify appropriate staff/positions that will be responsible for each of these functions.

Functions of the HIV/AIDS surveillance programme:

- solicit, receive, review and file HIV/AIDS case reports on a timely basis
- ensure case reports are filled out completely, accurately and clearly
- evaluate each case report to determine if it meets the HIV case definition and assess clinical staging
- classify HIV cases according to demographic characteristics, geographic region, mode of exposure, and other data collected
- conduct follow-up investigations on cases of epidemiologic importance
- maintain a complete and accurate HIV surveillance database that is secure and has limited access by authorized personnel
• identify reporting sources, provide an active liaison with physicians and institutions reporting cases, abstract medical records to generate case reports when necessary, and supply routine feedback to providers in cases reported
• analyse, interpret and disseminate HIV surveillance data
• critically assess the performance of the surveillance programmes through on-going evaluations of surveillance activity.

Description of Hardware/Software

This section describes computers, networks and software that are used in the surveillance system at the national level, sub-national level (if applicable) and reporting source sites (if applicable). Also should list the HIV database administrator and backup administrator for these systems.

Data Security and Confidentiality Procedures

This section details the data security and confidentiality procedures in place for your country. It describes how case information should be reported, transported and stored. It also describes actions taken if there is a breach in confidentiality. A confidentiality oath/agreement should also be in place for all persons working with HIV surveillance to sign annually. This includes staff at the Ministry Health, laboratories, healthcare providers etc. (See Unit 7). The confidentiality/oath agreement should be included in the Appendix of the Operational Manual (see sample in Unit 7 Annex).

Surveillance Case Definitions for HIV Infection and Reportable Events

This section contains the conditions under surveillance and the surveillance case definitions for the conditions (See Unit 4).

Diagnostic Testing Algorithm

This section details the HIV diagnostic testing algorithm in your country.

Data Reporting Procedures

This section details what persons are required to report, how to report, whom to report and when to report. This will complement the data flow diagram.

Data Flow Diagram

This section diagrams the data flow (case report forms, laboratory reports) from the laboratories and healthcare providers to the surveillance unit and back (the dissemination feedback loop).
HIV Case Report Form

This section provides instructions on how to complete the case report form, including the variables on the form, definitions of the variables, data sources where this information should be abstracted.

Standards and Monitoring

This section details how the surveillance system will be monitored in your country. There are general monitoring principles that should be adapted to your setting (See Unit 6).

Data Quality

This section contains information on how to monitor data quality adapted for your setting. (Unit 6)

Timeliness

This section contains information on how to monitor timeliness adapted for your setting. (Unit 6)

Data Management and Analysis

This section contains information on who is responsible for entering, maintaining, cleaning and analysing the surveillance data. The section details when each of these activities occurs.

Additional information to consider:

- type of statistical software programmes that should be used
- which analyses should be conducted monthly, quarterly and annually
- suppression of small cell sizes in publications (Unit 7 and Unit 8).

HIV Data Dissemination Plan (Surveillance Reports, Epi Profile, NAP Indicators, etc.)

This section details all the external and internal HIV reports and publications the surveillance unit produces, and when these reports/publications should be available. The purpose of collecting HIV surveillance data is to use it for programme planning. The surveillance unit should work with stakeholders, including other programmes in the MOH, national AIDS programmes, and national AIDS committees to determine their data needs, and incorporate them in the reports.

The HIV surveillance data should also be disseminated to the reporting sources and others involved in the surveillance system.
Appendices

- HIV confidentiality oath/agreement
- HIV case report form (including directions on how to fill out the form).
### Operational Manual Checklist

<table>
<thead>
<tr>
<th>Manual Section</th>
<th>Section completed in workshop</th>
<th>Source of information</th>
<th>Comment</th>
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<td>Mission statement</td>
<td>To be done in-country</td>
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<td>Organizational chart</td>
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<td>Description of geographic area</td>
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<tr>
<td>List of reporting sources</td>
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<td>List of key contacts</td>
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<td>Staff training</td>
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<td>Diagnostic testing algorithm</td>
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<td>Data reporting procedures</td>
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<tr>
<td>Data flow-diagram</td>
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<td>Data analysis (less than 5 cases: how to present data)</td>
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<tr>
<td>Dissemination plan (surveillance reports, Epi profile, NAP, indicators, etc.)</td>
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<td>How to fill out case report form - variables, definitions etc.</td>
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<tr>
<td>• timeliness.</td>
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</table>
This training module introduces HIV case surveillance with an emphasis on WHO clinical staging and surveillance case definitions, ethical and confidentiality considerations, analysis and presentation of surveillance data and operationalizing an HIV case reporting system. After completing this course, participants will learn how to:

- set up an HIV case reporting system
- analyse reported HIV and AIDS data
- use surveillance data for planning of prevention, care and treatment services
- monitor the HIV case reporting system
- prepare national guidelines on HIV/AIDS case reporting.

This course is meant primarily for district-level surveillance officers. This module can also be used for self-study.
Module 3

HIV Serosurveillance

World Health Organization
Regional Office for South-East Asia
2007
Module 3

HIV Serosurveillance

Participant Manual

2007
Other HIV surveillance training modules of this series

Module 1 - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual

Module 2 - HIV clinical staging and case reporting: participant manual

Module 4 - Surveillance for sexually transmitted infections: participant manual

Module 5 - Surveillance of HIV risk behaviours: participant manual

Module 6 - Surveillance of populations at high risk for HIV transmission

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We are grateful to all the national and international experts who reviewed earlier versions of the module.

**Bangladesh:** Dr Motiur Rahman, Associate Scientist & Head of RTI/STI Laboratory, ICDDR, B; Dr Md Hanif Uddin, Deputy Programme Manager, National AIDS/STD Programme; Dr Khondoker Mahbuba Jamil, Senior Scientific Officer, Department of Virology, Institute of Epidemiology, Disease Control and Research; Bhutan: Ms Neyzang Wangmo, Associate Lecturer of Royal Institute of Health Sciences.

**China:** Ms Wang Lan, National Center for AIDS/STD Control and Prevention.

**Cambodia:** Dr Ly Penh Sun, Deputy Director, National Center for HIV/AIDS, Dermatology and STD.

**India:** Dr Shashi Kant, Additional Professor, Centre for Community Medicine, All India Institute of Medical Sciences (AIIMS); Dr A.S. Rathore, Joint Director (Training), National AIDS Control Organization; Dr B.S.N. Reddy, Head, Dermatology Department, Maulana Azad Medical College; Dr Madhulekha Bhattacharya, Professor and Head Department of CHA National Institute of Health & Family Welfare; Dr Jagadeeshan, Tamil Nadu State AIDS Control Society.

**Indonesia:** Ms Naning Nugrahini, Technical Officer for STI and Surveillance, Monitoring and Evaluation, Directorate of Direct Transmitted Disease Control; Dr Dicky Budiman, Sub-Directorate of AIDS & STI; Dr Dyah Erti Mustikawati, Head of Section for Evaluation and Reporting, Sub-Directorate of AIDS/STI.

**Maldives:** Mr Mohammed Rameez, Programme Coordinator, Department of Public Health.

**Myanmar:** Dr Min Thwe, National AIDS Programme Manager, Ministry of Health, Government of the Union of Myanmar; Dr Tun Myint, Divisional AIDS Officer, Mandalay AIDS/STD Prevention and Control Programme; Dr Htay Naing, Medical Officer, National AIDS Control Programme.

**Nepal:** Dr K. N. Thakur, Dermatologist, Koshi Zonal Hospital; Dr Devi Prasad Bhusal, Teku Hospital.

**Sri Lanka:** Dr N. Punchihewa, National STD/AIDS Control Programme; Dr K.A.M. Ariyaratne, National STD/AIDS Control Programme; Dr Sriyakanthi Beneragama, Epidemiologist, National STD/AIDS Control Programme.

**Thailand:** Ms Thanapan Fongsiri, AIDS Cluster, Bureau of AIDS, TB and STI, Department of Disease Control, Ministry of Public Health; Dr Tanarak Plipat, Medical Officer, Head of HIV, TB and STD Surveillance Section, Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health; Mr Surasak Thanaisawanyangkoon, Health Technical Officer, Bureau of AIDS, TB and STIs, Ministry of Public Health; Mrs Mattana Herber, Health Technical Officer, Office of Disease Prevention and Control.
Timor-Leste: Mr Virgilio Soares, HIV/AIDS Officer, Ministry of Health.


United States Department of Health and Human Services, Centers for Disease Control and Prevention (HHS-CDC), Global AIDS Programme(GAP) Surveillance Team.

University of California at San Francisco (UCSF), Institute for Global Health, AIDS Research Institute through the University Technical Assistance Programme(UTAP) with CDC/GAP.
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How to Study this Module

What you should know before the course
This course is meant primarily for district-level surveillance officers. As a participant, you should have a basic medical understanding of HIV/AIDS and public health surveillance before taking the course.

Module structure
The module is divided into units. The units are convenient blocks of material for a single study session. This module can also be used for self-study.

We begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answer may just be a guess. Answer the questions as best you can.

You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions. You can then check your work.

Appendices
More information is provided:

Appendix A: Answers to Warm-Up Questions and Case Studies
Appendix B: Unlinked Testing
Appendix C: Checklist for Quality Assurance of Surveillance Activities
Additions, Corrections, Suggestions

Do you want to suggest changes to this module? Is there additional information you would like to see? Please write or email us. We will collect your letters and emails, and consider your comments in the next update to this module.

Address
HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House,
Indraprastha Estate
Mahatama Gandhi Marg
New Delhi 110 002, India
Email: hiv@searo.who.int
Fax: 91 11 23370197
Objectives and Approaches to HIV Surveillance

Overview

What this unit is about
This unit gives an overview of HIV surveillance, including objectives and approaches. It provides the rationale for recommending HIV sentinel surveillance as a core activity of HIV surveillance for Asia.

Warm-up questions
1. HIV serosurveillance refers to the component of second-generation HIV surveillance that measures HIV__________________.

2. Which of the following is one of the epidemiologic principles that guide HIV surveillance?
   a. HIV infections are not evenly distributed in a population.
   b. There are a limited number of ways that HIV can be transmitted.
   c. HIV infection enters different areas and populations at different times, and spreads at different rates.
   d. All of the above.

3. Blood donation is ideally voluntary and entails selecting donors at lowest risk of infection. HIV prevalence data from blood banks are likely to __________ true prevalence in the general population.
   a. overestimate
   b. underestimate

4. True or false? In low-level epidemics, HIV surveillance should primarily focus on measuring HIV prevalence in antenatal clinics.
   True    False

5. Which type of surveillance better shows the clinical disease burden of the HIV epidemic?
   a. AIDS case surveillance
   b. HIV serosurveillance

6. Because of the long latent period from HIV infection to the onset of AIDS, AIDS case surveillance may ________ the magnitude of the epidemic early on, when the HIV epidemic is expanding.
   a. over-represent
   b. under-represent

7. Which of these is a goal of HIV surveillance?
   a. identifying sub-groups at greater or lesser risk for infection
   b. monitoring trends in the prevalence of infection over time
   c. assessing risk factors of HIV transmission
   d. all of the above
8. True or false? Sentinel surveys are harder to do than population-based surveys. They give a more accurate picture of the overall HIV prevalence in a population.

   True       False

9. Selection bias is a big concern for _____ surveys. People who attend a particular facility may be different from those who do not use that site.
   a. population-based
   b. sentinel

**Introduction**

**What you will learn**

By the end of this unit, you should be able to:

- define the terms HIV surveillance, second-generation HIV surveillance, HIV serosurveillance, and HIV sentinel surveillance as used in this module;
- describe how certain epidemiologic principles and also the stage of the epidemic in a location guide HIV serosurveillance;
- compare AIDS case surveillance and HIV serosurveillance, identify the strengths and weaknesses of each, and describe how the two are complimentary;
- identify the main objectives of HIV serosurveillance;
- describe the three main approaches to conducting HIV serosurveillance;
- describe HIV incidence surveillance;
- identify alternative sources of HIV testing data that can be used for HIV surveillance in a second-generation surveillance system.

**Definitions and Terms**

**HIV surveillance**

_HIV surveillance_ is the systematic and regular collection of information on the occurrence, distribution and trends in HIV infection and factors associated with infection for use for public health action. It monitors the risk of infection among specific populations on an ongoing basis for the purpose of public health action.

**Second-generation surveillance**

_Second-generation HIV surveillance_ is not a single method of conducting HIV surveillance, but rather a collection of principles for tracking the epidemic. These principles include:

- a focus on trends over time;
- a better understanding of the behaviours that drive the epidemic;
- emphasis on the sub-populations at highest risk for infection;
- better use of existing data;
- flexibility to the stage of the epidemic.

The principle of flexibility means that many component activities can make up second-generation HIV surveillance depending on the setting and resources.
Serosurveillance

HIV serosurveillance refers to measuring HIV prevalence (the proportion of a population with HIV infection). When HIV prevalence is determined by testing blood for HIV antibody, the term HIV seroprevalence is used. For practical purposes, the two terms are usually used synonymously. Surveys that collect blood for HIV or other testing are generally referred to as serosurveys.

Sentinel surveillance

HIV sentinel surveillance is considered a core activity of HIV serosurveillance and the primary focus of this training manual. Its characteristics include the following:

- It measures the prevalence of HIV infection in a selected sentinel population in serial cross-sectional surveys in a consistent manner on an ongoing basis.
- It involves the collection and testing of blood for HIV.
- In most settings, demographic characteristics and limited data on risk behaviour are also collected.

The populations selected for HIV sentinel surveillance include persons at risk for HIV infection who are regularly and routinely seen in defined locations. These defined locations, also known as sentinel sites, are usually clinics with a surrounding geographic base.

- Sentinel sites may be selected because they include persons that are proxies for the general population; for example, antenatal clinics.
- Or, sentinel sites may be selected because they include persons at particularly high risk of HIV infection, such as STI clinics, drug treatment centres, jails, TB clinics or hospital wards.

In some settings, HIV sentinel surveillance may refer to regular cross-sectional serosurveys conducted in communities outside clinics or other facilities. For example, targeted intervention programmes among sex workers or men who have sex with men (MSM) are sometimes used for sentinel surveillance.

Case reporting

Do not confuse sentinel surveillance with case reporting, although case reporting can be an integral part of second-generation HIV surveillance.

- HIV case reporting entails the systematic identification and reporting of HIV cases to public health authorities. HIV case reporting is not usually done in SEAR countries except in Sri Lanka.
- AIDS case reporting or AIDS case surveillance is the identification and reporting of persons meeting the AIDS case definition. Case reporting is not covered in this manual.
- The words active and passive are used to describe surveillance activities that depend on the public health officials conducting the activities (active) or rely on physicians or non-public health officials to collect or report data (passive).
Overview of HIV Serosurveillance

This manual focuses on one core activity of HIV surveillance: HIV serosurveillance. HIV serosurveillance measures HIV prevalence in specific populations on an ongoing basis.

Uses of HIV surveillance data

The uses of HIV surveillance data include:

- Advocacy;
- Mobilization of political commitment;
- Educating the public;
- Prevention and care programme planning and resource allocation;
- Targeting and developing new prevention and care programmes;
- Monitoring and evaluating existing prevention and care programmes;
- Estimating and projecting new and total HIV infections, AIDS cases, AIDS deaths, HIV-positive pregnancies and births, and numbers of orphans;
- Tracking the leading edge of the epidemic and monitoring trends over time;
- Guiding scientific research;
- Providing information on changes or trends in disease distribution by geographic, sociodemographic or exposure parameters;
- Identifying groups or geographical areas for targeted intervention efforts (national, district, local);
- Providing data for prevention programme management, such as for voluntary counselling and testing, prevention of maternal-to-child transmission and STI management (national, district, local).

Principles of HIV serosurveillance

Epidemiologic principles that guide HIV serosurveillance include:

- HIV infections are not uniformly distributed in a population. The distribution of HIV infection in the population depends on the prevalence of behaviours associated with an increased risk for HIV transmission.
- There are a limited number of modes of HIV transmission. These include:
  - through sexual intercourse
  - through contact with blood
  - from mother to child
- HIV infection enters into different geographic areas and populations at different times and spreads at different rates.

In order to most accurately measure HIV prevalence, surveillance data focuses primarily on three variables:

- person (for example, young women vs. older men)
- place (for example, by city versus rural health district)
- time (for example, an increase or decrease over the last three years)
Monitoring trends in HIV infection over person, place and time requires that surveillance be conducted in the same manner and in the same population groups each time it is done.

**HIV serosurvey designs**

There are three main survey designs for HIV serosurveillance:

*HIV sentinel surveillance* entails measuring the prevalence of HIV infection in a selected sentinel population in serial cross-sectional surveys in a consistent manner on an ongoing basis.

- Sentinel populations are usually clinic attendees (for instance, STI clinics) where blood that is routinely drawn for other purposes (such as syphilis testing) is used for HIV testing.
- The steps for setting up a sentinel surveillance system are presented in Annex 1.1.
- A template for a survey protocol is presented in Annex 1.2.
- The procedure for conducting sentinel surveillance is the focus of this manual.

*Community-based serosurveys* may be needed to reach populations that are not included in clinic-based sentinel sites and who are rare in surveys of the general population.

- Community-based surveys may be conducted to reach populations at particularly high risk for HIV infection.
- In Asia, such surveys may be conducted among sex workers, long-distance truck drivers, injection drug users or men who have sex with men.

*Population-based serosurveys* are designed to obtain a direct measure of HIV prevalence in the general population.

- Population-based surveys use a probability sample of a population defined by geographic boundaries, such as villages or provinces.
- In a probability survey, each person in that population has an equal or known probability of selection in the sample.
- An example is the Demographic and Health Survey Plus, which includes collection of blood for HIV testing. Such surveys are complex and costly. Nonetheless, periodic population-based serosurveys may be needed to calibrate sentinel surveillance data. That is, does the site over- or under-estimate the true prevalence of HIV in the population?

A recent study compared HIV prevalence estimates from ANC sentinel surveillance to community- and population-based studies in sub-Saharan Africa. Of note, there is reasonable correlation in HIV prevalence between the two approaches across various locations in diverse African countries.
**Module 3: HIV Serosurveillance**

**Figure 1.1**

**HIV prevalence in adults (community studies) and pregnant women (ANCs) by site**

<table>
<thead>
<tr>
<th>Site</th>
<th>Community</th>
<th>ANC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chelston#</td>
<td>35</td>
<td>30</td>
</tr>
<tr>
<td>Kasuru-Mupuli</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Yaounde&amp;Kisumu&amp;Ndola&amp;</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Manicaland£</td>
<td>35</td>
<td>30</td>
</tr>
<tr>
<td>Kagera 93$</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Kagera 96$</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Rwanda†</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Fort Portal‡</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Mwanza §</td>
<td>25</td>
<td>20</td>
</tr>
</tbody>
</table>


**HIV incidence and prevalence**

An assumption of HIV serosurveillance is that trends in HIV prevalence reflect patterns in HIV transmission, that is, HIV incidence.

- **Incidence** is defined as the rate of new infections occurring in a population over time. HIV incidence is expressed as per cent per year.
- In contrast, HIV **prevalence** is defined as the proportion of persons living with HIV in a population at one point in time.

The following table compares these two measures of infection in a population:

**Table 1.1**

**Comparing incidence and prevalence**

<table>
<thead>
<tr>
<th>Type of measure</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence</td>
<td>• provides a measure of the speed of spread of HIV in a population</td>
</tr>
<tr>
<td></td>
<td>• indicates where HIV prevention is needed influenced by levels of risky behaviours</td>
</tr>
<tr>
<td>Prevalence</td>
<td>• a measure of the level of infection in a population</td>
</tr>
<tr>
<td></td>
<td>• provides a measure of current and future need for care</td>
</tr>
<tr>
<td></td>
<td>• influenced by both the rate of new infections (incidence) and the rate at which infected people leave the population for reasons such as death or migration</td>
</tr>
</tbody>
</table>

Early in epidemics, trends in HIV prevalence may indeed reflect trends in HIV incidence as most infections are new infections. In mature epidemics, however, an increasing
number of infections may be old infections. Direct measures of HIV incidence may be needed to track current trends in the epidemic.

Monitoring indicators
Unfortunately, direct measures of HIV incidence are logistically difficult and costly to obtain. Several methods to measure or estimate HIV incidence include:

*Cohort studies* - The traditional method to measure HIV incidence entails enrolling persons who are uninfected into a cohort study. Subjects are periodically tested for HIV (for instance, annually) to measure the rate of new infection.

- For example, "HIV incidence and factors contributed to retention in a 12-month follow-up study of injection drug users in Sichuan Province, China," (Ruan, Y. et al., J Acquir Immune Defic Syndr. 2005 Aug 1;39(4):459-63) studied a cohort of HIV-negative 333 IDUs to determine rates of new infection.

*Laboratory-based methods* - Several laboratory tests can identify persons in the early period of HIV infection. A promising technique to measure HIV incidence in cross-sectional serosurveys is the HIV-1 BED incidence EIA. The assay identifies persons who were infected in approximately the past six months.

- *Repeat testers* - HIV incidence can be calculated from persons who are repeatedly tested for HIV, for example, at voluntary counselling and testing sites or through routine testing at STI clinics. New infections are identified by persons who tested HIV-negative at one visit and later test HIV-positive at another.
- *Mathematical modelling* - Various equations to estimate HIV incidence have been developed based on a variety of data and assumptions, including HIV prevalence by age groups, the chance of transmission through certain behaviours, or back-calculation from AIDS cases.
- *HIV prevalence in young age groups* - HIV incidence is often estimated from the HIV prevalence among the youngest individuals such as 15- to 24-year-old women in ANC surveys. Because they have not been sexually active for very long, their infections are relatively new.
- Until there is further validation of and experience with the methods to directly measure HIV incidence, it is recommended to use trends in HIV prevalence among 15- to 24-year-olds as a practical proxy measure for trends in HIV incidence.

Additional sources of prevalence data
HIV testing is done in a large number of programmes and settings. Testing in these sites is not usually conducted for surveillance reasons, but the data from these sites may be used to enhance HIV serosurveillance activities. The data, however, must be interpreted cautiously. The list below outlines the five general types of HIV testing programmes.
1. **Voluntary counselling and testing programmes** - Persons may seek HIV testing in order to be counselled on their care and treatment options and to reduce their risk of acquiring and transmitting infection. To the extent that persons who suspect they are infected seek out HIV testing, using HIV prevalence data from voluntary testing programmes may overestimate the true prevalence in a population.

2. **Routine HIV testing** - In some settings, HIV testing is routinely offered and conducted as part of standard care. For example, many ANCs in Asia are scaling up programmes to prevent mother-to-child transmission of HIV. As coverage of all women increases, data could approximate prevalence determined by ANC-based HIV sentinel surveillance. STI and TB clinics are other settings where routine or universal HIV testing of patients is indicated for their care.

3. **Blood transfusion safety** - In order to prevent transmission of HIV from transfusion of blood and blood products, universal HIV testing is indicated. Ideally, blood donation is voluntary, and measures to select donors at lowest risk of infection are in place. HIV prevalence data from blood banks are therefore likely to underestimate true prevalence in a population.

4. **Scientific research** - HIV testing is often done in the context of scientific research whose purposes may range from epidemiologic surveys to characterize populations at high-risk to prevention interventions to reduce risk. HIV prevalence data from studies must therefore be interpreted in the context of the objectives of the research and the study subjects included.

5. **Screening of persons entering the military, seeking employment, or other benefits** - In some instances, persons are routinely tested for HIV for a particular purpose, such as entering the military or to get health insurance. HIV prevalence data from these sources may be biased by self-selection. For example, data from screening in the military may be more representative of the young adult male population if there is universal conscription, but less representative if based on voluntary service or if there are many restrictions on who may enlist.

While HIV testing data collected for purposes other than surveillance may under- or over-estimate true population prevalence, they are still a potential source of information regarding HIV prevalence in different populations. Next we turn to the main source for collecting information about HIV prevalence, HIV sentinel surveillance.

**Summary**

For South-East Asia, serosurveillance is the core activity of HIV surveillance. HIV serosurveillance measures HIV prevalence in specific populations on an ongoing basis. There are three main survey designs for HIV serosurveillance:

- HIV sentinel surveillance
- Community-based serosurveillance
- Population-based serosurveillance.
HIV incidence is a measure of new infections in a population, while prevalence is a measure of the defined as the proportion of persons living with HIV in a population at one point in time. There are different methods for estimating HIV incidence and prevalence.

Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to.

Small group discussion
Get into small groups to discuss these questions.

1. List all of the groups where HIV testing is conducted in your district or province.

2. For what reasons is testing being conducted in each group?

3. Can you suggest groups in which HIV serosurveys might be useful in your district or province?

4. What methods have been used to assess HIV prevalence and monitor trends in your district or province?

5. To what extent are the above objectives for HIV sentinel surveillance applicable to the HIV sentinel surveillance system in your country? List which ones need improvement.

Apply what you have learned/case study
You are the surveillance officer for the Panga district of the country of Nodesh. Your district is large and located on a major highway on the border of a country with a large refugee population. New funding for surveillance has made possible the expansion of activities in your district.

Currently, two of the four antenatal clinics in your district participate in the national HIV sentinel surveillance system. One is located in the main city of your district, Bangalay, which is also the provincial capital. The other is in a rural area near the provincial capital. Of the remaining two antenatal clinics, one is located far from the capital, far from the main highway, near a refugee camp across the border. The other is in a private hospital funded by international charities in the provincial capital.

There is a rapidly growing town, Datapur, on the national border where truck drivers wait long hours to pass customs inspections. Sex workers congregate in the border town, along the highway, and in two distinct areas of Panga. There are also an STI clinic and outpatient TB programme in the hospital in the provincial capital. You have sufficient funds to add one surveillance activity in your district.

a. What types of surveillance activities could you consider?

b. What are the advantages and disadvantages of each?
Annex 1.1 Steps for Setting Up an HIV Sentinel Surveillance System

Before an HIV sentinel surveillance system is set up or expanded to an area where it does not exist, take the following steps as part of a strategic plan and develop a surveillance protocol.

Background preparation
- Review existing epidemiologic situation and need for HIV surveillance
- Assess current HIV surveillance activities at the national, provincial and district level
- Review additional, existing sources of HIV prevalence data

General survey methods
- Select sentinel populations.
- Select sites for sentinel surveillance.
- Select inclusion criteria for sample.
- Review methods for collecting blood samples for HIV testing.
- Review procedures for maintaining confidentiality of HIV test results.
- Determine data to be collected with blood samples.
- Determine methods for compiling, analysing, presenting and disseminating data at national, provincial and district levels.

Sampling methods
- Determine the overall sample size.
- Determine the frequency of sampling.
- Determine the duration of sampling.
- Determine the minimum sample size per sentinel site.

Laboratory testing
- Review recommended Joint United Nations Programme on AIDS (UNAIDS)/WHO HIV testing strategy.
- Select HIV tests to be used for surveillance specimens.
- Develop HIV testing protocol for local and national use.
- Develop quality assurance plans for laboratory HIV testing.

Training
Provide training for:

- surveillance personnel
- sentinel site staff
- laboratory staff
- supervisory personnel
- data management and analysis personnel
Surveillance system supervision
- Develop a plan for supervision at sentinel sites.
- Be sure supervisory plans include district, regional and national staff.

Personnel requirements
- Identify personnel requirements for data collection and specimen processing.
- Identify personnel requirements for transport of specimens to the laboratory.
- Identify personnel requirements for HIV testing.
- Identify personnel requirements for data compilation, analysis, presentation and interpretation.
- Identify personnel requirements for district, provincial and national supervision.

Equipment needs
- Identify equipment needs for specimen collection, serum separation, storage and transport.
- Identify equipment needs for HIV testing.
- Identify equipment needs for data compilation, analysis and presentation.
- Identify general office equipment and space.

Budget
- Determine cost of identified required personnel and equipment.

Dissemination, presentation
Plan dissemination and presentation of results to audiences including:
- National AIDS Committee
- Ministry of Health, other government ministries
- Media and general public
- Sentinel sites/districts/provinces
- General public and community-based organizations

Finalization
Compile these elements into a plan of action and timeline for implementation of HIV sentinel surveillance protocol.
Annex 1.2 Outline of a Survey Protocol

Introduction
a. types of HIV/AIDS surveillance (biological, AIDS case, behavioural, etc.)
b. modes of blood collection for HIV testing (with/without informed consent, linked/unlinked/confidential anonymous)

Sampling, blood and data collection
a. sentinel population: Describe a clinic population, eligibility and ineligibility requirements
b. sampling frame
c. sample size (per site), sampling period, possibly by type of site (rural/urban)
d. blood and data collection at site: Describe methods step by step; highlight which steps are to take place in the clinic waiting room, and which in the laboratory (laboratory technician)
i. Tally sheet to count eligible women
ii. Routine blood draw for syphilis
iii. Filling in of laboratory request form
iv. Filling in of surveillance questionnaire
v. Syphilis testing
vi. Removing an aliquot of blood and unlinking the specimen
vii. Labelling of surveillance questionnaire and specimen
viii. HIV testing at site
ix. Hands-on demonstration of activities
e. overview: data and specimen flow chart to central/national office
f. forms and file keeping:
i. list forms to be used
ii. describe purpose of each form
iii. state who is to fill in form
iv. describe how to fill in form
g. specimen storage (temperature recording form)
h. specimen transport

Syphilis testing
a. introduction
b. serologic testing
i. introduction
ii. immunology of syphilis infection
iii. test principles
iv. interpretation of results of test used
v. recording of syphilis results, unlinking
vi. treatment of syphilis
vii. handling of blood taken for syphilis testing
HIV testing
   a. type of HIV test(s) used
   b. testing algorithm
   c. protocol for conducting testing (if done at site)

Supervision
   a. outline who supervises site staff, how, and when.
   b. explain how findings of supervision are forwarded to regional/national level

Roles and responsibilities during the surveillance round
   a. Ministry of Health
   b. regional level
   c. health centre
      i. health centre coordinator or manager
      ii. health centre laboratory technician
      iii. nurse

Other
   a. required materials and equipment for each sentinel site
   b. checklist for trainers
Overview

What this unit is about
This unit will describe selection of populations and sites for inclusion in HIV sentinel surveillance based on the local epidemiology and the ability to access populations at risk.

Warm-up questions
1. Which of the following are criteria for the selection of sentinel populations for HIV surveillance?
   a. The group should be definable and easily identified.
   b. The group should be readily accessible to surveillance staff.
   c. The group should be relevant to the epidemiology of HIV in the particular region.
   d. all of the above

2. True or false? When selecting sites for sentinel surveillance, the sites should be located in geographically diverse areas, both inside and outside major cities and towns.
   True    False

3. True or false? In the beginning of executing HIV sentinel surveillance, a large number of sites should be surveyed, in order to capture the scope of the epidemic.
   True    False

Introduction

What you will learn
By the end of this unit you should be able to
- identify appropriate sentinel populations according to the local epidemiological situation;
- identify potential venues that provide access to sentinel populations;
- list the criteria for selection of sentinel sites;
- identify sites in your district that fit the selection criteria.

Selecting Sentinel Populations

The key considerations in the selection of populations for HIV sentinel surveillance are the local epidemiology of HIV and the major risk behaviours that drive transmission. The stage of the epidemic guides the selection of sentinel populations, as shown in Table 2.1.
Although diverse stages of the epidemic exist throughout Asia and even within countries of Asia, many areas may be classified as having concentrated HIV epidemics. Therefore, the focus of sentinel surveillance in Asia should be on high-risk populations. Nonetheless, HIV prevalence exceeds 5% in many high-risk populations; therefore, ANC sites should constitute part of the sentinel surveillance system.

Table 2.1

**Stages of the HIV epidemic and relevant information for serosurveillance**

<table>
<thead>
<tr>
<th>Stage of the Epidemic</th>
<th>Associated HIV Prevalence</th>
<th>Description</th>
</tr>
</thead>
</table>
| Low-level             | HIV prevalence has not consistently exceeded 5% in any defined subpopulation and remains below 1% in pregnant women in urban areas. | • Serosurveys are usually targeted to the populations at highest risk where HIV infection may appear first and spread fastest.  
• These populations may include sex workers, truck drivers, TB or STI clinic patients. A prevalence of 5% or greater in any of these populations should trigger consideration of serosurveys in antenatal clinics.  
• Behavioural surveys and understanding the geography and social networks of high-risk populations are of paramount importance in low-level epidemic. |
| Concentrated          | HIV prevalence is consistently over 5% in at least one defined subpopulation and below 1% in pregnant women in urban areas. | • Serosurveys should remain focused on high-risk populations (such as STI clinics, sex workers, injection drug users).  
• Measuring HIV prevalence in antenatal clinics is also recommended, to detect bridging of infection to the general population. |
| Generalized           | HIV prevalence remains consistently over 1% in pregnant women. | • Serosurveys are largely conducted in antenatal clinics in order to track an epidemic that is fast spreading in the general population. |

**Access to Sentinel Populations**

Access to high-risk populations is challenging. For some high-risk populations such as sex workers and injection drug users, behaviours that lead to HIV infection may be illegal. For other high-risk populations, such as men who have sex with men, the behaviours may be highly stigmatized.

Three general approaches are used to access high-risk populations. Each is discussed below.

**Facilities**

High-risk populations are often concentrated in certain facilities. These are usually health care facilities such as STI clinics or de-addiction centres.
Table 2.2 presents potential facilities for accessing high-risk populations. Facility-based HIV sentinel surveillance, the most common approach in Asia, is the focus of the remainder of this training module.

**Targeted interventions**

Often high-risk populations do not attend particular fixed facilities or do not identify themselves at such facilities, but are served by non-governmental or community-based organizations (NGO or CBO). Sentinel surveillance activities can be done in collaboration with such organizations.

An example of sentinel surveillance conducted through a targeted intervention programme is provided at the end of the unit. While a large number of sentinel surveillance efforts in Asia are conducted with targeted interventions, the procedures vary according to the nature of the activities and NGO collaborations.

**Special epidemiological surveys**

At times, the high-risk population cannot be found at fixed facilities nor are they adequately served by outreach activities. In such instances, sentinel surveillance may require special epidemiological surveys.

Methods such as Time-Location Sampling (TLS) and Respondent-Driven Sampling (RDS) can be used for sentinel surveillance. These approaches are described in other training modules.

<table>
<thead>
<tr>
<th>High-risk population</th>
<th>Facilities or methods of access</th>
</tr>
</thead>
<tbody>
<tr>
<td>STI clinic attendees</td>
<td>STI clinics</td>
</tr>
</tbody>
</table>
| Female sex workers                       | STI clinics  
Detention centres  
Targeted interventions  
Special surveys  |
| Male partners of female sex workers      | STI clinics  
Targeted interventions                                                    |
| Injection drug users                     | De-addiction centres  
Methadone clinics  
Detention centres  
Targeted interventions  
Special surveys |
| Men who have sex with men                | STI clinics  
Targeted interventions  
Special surveys |
| Truck drivers                            | STI clinics  
Occupational health clinics  
Targeted interventions, borders, truck stops  
Special surveys |
| Prisoners                                | Detention centre intake examinations  
Detention centre clinics |
<table>
<thead>
<tr>
<th>High-risk population</th>
<th>Facilities or methods of access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Military, uniformed personnel</td>
<td>Military recruitment centres</td>
</tr>
<tr>
<td></td>
<td>Military health clinics</td>
</tr>
<tr>
<td>Voluntary migrant</td>
<td>STI clinics</td>
</tr>
<tr>
<td></td>
<td>Occupational health clinics</td>
</tr>
<tr>
<td>Involuntary migrants</td>
<td>Refugee health clinics</td>
</tr>
<tr>
<td></td>
<td>Border area health clinics</td>
</tr>
</tbody>
</table>

Using STI clinics

From Table 2.2, it is clear that many high-risk populations can be accessed through STI clinics. The remainder of this training module therefore uses STI clinic-based HIV sentinel surveillance as a model for methods and procedures. Table 2.3 below shows the advantages and disadvantages of using STI clinic attendees as sentinel populations.

Table 2.3

Advantages and disadvantages of using STI clinic attendees as sentinel populations

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>STI clinics include large numbers of sexually active adults.</td>
<td>Many persons with STI do not have symptoms and therefore do not seek care.</td>
</tr>
<tr>
<td>STI clinics include persons at high-risk for HIV as a result of their sexual behaviour and the co-factor effect of STI enhancing HIV transmission</td>
<td>Many persons with STI seek care outside government clinics (e.g., private clinics, pharmacies, traditional health care providers, or access antibiotics on the street).</td>
</tr>
<tr>
<td>STI clinics often include diverse hard-to-reach populations such as female sex workers, their male partners, and men who have sex with men.</td>
<td>High-risk populations may not identify themselves at STI clinics (e.g., MSM, FSW).</td>
</tr>
<tr>
<td>STI clinics may be able to provide HIV voluntary counselling and testing as well as referral to HIV care.</td>
<td>Many STI clinic patients may be repeat visits for the same STI episode.</td>
</tr>
<tr>
<td>STI clinics routinely collect demographic and sexual risk behaviour information.</td>
<td>STI clinics may not include persons at risk for HIV through injection drug use or other modes of transmission.</td>
</tr>
<tr>
<td>HIV testing can be accomplished on an unlinked, anonymous basis as blood specimens are taken for other purposes such as syphilis screening.</td>
<td>The STI clinic population has unclear representation to the general population.</td>
</tr>
<tr>
<td>STI clinics include men and women.</td>
<td></td>
</tr>
</tbody>
</table>

Using ANC clinics

Given that HIV prevalence exceeds 5% in many high-risk populations throughout Asia, HIV sentinel surveillance systems do include ANC clinics.
Table 2.4

Advantages and disadvantages of using women at ANCs as sentinel populations

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANCs include sexually active women aged 15 to 49, the age range for most sexual transmission of HIV.</td>
<td>ANCs do not include infertile women, women whose pregnancies end in abortion and women on contraceptives.</td>
</tr>
<tr>
<td>ANCs are attended by a large proportion of the adult female population in many countries.</td>
<td>HIV infection may affect fertility and women’s desire for more children.</td>
</tr>
<tr>
<td>HIV testing can be accomplished on an unlinked, anonymous basis as blood specimens are taken for other purposes, for example, haemoglobin measurement, blood typing or syphilis screening.</td>
<td>HIV prevalence in pregnant women aged 15-19 years is likely an overestimate as the proportion of sexually naive 15-19-year-old women may be substantial.</td>
</tr>
<tr>
<td>HIV prevalence among pregnant women is also a gauge of the potential level of mother-to-child transmission, the second most common mode of transmission in sub-Saharan Africa.</td>
<td>ANCs may underestimate HIV prevalence in older age groups.</td>
</tr>
<tr>
<td></td>
<td>ANC attendance may vary by gravidity and quality of care provided.</td>
</tr>
<tr>
<td></td>
<td>ANC-based sentinel surveillance data do not directly measure HIV prevalence among men</td>
</tr>
<tr>
<td></td>
<td>ANCs may not include or be able to identify the populations at highest risk for infection (for instance, sex workers).</td>
</tr>
</tbody>
</table>

Criteria for Site Selection

The choice of sites for HIV sentinel surveillance is a balance of including the sentinel population and logistical necessities. In order to ensure success, initial sentinel sites should:

- first be initiated in facilities with high personnel and laboratory capacity;
- be selected to include large numbers of persons at high risk for HIV.

List of selection criteria

The selection of sentinel sites is guided by the following criteria:

- The sites provide services for the selected sentinel populations, such as ANC or STI clinic patients.
- Information on the client make-up of the site is available.
- Blood is drawn from patients as part of routine care.
A reliable laboratory is available on-site or nearby to perform routine laboratory tests. Alternatively, reliable roads and transport options exist to send specimens to a reference laboratory.

The sites are readily accessible to surveillance staff for data collection or supervision of data collection.

The sites provide services or health care to relatively large numbers of persons so that the target sample size can be obtained within the sampling period.

The sites are located in different geographic areas, both in cities or towns and in rural areas.

On-site staff are cooperative and are capable of conducting surveillance; possibilities exist for mobilizing needed resources, including human resources.

On-site staff understand the need for HIV sentinel surveillance and are willing to be trained, supervised and implement activities.

Site-specific criteria
For Asia, sentinel surveillance systems should include a mix of ANC and STI clinics and or injection drug user (IDU) treatment clinics.

- In concentrated epidemics, HIV sentinel surveillance should be conducted where HIV transmission is occurring.
- In areas of lower HIV prevalence, the emphasis should be on setting up surveillance among population groups with high-risk behaviours such as STI clinics, injection drug user treatment clinics, or other venues that are accessed by high-risk groups such as commercial sex workers (CSWs), MSM, truck drivers, and migrants.
- Sentinel sites should then be picked according to geographic areas. The areas to consider include urban areas, border areas, and port cities.
- In areas with high HIV prevalence in high-risk populations, ANC clinics should be included.

The local epidemiology should guide the inclusion of special sentinel populations, such as CSWs, MSM and IDUs. Such populations may require collaboration with targeted interventions provided by NGOs or special epidemiological surveys.

India example
As of 2004, India has a countrywide sentinel serosurveillance system with 590 sites. The majority of these sites are among ANC attendees \(n=390\) or STI clinic attendees \(n=171\).

Access to high-risk/vulnerable populations like CSWs, MSM, IDUs and transgenders is difficult. Often, such groups are served by NGOs that provide targeted interventions (TI) such as medical care, condoms and education in prevention of HIV/AIDS.

The National AIDS Control Organization of India is collaborating with such NGOs to collect HIV serosurveillance data among high-risk groups. Unlinked anonymous testing is used for surveillance purposes from the participants of the TI sites.
In 2004, there were 59 TI sites: 11 IDU sites in seven states, 11 MSM sites in 11 states, and 37 CSW sites in 19 states. Figure 2.1 below gives the HIV prevalence among CSWs in selected states of India.

Figure 2.1

**HIV prevalence among female sex workers at targeted intervention sites, 2003**

While the surveillance data obtained from TI sites should be interpreted with caution, they serve as a useful addition to existing surveillance data. For the past two years, these data have been used in producing the national HIV estimates.

**Summary**

The HIV epidemic in South-East Asia is often concentrated, and sometimes low-level and generalized. Sentinel surveillance should include a mix of ANC and STI clinics and/or IDU treatment clinics. To best plan sentinel surveillance, you should take into consideration many factors, including the following:

- the state of the epidemic in your region
- accessibility of potential sentinel sites
- available resources.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit.
Small group discussion
Get into small groups to discuss these questions.

1. What populations in your district or province are at high-risk for HIV infection? Why?

2. For each group, indicate the following:
   - Is the population easily identifiable?
   - Does the population seek care/services in established facilities?
   - Is blood drawn routinely at facilities as part of the service they receive?

3. How many sites are currently involved in HIV sentinel surveillance in your district, province and country?

4. Do these sites meet the criteria listed in this unit?

5. Describe any plans to increase the number of HIV sentinel sites in your country. List the improvements that this addition will make to your sentinel surveillance system.

Apply what you have learned/case study
You are the surveillance officer for the Panga district of the country of Nodesh. Your district is large and located on a major highway on the border of a country with a large refugee population. New funding for surveillance has made possible the expansion of activities in your district.

Currently, two of the four antenatal clinics in your district participate in the national HIV sentinel surveillance system:

- One site is located in the main city of your district, Bangalay, which is also the provincial capital.
- A second site is in a rural area near the provincial capital.
- A third site is located far from the capital, far from the main highway, near a refugee camp across the border.
- A fourth site is in a private hospital funded by international charities in the provincial capital.

There is a rapidly growing town, Datapur, on the national border where truck drivers wait long hours to pass customs inspections. Sex workers congregate in the border town along the highway and in two distinct areas of Panga.

There are also an STI clinic and outpatient TB programme in the hospital in the provincial capital. You have sufficient funds to add one additional HIV sentinel surveillance population.

- In what populations might you consider conducting the additional serosurvey?
- What factors should you consider in selecting an appropriate population?
- Are TB patients a suitable group for the additional serosurvey? Why or why not?
Overview

What this unit is about
This unit describes the process of sampling, including sample size estimation and the frequency, duration and methods of sampling. The unit provides the rationale for using a consecutive sampling for HIV sentinel surveillance.

Warm-up questions
1. True or false? The goal of sampling is to use data from a representative subset of a larger population to estimate HIV prevalence of a larger population.
   - True
   - False

2. Which of the following is NOT a decision that needs to be made at the beginning of a sentinel survey?
   a. the sample size
   b. the sampling scheme
   c. the frequency of sampling
   d. none of the above

3. True or false? As much as possible, the sampling period should be limited, in order to compare HIV prevalence over time.
   - True
   - False

4. Match each sampling scheme with its description:
   - consecutive
     a. randomly selects the initial patient who meets inclusion criteria, and then selects every \( n \)th eligible patient thereafter
   - systematic
     b. uses a computer or other method to generate random numbers that identify patients to be included in the sample
   - simple random
     c. samples every patient who meets the inclusion criteria until the required sample size is achieved

5. Which of the above schemes is the most simple logistically and best reduces the likelihood of selection bias?

6. True or false? All subjects at the sentinel site who meet the eligibility criteria should be included in the survey.
   - True
   - False
7. True or false? When surveys are repeated, they should be carried out in different sites than the initial survey and during a different time of the year, in order to accurately capture the scope of the epidemic.

True    False

Introduction

What you will learn
By the end of this unit you should be able to:

• explain the process of sampling in the context of sentinel surveillance;
• determine eligibility criteria for inclusion in the sample;
• choose an appropriate sampling scheme;
• plan the duration and frequency of sampling required for sentinel surveillance in your sites.

The sampling process
The use of appropriate and consistent sampling strategies for the selection of individuals ensures that serosurveys are representative of the populations in which they are conducted, consistent from year to year, and consistent between sites.

Sampling is the process of selecting a representative subset of a larger population in order to estimate some unknown characteristic of that larger population. In the case of sentinel surveillance conducted in STI clinics, the characteristic of interest is the prevalence of HIV infection among persons attending these clinics. Ideally, the sampling of a subset of these patients provides an estimate of HIV prevalence in all patients at the STI clinic.

Components of Sampling

There are several factors to consider when choosing a sample. For each sentinel site, the following factors must be determined:

• the sample size, or number of individuals to include in the sample;
• the sampling scheme, or procedures for choosing individuals to be included in the sample;
• the duration and frequency of sampling, how long to sample and how often to sample.

Sample size
The number of subjects included in a sentinel surveillance sample is guided by the need to determine trends in HIV prevalence over time, and to identify sub-populations at high risk for infection. This means that the sample size needs to be large enough to be able to detect the difference between two prevalence estimates (for instance, between two clinic sites or between two years). Statistically, this is referred to as the margin of error (for example, ±3%).
A related, but somewhat different, statistical concept is **confidence interval or confidence limits**. In calculations, you specify what margin of error and what confidence interval you would like. These two numbers are then used to calculate sample size. A confidence interval of 95% with a margin of error of ±3% means that if the study were repeated 100 times, 95 times out of 100 the estimate would be within ±3 percentage points of the estimate you got the first time you did the study.

The standard statistical approach for determining the sample size per site requires:

- an estimate of HIV prevalence in the population to be surveyed;
- the margin of error considered acceptable (for example, ±3%). This is also called **width or interval width**;
- the level of confidence desired (a 95% confidence interval means that if the survey were done 100 times, the prevalence in 95 surveys out of the 100 would fall within the specified interval width).

Typically, sample size calculations are done at the level of the National AIDS Control Programme (NACP) rather than at the district or provincial level. Minimum sample sizes should be calculated for each sentinel site for each survey period.

**Practical issues**

In practice, sample sizes are balanced against the technical and financial resources available for survey implementation and collection. Very large sample sizes in a sentinel site can provide useful information on the local epidemic. However, there may not be enough resources to carry out surveys with very large sample sizes.

As a rule of thumb, a minimum sample size of 250 to 400 patients per site is recommended. This recommendation is based on the following:

- With the typical prevalence observed in sub-Saharan Africa, a reasonable margin of error of ±3%, and 95% statistical confidence can be reached.
- This is the maximum sample size that can be obtained in a typical clinic over 8 to 12 weeks.
- This will produce sufficient statistical power to determine trends in HIV prevalence over a three-year period.
- By taking all eligible patients into the study rather than only a sample of them, you can avoid **selection bias**. Selection bias involves picking a sample of patients who are not representative of the whole population of patients seen. For instance, they might be younger, older or less likely to have HIV infection.

**Determining sample size**

An exact formula to determine sample size (N) to achieve a certain pre-specified interval can be derived from the formula for the confidence interval around a point prevalence estimate. This formula takes into account both the level of confidence you desire in your estimate as well as the width or interval width that will be acceptable to you.
The formula for the confidence interval around a point prevalence estimate is:

\[
\text{Confidence interval} = \hat{P} \pm z \sqrt{\frac{\hat{P}(1-\hat{P})}{N}}
\]

Where \( \hat{P} \) is the point prevalence, \( N \) is the sample size and \( z \) is a constant determined by the degree of confidence you want. For instance, if you want to be sure that your point prevalence estimate falls within the confidence interval you calculate 95% of the time, \( z \) is 1.96. If you want to be right 99 times out of 100, \( z \) is 3.25. For instance, if the estimated prevalence were 20% and the sample size were 100, the 95% confidence interval would be:

\[
= 0.2 \pm 1.96 \frac{0.2(1-0.2)}{100}
= 0.2 \pm 1.96 \frac{0.0016}{100}
= 0.2 \pm 0.0784
\]

or

\[
= 0.1216 - 0.2784
\]

By rearranging the formula for the confidence interval above, we know that one half of the confidence interval (for example, from the estimated point prevalence to the upper confidence limit) is:

\[
= z \left[ \hat{P}(1-\hat{P}) \div N \right]
\]

The entire confidence interval from the lower confidence limit to the upper confidence limit is twice this number and is the equivalent of the width (\( W \)) or interval width described above:

\[
W = 2 z \left[ \hat{P}(1-\hat{P}) \div N \right]
\]

By squaring the entire equation (to remove the square root on the right-hand side), we have

\[
W^2 = 4 z^2 \frac{\hat{P}(1-\hat{P})}{N}
\]

Then by rearranging this equation, we now have

\[
N = 4 z^2 \frac{\hat{P}(1-\hat{P})}{W^2}
\]

which is shown in Figure 3.1.

Figure 3.1. Formula to determine sample size needed for pre-specified interval with specified confidence level.

\[
N = 4 z^2 \frac{\hat{P}(1-\hat{P})}{W^2}
\]
where

- \( z \) is a factor that corresponds to the desired confidence interval (for a 95% confidence level, \( z = 1.96 \)).
- \( P \) is the expected proportion of patients with the outcome (such as HIV prevalence).
- \( W \) is the width of the interval, for example the width for a margin of error of +/- 3% is 0.06.

**Practice sample size calculation**

Let us do a practice sample size calculation. You are a surveillance officer and you want to calculate how large your sample must be to measure HIV prevalence. You estimate that the HIV prevalence is 20% in your district, and you want a margin of error of +/- 5%.

Therefore, the calculation will look like this:

\[
N = \left[ 4 \times (1.96)^2 \times 0.20 \times (1 - 0.20) \right] \div (0.10)^2
\]

\[
N = 246 \text{ people}
\]

So, you need 246 people in your sample in order to achieve the confidence interval that you want.

**Using the Statcalc feature of Epi Info**

The Statcalc feature of *Epi Info*™ software provides a user-friendly sample size calculator for setting specific target sample sizes. The Epi Info™ software is distributed by the United States Centers for Disease Control and Prevention (CDC). You may learn more about Epi Info™ and download the software for free at this site: http://www.cdc.gov/epiinfo.

To use the Statcalc feature in Epi Info, follow these steps:

1. From the main menu, select *Utilities*.
2. Select Statcalc.
3. Select *Sample size and power*.

![Image of Statcalc feature of Epi Info](image.png)
4. Select Population serosurvey

5. A screen will appear where one is required to enter the following information:

- Size of population from which the sample will be selected
- Expected frequency of the factor under study (err towards 50%) - true rate in the population
- Worst acceptable rate (furthest from the rate you would accept in your sample, high or low)

6. Press F4 Calculate

7. The sample size is listed by confidence intervals.

Practice sample size calculation

In a country with a concentrated epidemic, ANC sentinel surveillance is conducted to monitor prevalence in a low-risk population. What sample size would you need in an ANC clinic that has an expected HIV prevalence of 1%? The size of the population is the
theoretical universe of people who would access this clinic, for example, 100,000. Use 2.0% as the worst acceptable rate.

In this example, Statcalc calculates the sample size at 366 at a 95% confidence interval.

Sample size rules of thumb
Rules of thumb for sample sizes are:

- The closer the estimated prevalence is to 50% the larger the sample size that will be required to achieve the same confidence interval width. This is because in the formula, the terms $P$ and $1-P$ are both in the numerator. If $P$ is 50% and $1-P$ is also 50%, the product of $P \times 1-P$ is 0.25. The farther $P$ and $1-P$ are away from 50%, the smaller the product will be. For example, if $P$ is 10% and $1-P$ is 90%, then $P \times 1-P$ will be $0.1 \times 0.9 = 0.09$.

- The sample size needed gets larger as the desired confidence interval gets smaller, therefore the margin of error is smaller.

- A sample size must be practical to achieve in the course of a few months.

- In some instances, you may wish to add additional members of a certain subgroup, for example, women 15-24 years old. This is referred to as oversampling. Its purpose is to have a sufficiently large sample of the particular subgroup to get stable estimates of prevalence.

Sampling Schemes
Three possible sampling schemes used to select individuals at sentinel sites are:

Consecutive sampling - Consecutive sampling consists of sampling every patient who meets the inclusion criteria until the required sample size is obtained or the survey period is over.

Systematic sampling - Systematic sampling consists of randomly selecting the initial patient who meets the inclusion criteria and then selecting every $n^{\text{th}}$ (for example, third or fifth) eligible patient thereafter until the predetermined sample size is reached or the survey period is over.
**Simple random sampling** - Simple random sampling requires the use of a random number table or other method (for instance, computer-based) to generate random numbers that identify the patients to be included in the sample. Table 3.1 presents the advantages and disadvantages of each.

### Table 3.1

**Advantages and disadvantages of sampling schemes**

<table>
<thead>
<tr>
<th>Sampling scheme definition</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consecutive sampling:</strong> sampling every patient that meets the inclusion criteria until the required sample size is obtained or the survey period is over.</td>
<td>• relatively easy to employ&lt;br&gt;• less opportunity for unintentional manipulation by clinic staff or errors due to confusion</td>
<td>• not based on randomization&lt;br&gt;• may be seasonal variations in who is seen at STI clinics at different times of the year (for example, accessibility during a rainy season may prevent persons from more rural areas from visiting a clinic)</td>
</tr>
<tr>
<td><strong>Systematic sampling:</strong> randomly selecting the initial patient who meets the inclusion criteria and then selecting every (^n^{th}) (for example, third or fifth) eligible patient thereafter until the predetermined sample size is reached or the survey period is over.</td>
<td>• more likely to produce a representative sample if done correctly</td>
<td>• more difficult to execute correctly than consecutive sampling&lt;br&gt;• requires more attention to procedural details&lt;br&gt;• advantages offered by the randomization or probability-sampling scheme negated by non-random selection of the first patient or failure to sample every (^n^{th}) patient&lt;br&gt;• may take longer to fill the sample size&lt;br&gt;• complex, prone to errors and confusion&lt;br&gt;• may take longer to conduct&lt;br&gt;• requires a census or a numbered list that includes all potential survey participants</td>
</tr>
<tr>
<td><strong>Simple random sampling:</strong> requires the use of a random number table or other method (for instance, computer-based) to generate random numbers that identify the patients to be included in the sample.</td>
<td>• most likely to produce a true sample of the total population if done correctly</td>
<td>• complex, prone to errors and confusion&lt;br&gt;• may take longer to conduct&lt;br&gt;• requires a census or a numbered list that includes all potential survey participants</td>
</tr>
</tbody>
</table>

**Recommended sampling scheme**

Of the three methods described above, consecutive sampling is recommended for use in sentinel surveillance. It reduces the likelihood of error or on-site personnel deliberate manipulation of who to include. Logistically, consecutive sampling is the most simple approach.
**Duration and frequency of sampling**

HIV prevalence is likely to change over time as new infections occur, persons with AIDS die, or people enter or leave the area. Ideally, therefore, HIV prevalence is measured at a single point in time (that is, a *point estimate*).

In sentinel surveillance settings, a point prevalence estimate is virtually impossible to obtain. Nonetheless, by limiting the time period for sampling as much as possible, prevalence estimates may be close enough to a point estimate to allow valid comparisons over time.

Experience has shown that it is more practical if health workers in local hospitals are given precise instructions on when to begin and end specimen collection for HIV sentinel surveillance. The given dates thus fix the sampling period.

The duration of sampling specified will vary according to clinic volume and the number of patients meeting the eligibility criteria. Generally, a compromise is found between desired sample sizes and the logistical and financial constraints of sampling for an extended period of time.

Many countries set their sampling period at or below 12 weeks. If volume at the clinic is low, the sampling period may be longer, up to 20 weeks for example in some areas. A criterion for site selection is the ability to meet the sample size in a relatively short time period. If a site does not meet the required sample size in the fixed sampling period, an extension may be considered with prior agreement from the national surveillance programme.

The sampling period should be selected as the same dates each year (for example, August through October, or the month of June). This ensures that data are comparable from year to year and from place to place if there is seasonal variation in clinic attendance.

To allow sufficient time for collation, analysis, interpretation and report writing, it is recommended that serosurveys be repeated every 1-2 years. Conducting surveys more frequently than once a year can exhaust personnel and other resources, and usually do not contribute additional information used for public health decisions.

Repeated surveys should be conducted in the same sentinel sites using the same methods every cycle. Among the most important considerations in determining the frequency of sampling is the availability of sufficient financial, technical and human resources to carry out sentinel surveillance.

**Eligibility criteria**

The term *inclusion criteria* refers to characteristics required in study participants, in order to be considered for the sample.

*Exclusion criteria* refer to characteristics of patients who should be excluded from the sample, but who would otherwise be eligible.
Typical eligibility requirements for sentinel surveillance in STI clinic settings include an age range of 15 to 49 years for comparability across sites. It is necessary to ensure that no STI patient is sampled more than once during the same surveillance round. This can be achieved by restricting sampling to STI patients on their first visit or linking sampling to specific events that are only scheduled once, such as initial screening for syphilis.

Exclusion criteria could be repeat STI clinic visits or referral from other STI clinics. The sample size determination and duration of the sampling period must account for some subjects at the site not being eligible for inclusion. Table 3.2 shows examples of this.

Table 3.2

**Examples of possible inclusion and exclusion criteria for STI clinic attendees**

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• age (only persons aged 15 to 49 years should be eligible for the sample)</td>
<td>• referral from another STI clinic</td>
</tr>
<tr>
<td>• attending the clinic for the first time in the sampling period</td>
<td></td>
</tr>
</tbody>
</table>

**Summary**

Sampling is the process of selecting a representative sub-set of a larger population, in order to estimate some unknown characteristic of that larger population. Consecutive sampling is the recommended sampling scheme. You should set inclusion and exclusion criteria in order to select patients that will produce the most accurate and reliable results. The frequency of sampling should be often enough that you are able to best estimate prevalence, but not so often that you strain the available resources.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to.

**Small group discussion**

Get into small groups to discuss these questions.

1. What sample sizes have been used for various HIV sentinel groups in your district or province?
2. What was the sampling period?
3. Was the required sample size obtained at each site? If not, why? Was the sampling period extended to obtain the sample size?
4. Describe how you avoided including the same individual twice during the sampling period.
Apply what you have learned/case study

Try this case study.

Using the formula for sample size estimation based on the precision of a point estimate, calculate the sample size required for the following scenarios.

\[ N = \frac{4 \cdot z^2 \cdot P \cdot (1-P)}{W^2} \]

a. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 10% within ± 5%. Remember that \( P \) and \( W \) are expressed as decimals (that is, \( P = 0.10 \) and \( W = 0.10 \)).

b. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 10% within ± 2.5%.

c. What happens to the required sample size as the width of the margin of error gets smaller?

d. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 35% within ± 5%.

e. What happens to the required sample size as the estimated prevalence gets closer to 50%?
Specimen and Data Collection

Overview

What this unit is about
This unit provides the rationale for conducting HIV tests using unlinked anonymous blood specimens. It also describes the process of data collection, including proper procedures for forms and data entry.

Warm-up questions
1. True or false? In unlinked anonymous testing, it is okay to keep information about the identity of the patient, in order to tell them about their results if they test positive.
   True    False

2. Place the following events in the correct order, corresponding to the proper procedure for unlinked anonymous testing:
   a. Blood is collected and labelled with a code.
   b. Specimen is tested for HIV.
   c. Personal identifying information is removed from specimen.
   d. An aliquot is removed into new tube for HIV testing.

3. True or false? Unlinked anonymous testing without informed consent can sharply reduce participation bias.
   True    False

4. Place the following events in the correct order, corresponding to the preferred data collection method for unlinked anonymous testing:
   a. Send form to laboratory.
   b. Add HIV test result to form.
   c. Add demographic data to form.
   d. Remove demographic section of form and send to data manager.

5. Which of the following is not a reason for the use of standardized data collection forms?
   a. to ensure that the necessary information is obtained
   b. to ensure that data from different sites can be easily compared
   c. to ensure that a patient’s personal information can be matched with their test result
   d. none of the above

6. True or false? For linked confidential surveys, a separate laboratory form for serologic results should be used so that laboratory personnel do not have access to the patient’s personal identifying information.
   True    False
7. For unlinked anonymous testing, as is used in sentinel surveillance, which of the following variables would be inappropriate to collect:
   a. patient’s age
   b. patient’s marital status
   c. patient’s number of children
   d. none of the above

Introduction

What you will learn
By the end of this unit you should be able to:

- understand the rationale for conducting unlinked anonymous testing for HIV sentinel surveillance;
- explain methods for keeping samples anonymous and unlinked;
- explain the importance of standardized forms for data collection;
- describe the protocols for data collection;
- identify the necessary demographic information to be collected for analysis.

Approaches to HIV Testing

Objectives of HIV testing
HIV sentinel surveillance uses HIV testing to track the prevalence of infection by person, place or time. There are other objectives of HIV testing, which include the following:

- counselling persons on their infection;
- referring them to care;
- reducing the risk of transmitting or acquiring HIV;
- ensuring the safety of the blood supply;
- scientific research;
- determining eligibility for certain types of employment or health insurance.

Preventing bias in the survey
In order to meet the objectives of surveillance, participation in HIV testing must be as complete as possible in the sentinel population. Persons offered HIV testing may have reasons to accept or decline the test.

- For example, persons at high risk for HIV may accept testing in order to learn their HIV status and obtain care.
- On the other hand, persons who already know they are HIV-infected may find testing unnecessary.
- Those who suspect they are HIV-infected may decline testing in order to avoid the stigma often associated with HIV infection. Stigma refers to a mark of disgrace or shame.

The degree to which higher- or lower-risk persons choose to be tested is referred to as participation bias. For surveillance data to be as unbiased as possible, participation bias must be minimised.
Considerations in selecting an approach

Table 4.1 outlines considerations that should guide the selection of approach to testing individuals for HIV.

Table 4.1
Considerations to guide the selection of a testing approach

<table>
<thead>
<tr>
<th>Factor</th>
<th>Description</th>
</tr>
</thead>
</table>
| Participation bias | • Approaches that allow for choice in who gets tested introduce the potential for participation bias.  
• Therefore, unlinked anonymous testing with no informed consent is preferred for HIV sentinel surveillance. |
| Informed consent   | • In general, HIV testing is done with the explicit consent of the person being tested.  
• An exception is often made for HIV sentinel surveillance using the unlinked anonymous approach. However, the decision not to obtain informed consent is determined by local ethical standards.  
• Having on-site or nearby access to HIV testing, if subjects wish to have it, can be an ethical obligation. |
| Confidentiality    | • Persons with HIV infection are subject to stigma, discrimination, and potential harm.  
• Therefore, all precautions should be taken so that persons other than the patient do not learn of someone else's HIV test results.  
• In confidential testing, staff members have access to patient-identifying information, but do not release information to anyone but the patient.  
• In anonymous testing, no one knows or records who the patient is, and, therefore, surveillance and clinic staff are not able to identify an individual. Anonymous testing ensures that no one learns the individual’s HIV test results. Results may be returned to patients using a code, but since only the patient knows the code, he or she is the only one to learn the results. |
| Linking            | • **Linking** refers to whether an individual’s name or identifying information is associated with HIV test results.  
• ‘Unlinked’ therefore refers to the deliberate removal of identifying information or means to link HIV test results to individuals.  
• Linking also refers to attaching demographic and behavioural information (but not personally identifying) to HIV test results.  
• Personal identifiers such as birth date and/or a name are recorded on the blood drawn for the HIV test, and these identifiers are attached to the HIV test result. The identifier is used to return HIV results to individuals. |
| Result disclosure  | • If test results are returned to individuals, activities should include:  
  • informed consent  
  • pre- and post- test counselling  
  • confirmatory testing  
  • referral to needed health care and other services |
Approaches to HIV testing

There are several approaches to testing individuals for HIV for surveillance purposes. The four main considerations that may affect participation bias in HIV testing are these:

- Is testing anonymous or confidential?
- Are specimens linked or not linked to identifying information about a patient?
- Does the patient consent to be tested, or not?
- Are the test results given to the patient, or not?

Additionally, testing can be done as a special study, done as part of routine medical care or compelled by authorities. The six main approaches to HIV testing for surveillance purposes are described below:

**Unlinked anonymous testing without informed consent**
- HIV testing is done on specimens of blood collected for other purposes (for instance, syphilis testing).
- Individuals do not consent to have HIV testing performed on their blood. They may, however, be aware that HIV testing is periodically done at the site, and that their blood may or may not be included.
- All personal identifying information (for example, names or codes that can be link to individuals’ names) is permanently stripped from specimen tubes and other records prior to testing for HIV. This is done so that no HIV test results can ever be linked to an individual person.
- Data are recorded using codes that do not identify individuals.
- Persons do not choose to participate, or not to participate.
- Persons do not get their HIV test results. They may be referred to HIV testing at the site or a nearby site. They can have blood drawn again for HIV testing. Then, they can receive counselling and their new test results.

**Unlinked anonymous testing with informed consent**
- Individuals consent to have HIV testing performed on their blood, and therefore may choose to participate or not participate.
- All personal identifying information (for example, names or codes that can be linked to individuals’ names) is permanently stripped from specimen tubes and other records prior to testing for HIV. This is done so that no HIV test results can ever be linked to an individual person.
- Data are recorded using codes that do not identify individuals.
- Persons do not get their HIV test results. They may be referred to HIV testing at the site or a nearby site.

**Linked confidential testing with informed consent**
- Persons choose to have their blood tested for HIV and can learn the results of the test.
- HIV testing may be performed on blood drawn for other purposes or explicitly drawn for HIV testing.
- They provide written informed consent, and receive pre-test and post-test counselling.
• Personal identifiers or names are recorded and used to return results to individuals.

**Linked anonymous testing** with informed consent
• Persons choose to have their blood tested for HIV and can learn the results of the test.
• HIV testing may be performed on blood drawn for other purposes, or explicitly drawn for HIV testing.
• Informed consent and pre-test and post-test counselling is required, but the consent may be verbal rather than written.
• No personal identifiers or names are recorded. Instead, each individual is given a unique, non-identifying code.
• Individuals obtain their test results and post-test counselling by presenting the code.

**Mandatory testing**
• Done when HIV testing is a necessary pre-requisite to obtain a certain benefit or service. Persons may choose to seek the benefit or not.
• Most commonly recommended for blood transfusion safety.
• Not recommended for HIV sentinel surveillance, because populations who are tested on a mandatory basis are typically not representative of the general population.

**Compulsory testing**
• Testing is required, and the individual does not have the choice to accept or refuse the HIV test. This is done rarely in police investigations (such as in the criminal investigation of rape or of intentional HIV transmission), or as part of a physical examination at entry into the military of some countries.
• Not typically recommended for HIV sentinel surveillance because the results from the population tested cannot be generalised to a larger population. In countries with universal conscription and mandatory testing of military recruits, however, compulsory testing data can provide a good estimate of HIV prevalence among young men.

**Recommended sentinel surveillance**
Given the high importance of minimizing participation bias and preserving confidentiality, unlinked anonymous HIV testing without informed consent is the recommended testing approach for sentinel surveillance.

Unlinked anonymous testing is done only on blood that is left over from specimens that are regularly collected for other purposes (such as syphilis testing). The major disadvantage of unlinked anonymous testing is that persons do not get their test results. Since such information may directly impact their health and risk of acquiring or transmitting HIV, unlinked anonymous testing should be done in settings where patients can be referred to voluntary counselling and HIV testing programmes.

Linked testing (confidential or anonymous) with informed consent is the preferred approach when the specimens are collected explicitly for the purpose of HIV testing. One example of this is HIV serosurveillance carried out in populations not easily accessed
in health settings, such as sex workers and truck drivers. In these cases the preferred method for estimating HIV prevalence may be a *community-based serosurvey*. In this type of survey, members of a high-risk group are sampled, and then those included in the sample are counselled and offered HIV testing after giving informed consent in a community setting. They also receive their test results.

Linked testing with informed consent is also the method used in *population-based surveys*. This type of survey is usually a household survey in which members of a household consent to a behavioural questionnaire and HIV counselling and testing. Survey participants may or may not receive their results from those conducting the survey. If they do not receive their results from the conducting the survey, they will be referred to nearby counselling and testing centres to learn their status.

**Procedures for Unlinked Anonymous Testing without Consent**

**Guiding principles**

The guiding principles of unlinked anonymous testing (UAT) without consent are:

- HIV testing should only be done on leftover blood that was drawn for routine care.
- All information that could link an HIV test result to an individual is permanently destroyed, prior to HIV testing.

**Determining eligibility**

The very first step in unlinked anonymous testing is to identify persons who are eligible for the sample. This is done at the time of the visit by clinic personnel knowledgeable about the inclusion and exclusion criteria. This is the most straightforward way of identifying a sample.

Another way to decide who is eligible or not eligible for the sample is to review information from the clinic records, after the visit. For example, this could be done at the end of the day, but prior to sending the samples to the laboratory. Because clinic records are often not sufficiently detailed, and patients are no longer at the site to clarify information about eligibility (for instance, if they had been seen earlier in their pregnancy at another ANC), this method is less preferable.

**Obtaining information**

A minimum amount of information that is already routinely collected as part of the clinic visit is collected on all individuals for the purpose of determining HIV prevalence by sub-populations (for example, by age group, gender or geographical location). Procedures for getting this information, while preserving patients’ anonymity, must be clear.
For anonymous unlinked surveys, the types of information that should be collected include:

- basic demographic information such as:
  - age
  - sex
  - geographic area of residence

- additional helpful information that can confirm eligibility, such as:
  - date of visit
  - reasons for the current visit
  - date of last visit (if available) in order to verify eligibility.

**Obtaining information, continued**

To protect anonymity in unlinked anonymous surveys, data collection instruments should record only the month and year of the visit, rather than the day, month and year.

**Additional data**

When other data are available that are routinely collected as part of the clinic visit, it may be desirable to collect them. Table 4.2 outlines some of additional data that may be collected.

Table 4.2

<table>
<thead>
<tr>
<th>Additional data types</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic data</td>
<td>• socioeconomic or educational level</td>
</tr>
<tr>
<td></td>
<td>• occupation</td>
</tr>
<tr>
<td></td>
<td>• marital status</td>
</tr>
<tr>
<td>Behavioural data</td>
<td>• number of sexual partners</td>
</tr>
<tr>
<td></td>
<td>• condom use</td>
</tr>
<tr>
<td>Clinical data</td>
<td>• signs and symptoms of HIV</td>
</tr>
<tr>
<td></td>
<td>• signs and symptoms of other STIs</td>
</tr>
<tr>
<td></td>
<td>• gravity and parity</td>
</tr>
</tbody>
</table>

**Step-by-step procedure for UAT**

There are nine steps in unlinked anonymous testing. Table 4.3 summarizes the steps. See Annex 4.2 at the end of this unit for more information.
Table 4.3
Steps in unlinked anonymous testing

<table>
<thead>
<tr>
<th>Illustration</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="Image" alt="Code" /></td>
<td>Clinic staff member #1 collects a specimen from patient, and labels it with a code (for example, clinic name and an identification number).</td>
</tr>
<tr>
<td><img src="Image" alt="CLINIC FORM Code" /></td>
<td>Clinic staff member #1 labels a clinic form with the same code, and collects demographic and routine clinical information, including identifying information, from the patient.</td>
</tr>
<tr>
<td><img src="Image" alt="Code" /> <img src="Image" alt="Code" /></td>
<td>Clinic staff member #1 removes an aliquot, or portion, of the blood sample and places it in a second tube or dry blood spot.</td>
</tr>
<tr>
<td><img src="Image" alt="New Code" /></td>
<td>The second specimen with the aliquot of blood is labelled with a new code not linked to personally identifying information.</td>
</tr>
<tr>
<td><img src="Image" alt="Code" /> <img src="Image" alt="Code" /></td>
<td>The first tube of blood is sent for routine clinical testing (for example, haemoglobin, syphilis).</td>
</tr>
</tbody>
</table>
Ensuring patient anonymity

To ensure patient anonymity at the clinic and laboratory, one staff member should collect the blood specimen, and a different staff member should perform HIV testing.

- One staff member (a clinician or laboratory technician) should collect and process the specimen for routine clinical testing.
- Another staff member should perform the unlinked anonymous HIV test, and record the results.

If one staff member is responsible for both collecting the specimen and performing unlinked anonymous testing, it is best if another staff member processes the specimen for unlinked anonymous testing. Processing the specimen for unlinked anonymous testing involves removing an aliquot of blood and placing it in a new tube labelled with a new code that is not linked to any personal identifying information. In addition, if testing is to occur at the clinic site, samples should be stored for batch testing rather than conducted in real-time to avoid linkage back to name-based logs at the clinic or sentinel site.
An alternative approach to ensure confidentiality of HIV testing results is to move unlinked anonymous HIV testing off-site to provincial or national laboratories. In this case, the laboratory provides only aggregate HIV results back to the site as feedback and no individually listed HIV test results.

**Collecting demographic information**

There are several important steps in the process of collecting demographic information. It is important that the anonymity of the specimen not be compromised by the collection of too much, or too detailed, demographic information which could result in the possible identification of individuals.

- At the time of specimen collection, a staff member collects demographic information (such as age, sex, marital status or geographic area of residence) and medical history from the patient as part of routine care.
- This information is recorded onto a clinic form along with the code on the specimen (for example, name or clinic identification number).
- After the specimen is processed for unlinked anonymous HIV testing and the aliquot is labelled with a new code, the same staff member records the new code onto a surveillance form and abstracts the needed demographic information (such as age, sex or marital status) onto the surveillance data form. This abstracted information is therefore not linked to any personal identifying information.
- The unlinked anonymous HIV test results can then be matched with the demographic information for analysis with the new code.

**Labelling specimens**

There are several important steps in the process of labelling specimens.

- The specimen collected for HIV testing is placed in a plastic tube, cryovial (a vial designed for freezer storage) or on filter paper (porous paper) and labelled with the code.
- If labels are used, the label should be placed on the side of the tube, not on the cap.
- Pre-printed cryolabels, which are labels designed to adhere during freezer storage, should be used when specimens are stored in cryovials.
- Surveillance coordinators should provide the field staff responsible for specimen collection with a series of labels or permanent markers and the codes to be used.

**Logging test results**

You should keep individual test results completely secure and confidential. There are certain procedures you can follow to ensure this.

- A separate laboratory logbook for surveillance activities should be maintained to record HIV test results by their corresponding codes.
- The logbook should be accessible only to laboratory and surveillance staff. It should be secured in a locked drawer or cabinet when not in use to ensure the confidentiality of the persons’ test results, as well as their participation in surveillance activities.
• These logbooks should be only kept as long as they are needed and then destroyed. Usually they are needed to resolve questions when the data are entered into a computer. There should be a clear clinic policy on how long to retain these logbooks.
• For unlinked, anonymous testing, the logbook should contain only the codes and corresponding HIV test results.
• There should be no personal identifying information for the patients whose specimens are tested. HIV test results can be matched by the new code to the demographic information abstracted earlier, on the surveillance form.

Flow of data collection forms: Approach A
You can use either of the following two options to collate demographic and serologic data. In the first approach (Approach A in Figure 4.1):

• Demographic data are recorded on the top portion of the form, which is removed and sent to the national data manager.
• The lower portion is sent to the laboratory, where the HIV test result is entered. This portion is then forwarded to the person responsible for data management at the clinic.
• The data entry clerk then enters data from both forms separately into the logbook, matching by the identical survey number on each form and merging them into a single record. This is also the way the data are handled if they are directly entered into a computer, rather than into a logbook.

Flow of data collection forms: Approach B
In the second approach (Approach B in Figure 4.1):

• Demographic and serologic data are recorded on the same form.
• This requires that the form be sent to the laboratory and then back to surveillance staff for entry into the logbook after it has been completed.

This method is less desirable for use in unlinked anonymous testing because an individual’s identity and test result can be disclosed more easily.

• To protect confidentiality in linked confidential surveys, laboratory personnel should not have access to demographic, risk behaviour or identifying information.
• Thus, you should have a separate laboratory form for serologic test results.
• The form should contain the same survey number as on the risk assessment instrument, along with a code number for reporting results to the clinic, and ultimately to the patient.

These data are then either entered into a computer at the site or sent the national data manager for data entry. The data will must be cleaned and checked for duplicates. The size of the individual sample in each clinic or sentinel site should be the same as the number of forms received at the national level.
The CDC guidelines for UAT are given in Annex 4.2. These guidelines should be used as a checklist when developing a sentinel surveillance protocol using UAT that will be submitted to ethical review boards.

Figure 4.1

**Approach to HIV surveillance data management**

<table>
<thead>
<tr>
<th>Sentinel Site</th>
<th>Regional/National Laboratory</th>
<th>National Surveillance Programme’s Data Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add demographic data to top portion of form; remove and send to Data Manager. Send lower portion to laboratory.</td>
<td>Add HIV test result to lower portion; send form to Data Manager</td>
<td>Add demographic data</td>
</tr>
</tbody>
</table>

Summary

Unlinked anonymous testing for HIV sentinel surveillance helps to produce the least biased results, giving an accurate picture of the epidemic. It is essential that the samples are completely anonymous and unlinked, to protect patient confidentiality. Data collection forms should be standardized so that results can be compared across sites. Be sure to collect appropriate demographic information (for example, sex and age) so that meaningful conclusions can be drawn from the data.
Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion
Get into small groups by country, region or province to discuss these questions.

1. Review the sample national form used to collect information on each sampled pregnant woman for HIV sentinel surveillance in ANCs (Annex 4.1). What demographic information is obtained at sentinel sites in your country? How is that information linked to the test results?

2. Discuss all the steps that may be taken to ensure confidentiality in HIV sentinel surveillance. What are the likely negative outcomes of breached confidentiality? To what extent have these been experienced in your district or province?

Apply what you have learned/case study
Try this case study.

You identify an STI clinic in your district that serves a population located on the border area of a country with high HIV prevalence and a large refugee population. It is located on a major highway. You wish to determine HIV prevalence in the STI clinic population. Funding to establish the clinic as a sentinel surveillance site will be available starting next year.

You visit the hospital laboratory that conducts syphilis testing for the STI clinic. The laboratory director tells you that she has saved blood specimens from the clinic for the last six months. She was about to discard them, but asks whether these specimens could be tested for HIV to determine the prevalence in the clinic population.

Now answer the questions that follow.

a. Do you think that testing these specimens would produce an estimate of HIV prevalence that could be compared to the sentinel surveillance estimate planned for the following year?

b. What information do you need to know about the specimens and their source in order to assess their suitability for estimating HIV prevalence?

c. Describe the steps you would take to ensure that HIV test results could not be linked back to clinic patients.

d. Would you use the voluntary HIV testing data from the STI clinic as a measure of prevalence? Why or why not?
Annex 4.1 Unlinked Anonymous HIV Surveillance Data Collection Form for Antenatal Clinic Attendees, India

Name of the State _____________ Name of the Sentinel Site ___________

1. Sentinel site Code _______________________
2. Sample Number _______________________
3. Date: DD/MM/YY _______________________
4. Age in years _______________________
5. Local Status   
   1-Urban, 2- Rural
6. Whether Migrant**  
   Yes-1, No-2
7. Education   
   1- Illiterate, 2-Literate and till 5th,  
   3-Till 12th, 4-Graduate & above
9. Occupation of Spouse   
   1-Agriculturer & unskilled workers,  
   2-Truck/Auto/Taxi driver & cleaners,  
   3-Industrial & factory workers, 4-Hotel staff, 5-Service class people,  
   6-Business, 7-Unemployed, 8-Student, 9-Housewife
10. Testing results   
   HIV   
   1- Positive, 2- Negative
   Confirm: Second Test   
   1- Positive, 2-Negative
   2- Not applicable if first test is negative

Signature _______________________

Name__________________

(In-charge of HIV Testing Laboratory)

• The request form must be sent to HIV testing laboratory along with coded samples.
• Inclusion criteria: All pregnant women attending antenatal clinic to be tested only once during the round.
** Migration as ‘Yes’, when the spouse of the study object is living at a place other then her place of residence, without her spouse.
Annex 4.2 Operational Procedures for Unlinked Anonymous HIV Sentinel Surveillance Supported by the CDC Global AIDS Programme

Introduction

In most countries where CDC’s Global AIDS Programme (GAP) is active, surveillance activities include HIV unlinked anonymous testing (UAT). The purpose of UAT is to:

- monitor trends
- develop estimates and projections
- assist with programme planning
- target interventions

CDC ethical consultations as well as technical guidelines on UAT have established criteria for the conduct of UAT for surveillance. To assure that CDC supported UAT HIV surveillance activities follow these guidelines, we are providing you with a list of elements that should be included in protocols for UAT for HIV surveillance.

Definitions of HIV Testing Procedures for Surveillance

HIV testing terms

Table 4.4

<table>
<thead>
<tr>
<th>Testing type</th>
<th>Purpose</th>
<th>Requirements</th>
<th>Specimen coding</th>
</tr>
</thead>
</table>
| Unlinked anonymous testing (without informed consent) | testing of unlinked specimens and use of data collected for other routine purposes | • no personal identifiers obtained
• no counselling required | coded specimen |
| Unlinked anonymous testing (with informed consent) | testing of unlinked specimens collected solely for surveillance purposes | • informed consent required
• no personal identifiers or names obtained
• no counselling required | coded specimen |
| Linked confidential testing (with informed consent) | testing of samples linked to the person by name, collected primarily for surveillance | • informed consent, pre- and post- test and counseling required
• personal identifiers or names obtained | coded specimen; code linked to personal identifying information |
| Linked anonymous testing (with informed consent) | testing of samples linked to the person by code (which they retain to retrieve test results) collected primarily for surveillance | • informed consent and pre- and post-test counselling required | coded specimen; specimen linked to person by code |
Unlinked Anonymous Testing without Informed Consent

UAT without consent is the most common HIV testing approach for HIV sentinel surveillance because of minimal participation bias and because of logistical simplicity. This surveillance activity is often conducted in clinical settings.

Essential procedures

1. UAT without informed consent must only use leftover blood/ fluids from routinely collected specimens.

   - Leftover blood/ fluid - blood/ fluid remaining after completion of a routine test/ procedure for which the blood/ fluid was collected. An additional tube of blood or extra fluid cannot be collected solely for the purpose of HIV testing for surveillance without consent.
   - Routine blood draw - blood drawn for routine health care, not surveillance. Routine blood draws are those that are recommended by the Ministry of Health (MOH) or other health care service provider as part of defined health care programmes. Examples of routine blood draws include:
     - syphilis testing
     - haemoglobin measurement in antenatal care clinics

   Routine health-care programmes must not be created exclusively to "provide" leftover blood for surveillance. No additional blood specimens can be collected to assure specimen availability for surveillance.

   - Ongoing specimen collection - programmes for which the specimens are collected are continuous and ongoing, occurring independently of surveillance activities, and not just during the surveillance sampling period.

2. Data resulting from surveillance using UAT methods must be irreversibly unlinked and rendered anonymous prior to HIV testing.

   - Anonymous means that the specimen is labelled with a code other than the subject’s name or medical record number.
   - Unlinked means that the bond between personal identifiers (name, medical chart number, etc) and specimen is irreversibly removed before HIV testing.
   - When a sample is collected using unlinked and anonymous methods it is impossible for the test result to be traced back to an individual.

3. Rapid HIV testing for UAT surveillance should not be conducted at the point and time of service provision.

   - HIV testing for UAT should guarantee client anonymity. To avoid the possible identification of a specific person, rapid HIV testing for UAT surveillance should not be conducted at the point and time of service provision (i.e at the site or clinic when the patient is still in the clinic).
• In situations where rapid HIV testing is conducted at a sentinel site, make the following provisions:
  - use leftover blood (see #1 above)
  - make samples unlinked and anonymous before any HIV testing (see #2 above)
  - use different staff for:
    - collecting samples and demographic data
    - performing HIV rapid testing
  - store samples for batch testing rather than conducting in real-time to avoid linkage back to clinic name-based logs

4. Data collection for UAT surveillance should be limited to that which is routinely collected as part of clinical services.

• Administration of a questionnaire to the client who has not provided consent, specifically to collect additional information for surveillance, is not following the ethical principals of UAT. Therefore, all data collected for the serosurvey should be information routinely collected at the site, for example during the registration process. Do not collect information on risk of infection or sexual behaviors if these data are not routinely collected as part of a routine clinic visit (i.e., do not ask/add questions to the clinical service process for the singular purpose of enriching surveillance data).

• In serosurveys that use UAT, sociodemographic data collected for each person, for example, must not be so comprehensive that they facilitate identification of a specific individual. Therefore, it is suggested that a minimum of sociodemographic information be collected during serosurveys using UAT.

5. Voluntary counselling and testing (VCT) should be available and accessible to patients from sites where UAT surveillance is being conducted.

• Surveillance and prevention activities have different objectives: surveillance aims to measure the level of an HIV epidemic and to monitor trends, while prevention activities aim to provide services to prevent and to treat HIV. Inadequate prevention, treatment, and support services in many countries are often a result of limited human and financial resources and inadequate infrastructure. These services are important and should be offered, but generally not through surveillance activities, given that the objectives of the two programmes (i.e. VCT and surveillance) are different. However, the programmes responsible for surveillance should, in general, work towards making VCT services available.

• Clients should be informed of all available VCT services.

• In some countries surveillance activities may be in their early stages. VCT services may not already be available when the surveillance site is selected. In fact, data from surveillance activities may be required to indicate the need for and to advocate effectively for establishing this service. The plan to use these data to advocate or plan for VCT services should be mentioned in the protocol.

• Accessibility to VCT should be defined by the country MOH and described in the protocol.
6. Data generated through UAT-based HIV sentinel surveillance should be used for programme planning and evaluation, and advocacy purposes.

- In addition to plans for creating estimates and projections for HIV, data from UAT sentinel surveillance should have been used previously or there should be documentation on how these data have or will be used for programme planning, evaluation, and advocacy. Potential uses of these data include:
  - targeting prevention programmes;
  - deciding how to distribute resources within countries;
  - evaluating the national collective success of prevention programmes;
  - evaluating the coverage of prevention of mother to child transmission (PMTCT) programmes, particularly using ANC sentinel surveillance data;
  - advocacy to obtain additional resources;
  - determining the type and scope of the epidemic, and monitoring trends.

- Merely conducting surveys year after year but not using UAT surveillance data should be discouraged.

**Unlinked Anonymous Testing with Informed Consent**

UAT with informed consent, also known as voluntary anonymous testing, is the second most common method used to carry out HIV surveillance in clinical settings. Countries that wish to collect additional data or do not have leftover blood to do UAT without informed consent can use this option. This method can also be used outside clinical settings.

**Essential procedures**

1. The procedures for conducting UAT with informed consent are the same as those for UAT without informed consent, except:
   - blood/fluids collected for non-routine purposes may be used (see #1 above);
   - data collected does not need to be limited to that which is routinely collected as part of clinical services (see #4 above).

2. The consent must explain the purpose of the survey and the fact that HIV test results would not be returned. Seriously consider whether it is feasible to return HIV test results. If this is not deemed feasible, please explain in the protocol. If verbal consent is obtained, a script of the consent should be included in the protocol.

3. The anonymizing procedure methods must be irreversibly unlinked and rendered anonymous prior to HIV testing (see #2 above), with additional provisions to assure anonymity despite face-to-face contact between the client and the surveillance staff.
   - As there would be direct contact with participants, the process of maintaining anonymity must be fully explained. Signed consent forms should not be stored with questionnaires, and consideration should be given to obtaining verbal
consent. Handling of specimens and questionnaires by surveillance staff in the field should be standardized and fully explained.

- All procedures for assuring anonymity will be reviewed carefully to determine if a request for exemption from HIV test notification is needed. If at any time the patient-identifying information could be conceivably linked to HIV test results or if the amount and nature of data collected could result in identification of an individual, a request for exemption from HIV test notification will need to be initiated as per US Department of Health Human Services policy.

**Recommendations**

Many countries and programmes are supporting UAT surveillance in ANC clinics. In addition, countries are encouraged to collect information on the availability and uptake of PMTCT services located in UAT ANC clinic sites. Examine the possibility of using PMTCT data for surveillance.
Overview

What this unit is about
This unit describes different options for HIV testing and provides the rationale for each.

Warm-up questions
1. Which of the following factors are involved in the decision to select an HIV testing strategy?
   a. sensitivity and specificity of test being used
   b. objective of the test
   c. HIV prevalence in the population being tested
   d. all of the above

2. Match each phase of the HIV testing process with the components it includes:
   ___ pre-analytical a. interpreting results, entering data into tracking system, reviewing quality control
   ___ analytical b. training, laboratory safety, selection of test kits
   ___ post-analytical c. specimen processing and storage, analysis of testing performance, reagent preparation

3. The process by which reference specimens are tested externally to ensure accuracy of a technician’s or laboratory’s performance is known as:
   a. internal quality assurance
   b. external quality assurance
   c. quality performance
   d. none of the above

Introduction

What you will learn
By the end of this unit you should be able to:

• describe the advantages and disadvantages of different HIV testing options;
• describe how to choose a strategy for HIV testing;
• understand the difference between sensitivity and specificity of a laboratory test;
• identify the phases of the testing process, and what quality control and quality assurance programmes should be implemented in each phase.
Selecting an HIV Antibody Test

There has been much development in HIV diagnostic technology since the first HIV antibody tests became commercially available in 1985. Currently a wide range of different HIV antibody tests is available. Most are enzyme immunoassays (EIA, formerly known as ELISA) tests and can be performed either as conventional tests in the laboratory or as rapid tests.

Conventional EIAs

For many years, HIV testing was done using two different types of antibody tests to determine if someone was infected with HIV. The testing algorithm consisted of two separate tests done on the same small sample of blood:

- an initial EIA
- if the EIA was positive, a confirmatory test (a Western blot assay or indirect immunofluorescence assay, which use different technologies to measure the presence of antibodies to HIV)

WHO has subsequently designed three different strategies for HIV testing that use only EIA tests. These different strategies are discussed later in this unit (Table 5.4).

Conventional EIAs are quantitative tests. That is, they measure the concentration of HIV antibodies in a specimen. Some EIAs can measure antibodies to both HIV-1 and HIV-2, which is an important consideration in countries where both strains are present. These tests usually require a properly trained laboratory technician and specific laboratory equipment. They use chemicals that combine with HIV antibodies and cause colour changes.

- The more the amount of HIV antibody, the darker will be the colour.
- The colour change is read by a machine that reports the intensity of the colour as optical density.
- Test kit manufacturers establish a certain optical density above which specimens are positive and below which specimens are negative.
- Depending on the testing strategy used, either a single positive specimen or a series of positive specimens will be reported as positive to the surveillance system or clinician.

Rapid tests

Rapid tests are a type of EIA that produces results in 10 to 30 minutes. They are simpler to use than conventional EIAs and can be done either in laboratories or in the field. They are qualitative tests that also use EIA methods to determine if a specimen is positive or negative. Unlike conventional EIAs though, no optical density readings are reported for rapid tests. Instead, there is a predetermined optical density built into the test kit, above which a colour change will occur, indicating a positive result. In countries with limited laboratory infrastructure, the use of HIV rapid testing algorithms has been more feasible and as effective as conventional EIAs done in laboratories.
Advantages of rapid test

The major advantage of rapid tests is that results are available quickly - usually within 10-30 minutes. They are also simpler to perform. Rapid tests require less laboratory equipment and less skilled staff than conventional EIAs. Rapid test kits do not need to be refrigerated. Also, they can be used for testing small quantities of blood (such as from finger-sticks).

The characteristics of EIAs and HIV rapid tests are compared in Table 5.1.

<table>
<thead>
<tr>
<th></th>
<th>EIAs</th>
<th>Rapid Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time to result</td>
<td>&gt;60 minutes</td>
<td>10-30 minutes</td>
</tr>
<tr>
<td>Testing volume</td>
<td>Suitable for large volume and batch testing</td>
<td>Suitable for small and large volumes</td>
</tr>
<tr>
<td>Staff requirements</td>
<td>Skilled technical staff required</td>
<td>Less skill required</td>
</tr>
<tr>
<td>Equipment requirements</td>
<td>Requires complex equipment, maintenance</td>
<td>None to minimal equipment</td>
</tr>
<tr>
<td>Storage</td>
<td>Test kits require refrigeration</td>
<td>Most test kits stored at room temperature</td>
</tr>
</tbody>
</table>


Oral and urine tests

More recently developed EIAs look for antibodies in oral fluid or urine. In general, oral tests are more sensitive than urine tests, and urine tests are rarely used. Oral tests are not suitable for UAT because they cannot be performed on specimens left over from other testing or stored.

Whichever test is chosen, it is essential that the results given to individuals be reliable. Additionally, in HIV surveillance, it is important to carefully consider the step-by-step procedure, the laboratory-testing algorithm, which will most accurately detect HIV infections in a population.

Selecting an HIV Testing Algorithm

Selecting an HIV testing strategy

The selection of the HIV antibody tests and testing algorithms to be used is a responsibility of national governments and is generally performed by health ministries and national AIDS control programmes.
UNAIDS and WHO recommend three criteria for choosing an HIV testing algorithm or strategy (that is, selecting the appropriate HIV testing technologies and combination of tests):

- objective of the test (surveillance, blood screening or diagnosis);
- sensitivity and specificity of the test(s) being used;
- HIV prevalence in the population being tested.

After these three criteria are defined, an HIV testing strategy can be selected to maximize sensitivity and specificity while minimizing cost.

Reliability and accuracy of tests
Different algorithms have certain limitations on how well they can detect all persons who have a disease and, conversely, how well they can detect all persons who do not have a disease. These are described below, and shown in Table 5.2.

- Test results can be true positives if they are positive and a patient truly has the disease the test is for.
- They can be false positives if a person who does not have the disease tests positive for it.
- They can be true negatives if a person who does not have the disease tests negative.
- Finally, they can be false negatives if a person who truly has the disease tests negative.

<table>
<thead>
<tr>
<th>Table 5.2</th>
<th>True positives, false positives, true negatives, false negatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive test result</td>
<td>Patient has the disease</td>
</tr>
<tr>
<td>True positive</td>
<td>False positive</td>
</tr>
<tr>
<td>Negative test result</td>
<td>False negative</td>
</tr>
</tbody>
</table>

Sensitivity and specificity
Two terms - sensitivity and specificity - are used to quantify how well a test performs.

- Sensitivity refers to the ability of a test to detect all persons with a disease. It is the proportion of those who are positive by the test, divided by all persons who truly have the disease. See Table 5.3. In the table it is a/(a+c).
- Specificity refers to a test’s ability to detect all persons who do not have a disease. It is the proportion of persons who test negative, divided by all persons who truly do not have the disease. See Table 5.3. In the table it is d/(b+d).

Positive and negative predictive values
There are two other ways to convey how well a test performs. These are positive predictive value (sometimes called predictive value positive) and negative predictive value (sometimes called predictive value negative). They are expressed in terms of what proportion of positive (or negative) tests identify people who truly have (or do
not have) a disease. In Table 5.3, positive predictive value is $a/(a+b)$ and negative predictive value is $d/(c+d)$.

In general, the more frequent a disease is in a population, the higher the positive predictive value of a test will be. Thus, positive predictive value of an HIV test will be higher in higher prevalence areas. It will also be higher in populations more likely to be infected, such as patients with AIDS.

<table>
<thead>
<tr>
<th>Test result</th>
<th>Disease</th>
<th>Absent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>a</td>
<td>b</td>
<td>$a + b$</td>
</tr>
<tr>
<td>Negative</td>
<td>c</td>
<td>d</td>
<td>$c + d$</td>
</tr>
<tr>
<td>Total</td>
<td>$a + c$</td>
<td>$b + d$</td>
<td>$a + b + c + d$</td>
</tr>
</tbody>
</table>

An ideal test will have high sensitivity, specificity, positive predictive value and negative predictive value.

**How HIV prevalence affects test selection**

The determinants of predictive values are the specificity and sensitivity of the test and the prevalence of HIV in the population concerned. Even with a very accurate test (high sensitivity and high specificity), the positive predictive value of a test may not be sufficiently high in settings with a low HIV prevalence.

In general, the higher the prevalence of HIV infection in the population, the greater is the probability that a person testing positive is truly infected. Conversely, the probability that a person with a negative test result is uninfected declines slightly as HIV prevalence increases. It is necessary to conduct a second or supplemental test if the first test is reactive, as this markedly increases the positive predictive value.

In settings with a low-level HIV epidemic, tests with a sensitivity or specificity greater than 99% should be used in order to achieve satisfactory positive predictive values.

Studies have shown that the sensitivity and specificity of rapid tests are similar to those of the conventional EIAs.

**HIV testing algorithm for surveillance**

Recently, the WHO/UNAIDS HIV surveillance working group recommended that the testing strategy of serial testing with two tests be used irrespective of HIV prevalence (Fig. 5.1) This concept replaces the previous options of strategies according to prevalence. The strategy states:

- A two-test strategy is recommended *irrespective of HIV prevalence*.
- Rapid tests, automated EIAs and combinations are appropriate for the two-test strategy.
- The Western blot assay is not recommended for surveillance testing.
- Test 1 should be more sensitive and test 2 should be more specific.
Ensuring Quality in the Laboratory

To ensure the reliability of test results, a laboratory needs to have quality control and quality assurance systems in place. The lab needs to carefully follow its quality control and quality assurance procedures.

Quality control

Quality control (QC) assesses a laboratory’s machinery to check that the HIV test results obtained from a specimen are correct. For QC of the laboratory equipment, positive and negative controls must be run on the machines from time to time to verify that the test device is accurately detecting HIV antibodies. The test kit manufacturer or a reference laboratory can provide these controls.

- Positive controls are specimens known to be positive.
- Negative controls are specimens known to be negative.

By running these specimens, laboratories can test their procedures and reagents to see if there are any problems. They should get the correct results 100% of the time.

Quality assurance

Quality assurance (QA) assesses a laboratory’s processes for obtaining tests results, comparing the results for a specific specimen with other tests conducted on the same specimen. This can be done by one of the two following entities, described in more detail later in this unit:

- laboratory itself (internal quality assurance)
- outside reference laboratory (external quality assurance)
To conduct quality assurance of the entire HIV testing process, laboratories should routinely be monitored during the pre-analytical, analytical, and post-analytical phases of the testing process.

- The pre-analytical phase includes activities that occur before a specimen is actually tested.
- The analytical phase occurs during the actual testing of the specimen.
- The post-analytical phase refers to activities done after a specimen has been tested.

**QA and the phases of the testing process**

There are a variety of components in each phase of the testing process that should be monitored by quality assurance programmes. These components are listed in Table 5.5.

**Table 5.5**

**Components for review by quality assurance programmes in the pre-analytical, analytical, and post-analytical phases of the testing process**

<table>
<thead>
<tr>
<th>Pre-Analytical Phase</th>
<th>Analytical Phase</th>
<th>Post-Analytical Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training</td>
<td>Specimen processing and storage</td>
<td>Interpreting results</td>
</tr>
<tr>
<td>Laboratory safety</td>
<td>Written procedure manual</td>
<td>Transcribing results, such as recording results on the correct identifier code</td>
</tr>
<tr>
<td>Number of trained personnel available and capable of performing HIV testing</td>
<td>Reagent preparation</td>
<td>Entering data into the tracking system (computer or hard copy)</td>
</tr>
<tr>
<td>Specimen collection, labelling and transport conditions</td>
<td>Testing performance</td>
<td>Maintaining records</td>
</tr>
<tr>
<td>Deciding on handling of specimens before testing</td>
<td>Performance and maintenance of equipment (such as spectrophotometers and washers)</td>
<td>Reviewing quality control</td>
</tr>
<tr>
<td>Deciding on the sources and types of specimens to be tested</td>
<td>Correct use of reagents</td>
<td></td>
</tr>
<tr>
<td>Deciding on the number of specimens tested</td>
<td>Inclusion of internal quality controls in the test kits</td>
<td></td>
</tr>
<tr>
<td>Selection of test kits</td>
<td>Quality control monitoring procedure</td>
<td></td>
</tr>
<tr>
<td>Expiration dates of test kits. Kits need to be used before expiration dates. Older kits should be used before newer kits.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV test kit reagents. Reagents must be stored at the appropriate temperature as specified by the manufacturer. Certain reagents (such as conjugates for ELAs) may require refrigeration.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Internal quality assurance

Internal quality assurance is meant to allow laboratory technicians to check their performance for themselves. Below is an example of a procedure for internally testing quality, although it may not be appropriate for all sites:

- Set aside an aliquot of every twentieth negative and every fifth positive specimen and mark it with an identification number. The specimens are stored in a ‘deep’ or non-frost-free freezer (-70°C).
- Once there are sufficient stored aliquots, the stored specimens are tested a second time.
- The laboratory technicians can then compare the initial results and the results of re-testing, to monitor the reliability of their techniques.

External quality assurance

Countries should require that all laboratories at all levels (including the national reference laboratory, HIV laboratories in hospitals, blood transfusion services and private HIV laboratories) participate in an external quality assurance programme to monitor and evaluate each laboratory’s performance.

External quality assurance programmes may be instituted either by a national or international reference laboratory. Reference laboratories are laboratories that function as a recognised centre of expertise and standardization of diagnostic techniques. The steps to implementing an external quality assurance programme, such as a proficiency testing programme are listed on the following page. Proficiency testing should be done once or twice each year.

1. The national reference laboratory sends all participating laboratories a proficiency panel of approximately six specimens to identify as HIV-positive or HIV-negative. Proficiency panels are a set of samples for which the test results are known by the reference laboratory. This panel should contain HIV-negative and HIV-positive samples (both weak and strong specimens) representative of the HIV strains circulating in a country, and from different stages of disease (for instance, from early HIV infection to late-stage AIDS).

2. The panels are tested at the local laboratories in much the same way as they routinely test their specimens for HIV.

3. The local laboratories report their findings to the reference laboratory.

4. The reference laboratory collates the results and provides feedback to each participating laboratory.

External quality assurance must be carried out for the national reference laboratory as well. This should be provided by an independent laboratory (such as the laboratory at a large university) or by one of WHO’s regional quality assurance programmes.
QA with limited laboratory infrastructure

In geographic areas with limited laboratory infrastructure, laboratories can prepare a dried blood spot on filter paper and send it to the national reference laboratory to be tested for quality assurance purposes.

Summary

HIV antibody tests can be performed using conventional EIAs in a laboratory or using rapid tests. You should take into consideration several factors when selecting a test for your region, including the epidemic state and the available resources. To ensure the accuracy and reliability of testing equipment, quality control and quality assurance programmes should be in place for each of the main testing phases.

Exercises

Warm up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

Describe the quality assurance procedures that are put in place for HIV sentinel surveillance in your country and list some ways to improve quality assurance at the local and national levels.

Apply what you have learned/case study

Try this case study. We will discuss the answers in class.

You are the newly hired district surveillance officer for Panga district in the country of Nodesh, and are charged with coordinating HIV seroprevalence studies. You have been asked to help set up a new laboratory at an STI clinic in Datapur, a town near the border. Prevalence at other STI sentinel surveillance sites in the district has been approximately 8% for the last three years. You choose a test that has a sensitivity of 0.9995 and a specificity of 0.995.

a. What is the positive predictive value of the test?

b. What testing algorithm would seem most appropriate for testing for HIV as part of the next HIV sentinel surveillance round at this new laboratory?

c. What are five steps that you would take to ensure quality of the laboratory before the first test was run?
Overview

What this unit is about
This unit outlines the responsibilities, training and supervision of personnel involved in HIV sentinel surveillance.

Warm-up questions
1. Which staff members should be trained prior to conducting serosurveys?
   a. supervisors and managerial staff
   b. laboratory staff
   c. clinic staff
   d. all the above

2. True or false? When planning for the supervision of testing facilities, the national surveillance organizers should hire an outside supervisor to staff each of the facilities where HIV testing occurs.
   True    False

3. List three types of personnel necessary to conduct an HIV serosurvey.

4. The national surveillance supervisor should be responsible for supervision of:
   a. specimen collection
   b. data management
   c. laboratory equipment
   d. sampling
   e. all of the above

Introduction

What you will learn
By the end of this unit you should be able to:

• describe requirements for staffing, training and supervising of HIV sentinel surveillance programmes;
• identify potential sources of conflict when adding supervisory staff to existing programmes.

Training

Sentinel surveillance staffing
A variety of people are needed to conduct a serosurvey. These include clinic staff, laboratory technicians, supervisory staff, data managers or statisticians and survey
coordinators. Responsibilities for each surveillance staff member (regardless of his or her position in the programme) should be clearly defined in the serosurvey protocol. Tables 6.1, 6.2 and 6.3 outline responsibilities for serosurvey personnel at local, regional and national levels.

Table 6.1
**Responsibilities of serosurvey personnel at local (clinic) level**

<table>
<thead>
<tr>
<th>Level and Title</th>
<th>Appropriate Responsibilities</th>
</tr>
</thead>
</table>
| Clinic staff (nurse or laboratory technician) | • ensure that eligible individuals are included in the serosurvey  
• draw blood specimens  
• split specimens for standard syphilis testing and for HIV testing  
• label and properly store specimens in preparation for transport to the testing laboratory  
• fill in data collection forms  
• transmit data collection forms to regional level  
• train for other staff members’ duties in the case of absence |
| Supervisory staff (nursing supervisor or senior laboratory technician) | • ensure efficient operation of serosurvey  
• supervise other surveillance staff  
• provide adequate oversight, ensure confidentiality |
| Courier (as needed) | • in some cases, someone from the Ministry of Health will be available to transport specimens to the testing laboratory. If not, the clinic laboratory technician may be required to do so, especially if specimens will be tested in the same town or city. |

Table 6.2
**Responsibilities of serosurvey personnel at regional level**

<table>
<thead>
<tr>
<th>Level and Title</th>
<th>Appropriate Responsibilities</th>
</tr>
</thead>
</table>
| Laboratory technician* | • order equipment, supplies, and test kits  
• conduct HIV testing  
• report results to data entry clerk  
• participate in quality control and quality assurance programmes |
| Data entry clerk | • examine data for missing values and try to resolve these by communicating with clinic  
• combine data from data collection forms and laboratory results into single data set |
| Survey coordinator | • ensure provision of equipment, supplies, and test kits  
• ensure adequate oversight and confidentiality at the regional level  
• provide training for local level and regional staff  
• disseminate survey findings |

*This table describes a system where laboratory testing and data entry occur at the regional level. These activities can also occur at the local level.*
Table 6.3
Responsibilities of serosurvey personnel at national level

<table>
<thead>
<tr>
<th>Level and Title</th>
<th>Appropriate Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laboratory technician</td>
<td>• ensure provision of equipment, supplies, and test kits to regional laboratories</td>
</tr>
<tr>
<td></td>
<td>• conduct HIV tests as needed, for example, for difficult or borderline specimens</td>
</tr>
<tr>
<td></td>
<td>• oversee quality assurance of testing procedures at regional and local levels</td>
</tr>
<tr>
<td>Data manager/statistician</td>
<td>• enter data in the programme’s computerized database if this is not done at the regional level</td>
</tr>
<tr>
<td></td>
<td>• examine data for missing values</td>
</tr>
<tr>
<td></td>
<td>• manage data</td>
</tr>
<tr>
<td></td>
<td>• analyse data</td>
</tr>
<tr>
<td>Surveillance co-ordinator</td>
<td>• develop serosurvey protocol with help from programme staff</td>
</tr>
<tr>
<td></td>
<td>• ensure adequate funding</td>
</tr>
<tr>
<td></td>
<td>• provide adequate oversight and training at the regional and national levels</td>
</tr>
<tr>
<td></td>
<td>• ensure confidentiality</td>
</tr>
<tr>
<td></td>
<td>• interpret findings in conjunction with regional level survey coordinators and prepare survey reports and national reports.</td>
</tr>
</tbody>
</table>

Identifying training needs

Skilled and knowledgeable personnel are essential for a successful surveillance system. It is necessary to assess training needs while planning surveillance activities. The survey coordinator should identify the training needs of staff in the survey protocol. The survey protocol should be explicit about training needs.

- It should specify what types of personnel would need to be trained.
- It should specify where training would occur.
- It should specify who would be responsible for doing the training.

Assessing training needs should start with a comprehensive job description of all the activities to be carried out, the skills required to perform each task and the risks associated with improper performance of the tasks. The survey coordinator should then compare the job description with the staff assigned to each duty and identify the gaps in knowledge where trainings are needed.

Conducting training

All personnel involved in a serosurvey must be trained. After appropriate individuals are identified and selected at the local, regional and national levels to conduct the serosurvey, the national surveillance staff should conduct training before every serosurvey. It is important to identify all participants who should attend the training. These will include supervisors, laboratory staff and clinic staff. Vigorous attempts should be made to enable them to attend the training. The following should be included in all trainings:
• a review of the survey protocol, operational procedures and the field protocol;
• results from any previous serosurveys conducted at the site or in the region;
• an opportunity for participants to discuss their concerns and ask for any clarification of serosurvey operations.

Training sessions may be conducted either at the clinic site, or in a central location at the regional or national level. Sessions that involve staff from multiple sites offer the opportunity to share experiences, and can bring down the costs of conducting the training.

Maintaining motivation
It is important for personnel to understand the necessity and importance of conducting these surveys. Maintaining motivation among serosurvey personnel will make it easier to conduct high-quality, timely serosurveillance activities. Examples of ways to maintain staff motivation include:

• developing a sense of serosurvey ‘ownership.’ This might include:
  • discussing the importance of these surveys
  • showing results from previous surveys and how they can be used

• defining clearly responsibilities and roles for all staff involved - at all levels;
• emphasizing the importance of each person’s contribution to the serosurvey’s success;
• providing adequate staff training;
• ensuring that the needed equipment and forms are available before the survey starts;
• assigning data management and analysis responsibilities to regional coordinators.

Supervision
Supervision is an important part of quality assurance for serosurveys. At the national level, there must always be a person responsible for ensuring that all the required activities take place, and that surveillance is conducted uniformly in all sites. Appendix F is a checklist for monitoring operational activities.

The supervisor should monitor all aspects of sentinel surveillance, including:

• sampling
• data and specimen collection and management
• laboratory equipment

As it is impossible for one person to be present to supervise at all facilities, he or she may delegate to other supervisors. These other supervisors may then delegate, if need be, to a supervisor at the facility level. The levels of supervision should be kept to a minimum. At all levels, supervisors should be sensitive about their role in HIV surveillance.

When supervisory activities are planned, it is helpful to make use of the existing management structure at the facility level. As part of this, it is prudent to give the
supervisory role to the regular facility supervisors. This will minimize conflicts with the facility administrators, offer more ownership in the process and encourage effective management of the surveillance activities.

**Summary**

To ensure that the surveillance process is smooth and effective, be sure that all staff undergo the necessary training. Also, use existing management structures when you assign supervisory roles, in order to avoid conflict and inefficiencies.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

**Small group discussion**

Get into small groups by country, region or province to discuss these questions.

1. Your health facility has been selected as a sentinel site for HIV surveillance and needs to recruit a surveillance staff person. Discuss the activities, skills and duties that should be included in a comprehensive job description for the surveillance activities that will be taking place. What type of training will be necessary?

2. In a national HIV surveillance programme, where the chosen sentinel sites are at the health centre level, a national coordinator often supervises regional or provincial coordinators, who in turn supervise district surveillance officers. This chain of command goes down to the health centre level. What are the advantages of following this existing national structure, and what would be the advantages of decreasing the number of supervisory levels?

**Apply what you have learned/case study**

Try this case study. We will discuss the answers in class.

As part of your duties as the Panga district HIV surveillance officer, you are charged with assisting the central Ministry of Health staff in training personnel for a new STI clinic sentinel surveillance site. You have been asked to invite appropriate people to the training.

a. Whom do you plan to invite?
b. What elements of sentinel surveillance do you think need to be covered in this training?
c. A staff member asks a question about the difference between linked and unlinked testing and why unlinked testing is being done at the clinic. How do you respond?
d. You receive a report that an individual patient’s results were released inadvertently to clinic staff. You view this as a serious breach in study procedures. How would you investigate this, and what would you do?
e. At the end of the surveillance cycle, you discover that the clinic did not report any data for the last month of the survey period. How do you address this problem?
Overview

What this unit is about
This unit describes the process of data collection, including proper procedures for forms and data entry. It also explains the overall idea of data analysis and interpretation.

Warm-up questions
1. __________________ is the process of entering paper records into a computerized database.

2. True or false? The best way to summarize sentinel surveillance data is by calculating a single prevalence figure for the whole survey.
   True   False

3. True or false? Data dictionaries (electronic files that describe the basic organization of a project or database) should be developed at the local clinic level.
   True   False

Introduction

What you will learn
By the end of this unit you should be able to:

• describe the process for serosurvey data entry;
• list the variables for analysing sentinel surveillance data.

Data Entry and Management

Following demographic data collection and laboratory testing for HIV, results are brought to a site for data entry. This site can be at the clinic level, at the regional level or at the national level. At the clinic and regional levels, merging the results from HIV tests and the demographic and medical history data on the data collection forms is most often done by hand. Ideally, computers would be used to merge these results, but often computers are available only at the national level.

This unit starts with a brief discussion of steps to take when entering serosurveillance data into a computer, and then continues on to discuss analysis and interpretation of the data.
Databases

*Data entry* is the process of entering paper records, which in this case are the merged demographic data collection forms and HIV test results, into a computer *database*.

- Databases store the variables (for instance, age group, clinic site and district) for each patient in the survey sample.

- Data can be stored either as numbers or as text. Most variables will be converted into numbers. For instance, an HIV test result can be coded as ‘1’ for positive, ‘2’ for negative or ‘9’ for missing value.

- Databases and data entry screens are set up centrally by information technology staff at the national level. *Data entry screens* are the forms on the computer screen into which a data entry clerk enters the data. They are the primary mechanism for inputting data from paper forms into the computer. An example of one for antenatal clinic (ANC) serosurveillance is shown below.

**Figure 7.1**

*Sample data entry screen*

![Sample data entry screen](image)

**Data dictionary**

*A data dictionary* should also be developed centrally. Data dictionaries are electronic files that describe the basic organization of a project or database. They contain all of the rules that guide data entry.
**Steps for data entry**

The steps for data entry are as follows:

1. Enter data either as numbers or text, depending on the variable, for each patient on a data entry screen. Data entry screens are designed so that you can enter all the variables for one patient at one time. See the example in Figure 7.1, above. When you finish entering the data for one patient, the computer saves the data in a database. The next person’s record then appears on the screen. Data entry should be a continuous process, to avoid backlogs of forms to be entered, and the consequent increase in errors. Only persons trained in computer data entry should carry out this function.

2. Re-enter the data. Ideally, all data are **double-entered**, meaning they are entered two times in order to catch mistakes that may have been made.

3. Check data for errors either automatically or manually. Table 7.1 below describes each of these two options.

| Table 7.1  |
| Methods of checking data for errors |
| **Method** | **Description** |
| **Automatic** | The computer programme that runs the data entry screen and the database also contains rules on what values can be entered for each variable. This involves built-in check programmes (the ‘Check Code’ function in *Epi Info™*, a freely-distributed epidemiological software) that checks for impossible values as the data are entered. For instance, if ‘1’ is the code for a positive HIV test, ‘2’ for a negative test and ‘9’ for a missing value, the computer will recognize a value of ‘7’ as impossible, and will not allow it to be entered. |
| **Manual** | This method involves checking for errors after data entry. A data entry clerk will display the values for a single variable for all patients, and see if there are patterns that suggest problems with data recording or entry. Also, data can be displayed for each clinic site. For instance, one clinic may not have reported any results for one month. Another clinic may have reported everyone as being HIV-positive. |

**Analysis and interpretation**

According to the principles of **second-generation HIV surveillance**, data on HIV prevalence are only one component of a complete system. Data from **sentinel surveillance** should be analysed and interpreted in conjunction with other data. These data may include, for example, STI prevalence (which may be available from sentinel sites themselves), behavioural data, and **AIDS case surveillance**.
The process of analysing and interpreting sentinel surveillance data is guided by the following questions:

- Is the prevalence of HIV increasing, decreasing or remaining essentially stable?
- What is the trend in HIV prevalence among 15- to 24-year-olds?
- Which *sentinel sites* have the highest HIV prevalence? Which groups have the highest HIV prevalence? In which groups is HIV prevalence rising? Falling?
- What are the differences between sites where the prevalence of HIV infection is low (for example, <1%) and those where it is relatively high (for example, >5%)?
- What are the differences between sites where the prevalence of HIV infection is increasing, and those where there is a decrease or no change?

**Examining trends**

Analysis of HIV sentinel surveillance data should focus on the prevalence of HIV by person, place and time. However, changes in HIV prevalence by time are of greatest importance. Due to selection biases, sentinel surveillance data may over- or under-estimate the true prevalence of HIV in a population. If methods for conducting sentinel surveillance are consistent from year to year, changes over time may reflect real changes in prevalence.

Trends in time indicate whether the prevalence is rising, falling or remaining stable. A focus on the trend, rather than absolute prevalence, is a principle of second-generation HIV surveillance.

Trends in HIV prevalence among young persons aged 15 to 24 years merit special attention. Because young women have likely not been sexually active for many years, their HIV infections were probably acquired recently. Therefore, trends in HIV prevalence in this age group are most likely to reflect trends in HIV incidence.

**Analysis by variables**

In addition to analysis by age group, sentinel surveillance data should be analysed by each of the variables collected. Such analysis may indicate where HIV transmission is highest. Analyses should therefore include HIV prevalence by:

- year of survey
- sentinel site, district, province and region
- age group
- female and male (if other than ANC)
- residence (for example, rural versus urban)
- marital status
- other demographic variables if collected (for example, education, occupation)
- risk behaviour if collected (for example, number of partners, condom use)
- presence of STIs
Ideally, data should be analysed separately for each site according to the following guidelines:

- Results should be summarized for the entire survey sample at each site, and for each sub-group for which information on age and sex has been collected.
- It is not a good practice to summarize sentinel surveillance data by calculating a single prevalence figure for the whole survey.
- Because the sample represents only the population accessing the clinic in the survey, the overall prevalence does not necessarily reflect the true prevalence in that population in the whole country or region.
- Summary information that can, at best, be presented is the median and range for each type of sentinel site, on a regional and national basis.

Summary

Data entry is the process of entering paper records from surveillance into a computer database. Be sure to have procedures in place that prevent errors in the data entry process. You can then analyse and interpret that data, using variables such as the following:

- sentinel site, district, province and region
- age
- sex
- marital status

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. What variables are used in the analysis of HIV sentinel data in your country, region or province?

2. Answer the following questions about your district or province

   a. What were the highest and lowest prevalence rates during the last HIV sentinel surveillance period in your district or province?
   b. What are the sites with these rates?
   c. Are the rates increasing or decreasing at these sites?

3. Do you analyse the data by age group? Why?
Apply what you have learned/case study
Try this case study. We will discuss the answers in class.

You are the newly hired district surveillance officer for Panga district in the country of Nodesh, and are charged with coordinating HIV seroprevalence studies. Unlinked, anonymous annual HIV seroprevalence studies have been conducted in all five ANCs in this district for the past seven years. You decide to examine the trends in HIV prevalence at the ANCs to assess the status of the HIV epidemic in your district. Since you have included all the ANCs in the district in your survey, it is appropriate to calculate single prevalence values for the district.

The data in Table 7.2 are available for you to examine.

Table 7.2
Number of HIV tests and positive results for Panga district, by year

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of HIV tests done</td>
<td>400</td>
<td>450</td>
<td>500</td>
<td>475</td>
<td>425</td>
<td>486</td>
<td>499</td>
</tr>
<tr>
<td>Number of HIV+ tests</td>
<td>25</td>
<td>27</td>
<td>30</td>
<td>24</td>
<td>20</td>
<td>18</td>
<td>18</td>
</tr>
</tbody>
</table>

Use these data to calculate the annual HIV prevalence, and develop a figure or graph that you think would explain the trends.

a. What do you observe in seroprevalence trends, and what might these trends mean?

b. What additional information would be helpful in understanding these trends?

c. Are there additional ways to examine these data to assess the epidemic?
Notes
Overview

What this unit is about
This unit describes the uses of HIV sentinel surveillance data for public health action, and how to disseminate them most effectively.

Warm-up questions
1. True or false? Reading or hearing about HIV in the media strengthens basic information and prevention messages.
   True  False
2. List two potential audiences for surveillance data.
3. List three potential uses of HIV surveillance data.
4. True or false? When disseminating HIV surveillance results, a single message that can be used for all target audiences is the best way to transmit the information.
   True  False

Introduction

What you will learn
By the end of this unit you should be able to:

- discuss various uses for HIV sentinel surveillance data;
- discuss how to develop a clear and understandable message about surveillance data;
- understand the tools for disseminating data to target groups.

Uses of HIV Surveillance Data

A goal of second-generation HIV surveillance is to enhance the use of surveillance data for public health action. The impact of data can be enhanced when several sources of information are used. Data from HIV sentinel surveillance are therefore only one of several sources that can be used for public health action. Data can be used for a variety of purposes, such as:

- targeting prevention and care programmes
- monitoring and evaluation
- resource allocation and programme planning
- informing and educating the public
- guiding scientific research
- monitoring indicators
• triangulation
• mobilizing political commitment
• advocacy

Each of these uses is described in detail below.

Targeting prevention and care programmes
A principal use of HIV prevalence data is to identify groups of persons at highest risk for HIV infection. These groups may be persons in certain age groups or attending certain clinics. They may be from certain geographical areas. By identifying these groups or areas with the highest HIV prevalence, public health workers can direct information, education, health care and other programmes, in order to keep the uninfected members of the group uninfected, and to assist those already infected.

Table 8.1 illustrates the advantages and disadvantages of using sentinel surveillance data in guiding prevention and care programmes.

Table 8.1
Advantages and disadvantages of using sentinel surveillance data in guiding prevention and care programmes

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Presenting HIV sentinel surveillance data by person and place, using variables that are routinely collected, is helpful in determining where the burden of disease is greatest in a country.</td>
<td>• HIV sentinel surveillance data have not been very useful in identifying specific high-risk behaviours since only limited behavioural data are collected.</td>
</tr>
<tr>
<td>• It can also show which particular demographic groups are most severely affected.</td>
<td>• If sentinel surveillance is only conducted in antenatal clinics (ANCs), trends in HIV prevalence among men will be missed, prevalence among young women may be overestimated and prevalence in older women may be underestimated.</td>
</tr>
<tr>
<td>• Most countries have used sentinel surveillance data to direct increased attention to high-prevalence areas. This positive trend needs to continue.</td>
<td></td>
</tr>
</tbody>
</table>

Monitoring and evaluation
HIV serosurveillance data can be used to evaluate the long-term health impact of an HIV prevention programme, by detecting changes in the prevalence of HIV infection over time. Evaluation refers to determining how well a programme is functioning (process evaluation) and what its impact is (impact evaluation). Monitoring refers to looking at a programme’s performance over time. There are two limitations, however, in using prevalence for monitoring and evaluating prevention programmes.
• First, prevalence surveys measure prevalence, not incidence. Prevention programmes are designed to decrease the incidence of HIV, and then eventually its prevalence. Because there is no readily available non-experimental method to measure incidence directly in a sentinel survey, changes in incidence can only be approximated by changes in prevalence. Changes in prevalence among 15- to 24-year-olds best approximate changes in incidence, since these infections are likely to be recently acquired.

• The second limitation is that populations targeted for prevention are usually exposed to more than one prevention message, through mass media, schools, clinics and word-of-mouth. As such, changes in HIV serosurveillance data do not typically reflect the impact of a single prevention programme. They must be interpreted along with behavioural and other sources of data, to identify the plausible causes for changes in prevalence rates.

HIV sentinel serosurveillance data add power to the plausibility of the prevention programme’s results. It may take time for prevention efforts to translate into changes in HIV prevalence. Additionally, HIV serosurveillance data alone cannot give a complete picture of whether the epidemic is growing, decreasing or staying the same. HIV serosurveillance data are part of a package of information used to form the whole picture of the status and direction of the HIV epidemic in a country.

A specific sub-set of HIV serosurveillance data deserves special mention. Data from ANC sites can be used to estimate the number of newborns who will be exposed to HIV. Decreases in prevalence in pregnant women means that fewer babies will be exposed to HIV, and less mother-to-child transmission will occur.

Resource allocation and programme planning
You can use data from HIV sentinel surveillance to estimate the number of HIV-infected persons in a country. Prevalence data and other variables are fed into computer models such as Spectrum and EPP (Estimation and Projection Package). This data includes:

• the average time from HIV infection to an AIDS diagnosis
• survival after an AIDS diagnosis
• population size

This enables you to make short-term projections on HIV incidence and prevalence, and on the annual incidence of AIDS cases. These estimates of AIDS cases are more reliable than the total number of AIDS cases that can be obtained from AIDS surveillance systems, and can be used as a cross-check. More importantly, this information can be used to allocate resources for AIDS care. It can also help you make plans for future prevention, care and treatment services.

You can also use ANC sentinel surveillance data to predict the future number of children who will be born with HIV infection. These projections use similar models, which also include data on risk of transmission from mother to child, infant mortality rates and fertility rates of HIV-infected women.
Public education
Disseminating information on HIV prevalence data through the mass media or individual counselling can help to give people a realistic perception of the risk for HIV infection in their community. This is extremely important for those in high prevalence areas who continue to engage in high-risk behaviours. Reading or hearing about HIV in the media is likely to reinforce basic information and specific prevention messages. It also may help in removing stigma surrounding HIV infection.

Guiding scientific research
Epidemiologic and prevention research is most efficiently done where rates of HIV transmission are highest. HIV sentinel surveillance can also be an important part of scientific research. In epidemiologic research, which examines the distribution and determinants for disease, higher prevalence in certain populations will suggest where disease transmission is highest. This will be where its epidemiology and prevention are most easily studied. An example of a successful case is described below:

- A sentinel surveillance study of factory workers in Zimbabwe who donated blood found rapidly rising HIV prevalence.

- This, is in turn, led to a detailed examination of risk factors for getting infected at or near the factory.

- The answer turned out to be that the factory workers met sex workers at beer halls, and were subsequently infected.

- This, in turn, led to an intervention trial at the beer halls.

Monitoring indicators
HIV sentinel surveillance data are used as indicators for performing monitoring and evaluation of the impact of prevention programmes. Indicators are specific data that are gathered to measure how well a prevention or treatment programme is doing. UNAIDS has developed the concept of impact indicators to communicate these outcomes most effectively. Examples of impact indicators are listed below, with details for measuring the indicators.

Impact indicator 1 is HIV prevalence among pregnant women. Following the principles of second-generation HIV surveillance:

- This indicator is based on HIV prevalence in ANCs using unlinked anonymous testing in women aged 15 to 24 years.

- The indicator is measured by dividing the number of HIV-positive blood samples by the total number of blood samples taken from women aged 15 to 24 years at ANCs.

- It is used as a proxy measure of incidence in this youngest age group, because 15-to 24-year-old women with HIV probably were infected within the preceding few years.

- It is strongly recommended that two separate figures be reported: one for women aged 15 to 24 years and one for women across the entire reproductive age range of 15 to 49 years.
• Using the prevalence in women aged 15 to 24 years in the indicator gives a more accurate picture of recent infection.

Impact indicator 3 from UNAIDS is HIV prevalence in sub-populations with high-risk behaviours. In countries with low-level or concentrated epidemics, surveillance activities are more effective if resources are concentrated on tracking behaviours and HIV prevalence in sub-populations, where risk for HIV infection is concentrated. Examples of sub-populations at high risk for HIV infection include:

• STI clinic patients
• sex workers
• long-distance truck drivers
• frequent clients of sex workers

Sentinel sites for these populations typically include STI clinics and other general-medicine clinics, located near areas where sex work occurs.

Table 8.2 summarizes the information about impact indicators 1 and 3.

Table 8.2
Summary of impact indicators 1 and 3

<table>
<thead>
<tr>
<th>Impact Indicator 1</th>
<th>Impact Indicator 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population(s) it reflects</td>
<td>Pregnant women</td>
</tr>
<tr>
<td>Epidemic state(s) in which it is used</td>
<td>Generalized</td>
</tr>
<tr>
<td></td>
<td>Sub-populations with high-risk behaviour</td>
</tr>
<tr>
<td></td>
<td>Low-level or concentrated</td>
</tr>
</tbody>
</table>

**Triangulation**

An important way that you can use sentinel serosurveillance data is in combination with other data. The process of examining several different sets of data, which are measuring different things to come up with a better understanding of how and where the epidemic is spreading, is called **triangulation or data synthesis**.

Second-generation surveillance stresses comparing of HIV serosurveillance data and HIV behavioural surveillance data, to enhance the **explanatory power** of the surveillance data. Integrating these data with other sources of data can give a more complete picture of the HIV epidemic. Some other sources of data may include:

• STI and tuberculosis (TB) surveillance data
• blood donor data
• AIDS case reporting
• death registration information

STIs can indicate recent risk behaviour (for example, unprotected sex) because many STIs and STI syndromes are of short duration and have been acquired recently. As TB is an opportunistic infection associated with HIV, trends in TB surveillance data can indicate trends in HIV infection from some years earlier. Also, TB trends can reflect the
effectiveness of HIV treatment programmes in the future, because as HIV is treated with antiretroviral drugs, TB rates should come down.

Mobilizing political commitment
HIV prevalence data have been extremely useful in obtaining, reinforcing, and increasing the commitment of various governmental and non-governmental organizations (NGOs) to prevention and control programmes.

- HIV prevalence data are also extremely helpful for gaining political commitment.
- However, it is challenging to maintain political commitment, and efforts must be made to sustain it.

For continued political and financial commitment, you must effectively analyse and present HIV surveillance data to policy-makers and decision-makers. Selected kinds of people who need to be informed include politicians, potential donors or funders, public health planners, health personnel at national and local levels, health promotion and prevention staff and the media, as well as individuals, groups and communities. You should make efforts to release surveillance reports with the shortest possible delay, and to mould and target communications to the variety of audiences.

Advocacy
An important use of HIV surveillance data is advocating or lobbying for the health and social needs of populations impacted by HIV/AIDS. First and foremost, public and governmental recognition of the very existence of an HIV epidemic in a country or province depends upon demonstrating that HIV is present. HIV sentinel surveillance can fulfil this role as follows:

- In countries with low-level or concentrated epidemics, sentinel surveillance can confirm the presence of HIV in a population or region. This is most effectively done through selecting sentinel sites where infection is most likely to first appear, such as STI clinics.
- In generalized epidemics, the appearance and persistence of HIV in pregnant women makes a compelling argument for the spread of the infection beyond groups at highest risk.
- Governmental and NGOs are less able to ignore the reality of HIV when its existence and impact are documented thoroughly, through sentinel surveillance.

Disseminating HIV Surveillance Data
There are several distinct steps to disseminating HIV surveillance data. They include:

- establishing the message you want to communicate;
- selecting the audience to which you want to deliver the message;
- selecting the channel through which the message will be delivered;
- selecting the tool for delivering the message;
- evaluating the impact of the message.
Each of these will be discussed below:

Establish the message
The first step in effectively disseminating the results of a particular round of HIV sentinel surveys is establishing a message. Working with senior public health officers, the surveillance team needs to decide its objective. What is the most important information that the team wants to convey? Is the epidemic increasing or decreasing? Is there evidence that what is being done is working?

Messages will differ from audience to audience as well. That is to say, changes in HIV prevalence may have several explanations, and different audiences may be interested in different explanations.

- A foreign donor may be most interested in how well a new antiretroviral treatment programme is working. A falling HIV prevalence may, for instance, be the result of poorer survival of persons with HIV, and suggest that antiretrovirals are not getting to the sickest patients.

- The media may want to know how one country compares with another or how effective the overall prevention effort is. A falling HIV prevalence in this case might be interpreted as a result of an effective prevention programme.

In both cases the most likely reason for the declining prevalence needs to be worked out by a thorough review of all data. Next, the content of the message needs to be decided upon, crafted in a clear and concise way and expressed at an appropriate level for the target audience.

Select the audience(s)
Once the message has been established, the target audience should be defined. Today, especially with the multiple sectors of civil society and government involved in the response to HIV, the audience for up-to-date information on the HIV epidemic is much broader than just health professionals.

Important potential target audiences include:

- health professionals
- general public
- policy-makers and other decision-makers
- media
- other sectors
- NGOs
- other national and international organizations
- surveillance staff members at national and local levels who help conduct serosurveys

The content of the message and the target audience should be linked. The message sent to the recipient will differ if the country’s national AIDS control programme (NACP) wants to mobilize the population for World AIDS Day, for example, or if the NACP
wants to secure a greater commitment from the Ministry of Education for school-based prevention programmes.

Perhaps the most important audience for prevalence data is the people who generated them in the first place. HIV prevalence data should be communicated to the surveillance staff members, at the national and local levels, who conducted the serosurveys. They need to receive feedback about how well the serosurvey was conducted and what it found. Feedback enhances and helps maintain the system.

Select the communication channel(s)

The selection of an appropriate channel of communication increases the probability that the message will reach the target audience and achieve the objective.

Examples of communication channels for disseminating HIV surveillance results are listed below:

- television
- radio
- newspapers
- scientific journals
- conferences
- newsletters
- press releases
- the internet, including government websites
- epidemiologic bulletins and technical reports

Using the most widely read newspapers may be the most efficient and effective channel to make the results of an HIV sentinel surveillance round known to the general public. On the other hand, if the NACP wants to highlight results for decision-makers, a face-to-face briefing may be the best way to get the message across.

Select the tool(s)

It is essential to use the appropriate tools to transmit the message once the audience and channel of communication are defined (Table 8.3). For example, if decision-makers are the target audience and the channel is a face-to-face briefing, visual tools and graphs, with a short text explaining the major conclusions, will be much more efficient than technical reports, since this audience is pressed for time and may be less technically oriented.
Table 8.3
Examples of essential tools and audiences for communicating information about HIV prevalence

<table>
<thead>
<tr>
<th>Audiences</th>
<th>Channels</th>
<th>Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technical professionals involved in NACP and monitoring and evaluation</td>
<td>Dissemination or evaluation workshops</td>
<td>Full technical report on HIV, STI and behavioural surveillance</td>
</tr>
<tr>
<td>NGOs, other sectors and partners</td>
<td>Conferences</td>
<td>A non-technical review of data from different sources</td>
</tr>
<tr>
<td>Media, journalists, general population</td>
<td>Press conferences</td>
<td>A press release highlighting the main findings</td>
</tr>
<tr>
<td>Policy-makers, decision-makers</td>
<td>Face-to-face briefings and planning meetings</td>
<td>Brief summaries of main findings with some graphics</td>
</tr>
</tbody>
</table>

Discussing the table

a. Are the same tools used to disseminate the results of surveillance to each of the different audiences?

b. Why might it not be appropriate to distribute a full technical report to decision-makers or the media?

The tools used to transmit information should convey the information clearly. Whether a full technical report or a brief summary is used, visual tools such as graphs may help communicate the message. When you present the message in an easy to understand way, the audience is more likely to use the data.

Evaluate impact

An important final step is an informal evaluation of how well the surveillance message was delivered. While formal evaluation may be difficult and unnecessary, programmes should be able to have a sense of how influential their communications efforts have been in shaping policy.

- Informal conversations with the press may give ideas about what to include in press releases in future.
- Conversations with aides to senior policy-makers may similarly help to shape the scope and depth of future briefing materials.
- Finally, in behavioural surveys that are conducted as part of second-generation surveillance, you have the opportunity to ask people about the most effective ways to communicate messages about the HIV epidemic to them.

Surveillance staff should try to learn as much as they can about how they can improve messages, make more effective use of channels and tools, and better define the audiences for these important data.
Summary

HIV sentinel surveillance data can be used in many ways, including monitoring and evaluation, guiding scientific research, triangulation and public education. Several methods are available to disseminate this data, such as television, radio, newspaper or scientific reports. You should tailor the message itself, based on the target audience, so that it is most effective.

Exercises

Warm up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

How have HIV sentinel surveillance data been used in your province or district? How have they been disseminated to you? Have you disseminated them to others in your district?

How can HIV surveillance data be presented to different target audiences? What methods can be used to disseminate the results of the survey to the sentinel sites? What do you think would be most useful in your country?

Apply what you have learned/case study

Try this case study. We will discuss the answers in class.

You are the HIV seroprevalence coordinator for a province in the country of Nodesh. Annual seroprevalence surveys have been conducted at five ANCs in three districts of the province for the past four years. You are in the process of analysing your province’s local data and preparing the information for dissemination. The following table summarizes your analysis so far:

Table 8.2
Number of women (total and HIV+) at ANC sites.

<table>
<thead>
<tr>
<th>Women</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>All women, all sites</td>
<td>2 009</td>
<td>1 993</td>
<td>2 003</td>
<td>1 999</td>
</tr>
<tr>
<td>All HIV+ women, all sites</td>
<td>299</td>
<td>277</td>
<td>305</td>
<td>290</td>
</tr>
<tr>
<td>Women aged 15-24 years, all sites</td>
<td>491</td>
<td>507</td>
<td>497</td>
<td>501</td>
</tr>
<tr>
<td>HIV+ women, aged 15-24 years, all sites</td>
<td>39</td>
<td>31</td>
<td>25</td>
<td>19</td>
</tr>
</tbody>
</table>
Now answer the following questions.

a. At a local meeting of NGO directors, you are asked whether or not there is any indication that the money and effort spent on HIV prevention in the province has been successful. They request a brief summary of the antenatal sentinel surveillance data for their next meeting. What data would you include in this summary?

- How would you present the data?
- What data other than HIV prevalence would be useful to include?
- What conclusion do you present to NGO directors?

b. The Ministry of Health and the NACP inform you that the budgets for HIV prevention and care for your province are going to be reduced to US$300,000 for the coming year. Their policy is that money should be concentrated in the health districts in greatest need and that half should be spent on prevention and half on care programmes. They ask you to plan how you will allocate the $300,000 in the three districts within your province. You start by examining the ANC data by district and site and find the data shown in Table 8.4.

Table 8.4
Number of women, by district site, age group, and serostatus

<table>
<thead>
<tr>
<th>Women</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>All women</td>
<td>2,009</td>
<td>1,993</td>
<td>2,003</td>
<td>1,999</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>398</td>
<td>401</td>
<td>400</td>
<td>402</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>402</td>
<td>401</td>
<td>398</td>
<td>396</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>404</td>
<td>389</td>
<td>401</td>
<td>403</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>397</td>
<td>399</td>
<td>391</td>
<td>399</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>408</td>
<td>403</td>
<td>413</td>
<td>399</td>
</tr>
<tr>
<td>All HIV+ women</td>
<td>299</td>
<td>277</td>
<td>305</td>
<td>290</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>99</td>
<td>91</td>
<td>97</td>
<td>93</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>31</td>
<td>42</td>
<td>60</td>
<td>67</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>36</td>
<td>33</td>
<td>30</td>
<td>23</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>97</td>
<td>88</td>
<td>97</td>
<td>88</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>36</td>
<td>23</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Women aged 15-24 years</td>
<td>491</td>
<td>507</td>
<td>497</td>
<td>501</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>98</td>
<td>99</td>
<td>101</td>
<td>102</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>99</td>
<td>97</td>
<td>102</td>
<td>97</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>101</td>
<td>104</td>
<td>93</td>
<td>99</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>100</td>
<td>103</td>
<td>99</td>
<td>103</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>93</td>
<td>104</td>
<td>102</td>
<td>100</td>
</tr>
<tr>
<td>HIV+ women, aged 15-24 years</td>
<td>39</td>
<td>31</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>10</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>3</td>
<td>4</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>9</td>
<td>6</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>8</td>
<td>8</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>9</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
• Using the HIV sentinel surveillance data above, what are your recommendations on where the $150,000 for HIV prevention should be spent?

• Using the HIV sentinel surveillance data above, what are your recommendations on where the $150,000 for HIV care should be spent?

• What other factors would you consider before making your recommendations?

c. You receive a call from a reporter working for your national newspaper. She says that she heard a rumour that HIV cases have gone down in your province and would like your comments. You tell her that you are on your way to a meeting right now, but promise to call her back as soon as possible and also prepare a written press release.

Using the data presented above, what would you include in the press release? What further explanation would you provide? Whom would you contact before returning the call?
Module 3 Summary

- The objectives of the surveillance activity must be well defined. Three design options for HIV surveillance include sentinel surveillance, community-based surveillance, and population-based surveillance.

- In conducting HIV surveillance, useful sentinel populations in the diverse epidemics of SEAR are high-risk groups such as STI clinic patients, de-addiction clients, and CSW.

- It is prudent to begin HIV sentinel surveillance by selecting only a few sites and gradually increase them to cover a broad distribution of geographic areas, taking into consideration the availability of staff and financial and logistical resources.

- A sample size of 400 is usually adequate for surveillance among pregnant women attending an ANC. Higher sample sizes lead to more precise estimates. Consecutive sampling of patients is recommended. To examine prevalence trends, a survey frequency of once per year is sufficient.

- The recommended method of choice for testing blood specimens for surveillance is the unlinked anonymous method without informed consent. Participation bias is a critical issue for HIV sentinel surveillance.

- Data collected at each site and for each sentinel population at that site should be analysed separately. Results should be summarized for the entire survey sample at each site and for each sub-group for whom information on age and sex has been collected.

- If methods for conducting sentinel surveillance are consistent from year to year, changes over time may reflect real changes in prevalence. A focus on the trend, rather than absolute prevalence, is a principle of second-generation HIV surveillance.

- Ensure that the data generated are utilized. Some of the purposes for which HIV surveillance data may be utilized include mobilization for political commitment, increasing financial allocation, monitoring/evaluating HIV control programmes and educating and counselling individuals.
Notes
Appendix A: Answers to Warm-Up Questions and Case Studies

Answers are provided in italics for each unit’s warm-up questions and case study.

Answers to the questions within the unit are not included. Unit questions are designed to stimulate small group discussion among participants in the workshop or class.

Unit 1 Answers

Warm-up questions
1. HIV serosurveillance refers to the component of second-generation HIV surveillance that measures HIV prevalence. *HIV serosurveillance measures HIV prevalence in specific populations on a regular basis using serosurveys.*

2. Which of the following is one of the epidemiologic principles that guides HIV surveillance?
   a. HIV infections are not uniformly distributed in a population.
   b. There are a limited number of ways that HIV can be transmitted.
   c. HIV infection enters different areas and populations at different times, and spreads at different rates.
   d. *All of the above.*

   *HIV surveillance assumes that behavioural and biological risk factors result in a non-uniform distribution of infection in the population. Similarly, this will result in different populations being affected at different rates. Also, HIV can only be transmitted through sexual, parenteral, and mother-to-child pathways.*

3. Blood donation is ideally voluntary and entails selecting donors at lowest risk of infection. HIV prevalence data from blood banks are likely to *underestimate* true prevalence in a population.

   *Because HIV-uninfected people are more likely to be recruited to donate blood, the prevalence in this group will be lower than that of the general population.*

4. True or false? In low-level epidemics, HIV surveillance should primarily focus on measuring HIV prevalence in antenatal clinics.

   *False. Surveys should target high-risk groups where HIV infection will probably appear first and spread fastest.*

5. Which type of surveillance better shows the clinical disease burden of the HIV epidemic?
   a. *AIDS case surveillance*
   b. HIV serosurveillance
While HIV serosurveillance measures HIV infection in the blood, AIDS case surveillance deals with the presence of clinical symptoms.

6. Because of the long latent period from HIV infection to the onset of AIDS, AIDS case surveillance may ________ the magnitude of the epidemic early on, when the HIV epidemic is expanding.

   a. over-represent
   b. under-represent

   Often, HIV infection can exist without the presence of clinical symptoms. Thus, AIDS case surveillance, which measures the presence of clinical symptoms, will not capture HIV-infected individuals who have not yet displayed clinical symptoms.

7. Which of these is a goal of HIV surveillance?

   a. identifying sub-groups at greater or less risk for infection
   b. monitoring trends in the prevalence of infection over time
   c. assessing risk factors of HIV transmission
   d. all of the above

   All of the above are required in order to meet the overall goal of HIV surveillance, which is to detect, describe, and track cases of HIV infection for the purposes of public health action.

8. True or false? Sentinel surveys are harder to do than population-based surveys. They give a more accurate picture of the overall HIV prevalence in a population. False. Sentinel surveys are easier because they involve surveys at only a few defined locations. On the other hand, they do not represent the general population, since the individuals surveyed at sentinel sites often have unique behavioural risk factors (for example, STI clinic attendees).

9. Selection bias is a big concern for sentinel surveys. People who attend a particular facility may be different from those who do not use that site. For this reason, data from sentinel surveys cannot usually be generalized to the broader population.

Case study
You are the surveillance officer for the Panga district of the country of Nodesh. Your district is large and located on a major highway. It is on the border of a country with a large refugee population. New funding for surveillance has made possible the expansion of activities in your district.

Currently, two of the four ANCs in your district participate in the national HIV sentinel surveillance system. One is located in the main city of your district, Bangalay. Bangalay is also the provincial capital. The other ANC is in a rural area near the provincial capital. Of the remaining two ANCs, one is located far from the capital. It is far from the main highway, and near a refugee camp across the border. The other is in a private hospital funded by international charities in Bangalay.
There is a rapidly growing town, Datapur, on the national border. Truck drivers wait long hours there as they pass customs inspections. Sex workers congregate in the border town, along the highway, and in two distinct areas of Panga. There are also an STI clinic and outpatient TB programme in the hospital in Bangalay. You have sufficient funds to add one surveillance activity in your district.

a. What types of surveillance activities could you consider?

- Population-based surveys, of the district or major areas,
- Community-based surveys to measure HIV prevalence in high-risk populations, such as along the highway, along the border area or among truck drivers and sex workers.
- Addition of sentinel surveillance sites, including antenatal clinics in area outside the provincial capital or in the STI or TB clinics.

b. What are the advantages and disadvantages of each?

- Population-based serosurveys provide the most generalizable information on HIV prevalence in a population. However, they are complex and expensive, and it is unlikely that the funds available would be sufficient for an ongoing population-based serosurveys.
- Funds may be sufficient for targeted community-based surveys in a potential high-risk population, such as truck drivers, sex workers or refugees at the border. Finding these populations may be difficult.
- Sentinel serosurveys, on the other hand, are typically based in clinics, most commonly ANCs where blood is being routinely drawn for prenatal tests. Their primary advantage is logistic simplicity and cost-effectiveness. In generalized epidemics, ANC serosurveys can be used to approximate the prevalence of HIV in the general adult sexually active population. Sentinel serosurveys in the STI or TB clinic may include populations at higher risk for HIV infection and have similar logistical advantages as the ANCs.

Unit 2 Answers

Warm-up questions

1. Which of the following are criteria for the selection a sentinel population for HIV surveillance?

   a. the group should be definable and easily identified
   b. the group should be readily accessible to surveillance staff
   c. the group should be relevant to the epidemiology of HIV in the particular region
   d. all of the above

   The local epidemiology and risk factors should be considered. For example, if the main source of infection is injection drug use, you would focus on IDUs instead of truck drivers. Also, you should consider the epidemic state. For example, in a low-level epidemic, you would focus on high-risk groups instead of women at ANCs.
2. True or false? When selecting sites for sentinel surveillance, the sites should be located in geographically diverse areas, both inside and outside of major cities and towns. True. In this way, the sentinel sites will best reflect the countrywide epidemic.

3. True or false? In the beginning of executing HIV sentinel surveillance, a large number of sites should be surveyed, in order to capture the scope of the epidemic. False. Initial sentinel sites should be initiated in facilities with high personnel and laboratory capacity and should include large numbers of person at high risk for HIV.

Case study
You are the surveillance officer for the Panga district of the country of Nodesh. Your district is large and located on a major highway on the border of a country with a large refugee population. New funding for surveillance has made possible the expansion of activities in your district.

Currently, two of the four antenatal clinics in your district participate in the national HIV sentinel surveillance system:

- One site is located in the main city of your district, Bangalay, which is also the provincial capital.
- A second site is in a rural area near the provincial capital.
- A third site is located far from the capital, far from the main highway, near a refugee camp across the border.
- A fourth site is in a private hospital funded by international charities in the provincial capital.

There is a rapidly growing town, Datapur, on the national border where truck drivers wait long hours to pass customs inspections. Sex workers congregate in the border town along the highway and in two distinct areas of Panga.

There are also an STI clinic and outpatient TB programme in the hospital in the provincial capital. You have sufficient funds to add one additional HIV sentinel surveillance population.

In what populations would you consider doing the additional serosurvey?

Antenatal clinic patients, STI patients and TB patients are the most feasible, given the access to patients, the drawing of blood, and their risk for HIV infection. Specific high-risk populations that might be considered are sex workers and mobile populations such as refugees, long-distance truck drivers, or mobile populations coming to Panga. Given Panga district’s situation, probably the most important high-risk populations are refugees and long-distance truck drivers. However, special community-based surveys may be needed to reach these populations.

What factors would you consider in selecting an appropriate population?
State of the epidemic (low-level, concentrated, generalized); how easily the population can be identified; if facility-based, whether blood is drawn routinely.

Are TB patients a suitable group for the additional serosurvey? Why or why not?

While TB patients are certainly at high risk for HIV infection (TB is the most common HIV-related opportunistic infection in Africa), they are likely not the best population to study in a generalized epidemic if only one additional site can be added. They can be identified fairly easily, especially if there are dedicated TB clinics, but they are not necessarily representative of the entire population - both with and without HIV infection - nor do they always have blood routinely drawn. Infections among TB patients may also be longer-standing infections rather than recent, and therefore less representative of the current patterns of transmission. For these reasons, they would likely not be the highest priority for sentinel surveillance expansion.

Unit 3 Answers

Warm-up questions

1. True or false? The goal of sampling is to use the data from a representative subset of a larger population to estimate the HIV prevalence in the larger population. True. Since surveying the entire population is costly and impractical, sampling provides a less costly, more practical method of estimating prevalence.

2. Which of the following is NOT a decision that needs to be made at the beginning of a sentinel survey?

   a. the sample size
   b. the sampling scheme
   c. the frequency of sampling
   d. none of the above

   All the above factors need to be considered before sampling, in order to make sure that the survey will be representative and accurate.

3. True or false? As much as possible, the sampling period should be limited, in order to compare HIV prevalence over time.

   True. Because HIV prevalence changes over time (for example, people leave the area, new people become infected), it is best to limit the sampling duration in order to approximate a point estimate.

4. Match each sampling scheme with its description:

   c. consecutive
   
   a. randomly selects the initial patient who meets inclusion criteria, and then selects every n<sup>th</sup> eligible patient thereafter

   a. systematic
   
   b. uses a computer or other method to generate a list of random numbers that is used to identify patients to be included in the sample
b. simple random c. samples every patient that meets the inclusion criteria until the required sample size is achieved

5. Which of the above schemes is the most simple logistically, and best reduces the likelihood of selection bias? Consecutive. The other schemes require more complex methods, and are more prone to errors by clinic staff.

6. True or false? All subjects at the sentinel site who meet the inclusion criteria during the sampling period should be included in the survey. False. Individuals who meet the exclusion criteria should be excluded, even if they meet the inclusion criteria.

7. True or false? When surveys are repeated, they should be carried out in different sites from the initial survey and during a different time of the year. This helps give a clear picture of the epidemic's scope. False. Surveys should be conducted at the same locations during the same time of year, so that the results can be meaningfully compared across time.

Case study

Using the formula for sample size estimation based on the precision of a point estimate, calculate the sample size required for the following scenarios.

\[ N = 4 \times z^2 \times P \times (1 - P) \div W^2 \]

a. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 10% within +/- 5%. Remember that P and W are expressed as decimals (that is, P = 0.10 and W = 0.10)

138 subjects

\[ N = 4 \times 1.96^2 \times 0.1 \times (1 - 0.1) \div 0.1^2 = 138 \]

b. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 10% within +/- 2.5%.

553 subjects

\[ N = 4 \times 1.96^2 \times 0.1 \times (1 - 0.1) \div 0.05^2 = 553 \]

c. What happens to the required sample size as the width of the margin of error gets smaller?

For the same estimated prevalence, the sample size needed is larger in order to have better precision.

d. You wish to have a sufficient sample size to estimate an expected HIV prevalence of 35% within +/- 5%.

350 subjects
\[ N = 4 \times 1.96^2 \times 0.35 \times (1 - 0.35) \div 0.1^2 = 350 \]

e. What happens to the required sample size as the estimated prevalence gets closer to 50%?

For the same level of precision, the sample size required for the same precision increases as the estimated prevalence gets closer to 50%.

Unit 4 Answers

Warm-up questions

1. True or false? In unlinked anonymous testing, it is okay to keep information about the identity of the patient, in order to tell them about their results if they test positive. False. All personal identifying information should be removed, since testing is unlinked and anonymous.

2. Place the following events in the correct order, corresponding to the proper procedure for unlinked anonymous testing:

   a. Blood is collected and labelled with a code.
   b. Specimen is tested for HIV.
   c. Personal identifying information is removed from specimen.
   d. An aliquot is removed into a new tube for HIV testing.

   \( a, d, c, b \)

3. True or false? Unlinked anonymous testing without informed consent can sharply reduce participation bias. True. In this way, patients do not have a choice about whether their sample will be included.

4. Place the following events in the correct order, corresponding to the preferred data collection method for unlinked anonymous testing:

   a. Send form to laboratory.
   b. Add HIV test result to form.
   c. Add demographic data to form.
   d. Remove demographic section of form and send to data manager.

   \( c, d, a, b \)

5. Which of the following is not a reason for the use of standardized data collection forms?

   a. to ensure that the necessary information is obtained
   b. to ensure that data from different sites can be easily compared
   c. to ensure that a patient’s personal information can be matched with their test result
   d. none of the above
Standardized data collection forms allow for greater ease in data collection. Matching a patient’s information to their test result is irrelevant, and sometimes is even undesired.

6. True or false? For linked confidential surveys, a separate laboratory form for serologic results should be used so that laboratory personnel do not have access to the patient’s personal identifying information.

True. Since testing is confidential, laboratory personnel should not be able to identify the patient with his or her test result.

7. For unlinked anonymous testing, as is used in sentinel surveillance, which of the following variables would be inappropriate to collect:

a. patient’s age
b. patient’s marital status
c. patient’s number of children
d. none of the above

Knowing the patient’s number of children is not necessary.

Case study
You identify an STI clinic in your district that serves a population located on the border area of a country with high HIV prevalence and a large refugee population. It is located on a major highway. You wish to determine HIV prevalence in the STI clinic population. Funding to establish the clinic as a sentinel surveillance site will be available starting next year.

You visit the hospital laboratory that conducts syphilis testing for the STI clinic. The laboratory director tells you that she has saved blood specimens from the clinic for the last six months. She was about to discard them, but asks whether these specimens could be tested for HIV to determine the prevalence in the clinic population.

a. Do you think that testing these specimens would produce an estimate of HIV prevalence that could be compared to the sentinel surveillance estimate planned for the following year?

It is possible that these specimens could produce an estimate of HIV prevalence that is comparable to sentinel surveillance - providing that certain information is available and procedures for unlinking personal information from HIV results can be established. Because sentinel surveillance at facilities is based on the use of available information and blood collected for other purposes, on the face of it these specimens could be used to produce an estimate of HIV prevalence in a cross-section of the clinic population in a manner similar to one planned for next year.

b. What information do you need to know about the specimens and their source in order to assess their suitability for estimating HIV prevalence?
- Do the stored specimens represent a complete, consecutive sample of STI clinic patients? During what time-period were they collected? Are specimens missing? Are specimen volumes sufficient? Were the specimens stored adequately?

- Are the specimens linked to clinic records that contain a minimum amount of information on the patients needed for interpreting data. Can the eligibility of the patients be determined? Do the records completely record date of clinic visit, repeat or first time visit, age, sex, residence. Is additional information required by sentinel surveillance also available (for instance, marital status, education, occupation)?

c. Describe the steps you would take to ensure that HIV test results could not be linked back to clinic patients.

Of note, as an effort that differs from the planned sentinel surveillance activity, it may first require consideration for ethical review and, at a minimum, a fully written and detailed protocol. The steps actually taken to conduct this effort may vary, but will closely parallel the steps outlined in this unit. Participants should clearly detail how information from medical records will be permanently unlinked from HIV test results prior to HIV testing of specimens. The following is one example:

Identify the time-period to be used. This should correspond to the same consecutive time-period planned for next year’s sentinel surveillance effort. The period should include enough saved specimens to complete the same sample size projected for next year.

- Confirm that all the specimens collected during the time-period are available. This may be accomplished by comparing actual stored specimens with labels to laboratory records of syphilis test results.

- Create a temporary database that lists all specimens to be included. The database will temporarily include the original specimen identification number. A new, unique non-identifying study identification number is then assigned to each specimen number. The database also temporarily includes the patient medical record number.

- Data from the medical records are abstracted onto a data abstraction form (preferably the same form used for routine sentinel surveillance as planned next year). One part of the form contains the patient’s medical record number. This form does not personally identify information on the patients, but does include the required demographic characteristics and other routine data collected for surveillance.

- Data are entered into the database and checked for errors.

- Aliquots of stored blood are placed in tubes labelled only with the new, non-identifying study numbers corresponding to their original specimen numbers.

- Ensure that all linking information is destroyed. This includes: removal of medical record numbers from the data abstraction form (for instance, physically cutting off the portion and destroying them), deletion of original laboratory specimen numbers from the database, and permanently discarding (or replacing in storage) the original specimen tubes.

- Once unlinking is confirmed, HIV testing is done. Test results are entered into the database according to their unique, non-identifying study numbers.
d. Would you use the voluntary HIV testing data from the STI clinic as a measure of prevalence? Why or why not?

While the data from voluntary HIV testing may be informative, it is subject to many potential biases. For example, persons who already know they are infected may not choose to test, thus lowering prevalence. On the other hand, physicians noting signs and symptoms of HIV infection may only test those most likely to be infected. The unlinked, anonymous approach eliminates many of these potential biases. Nonetheless, voluntary HIV testing data may be useful in certain situations. For example, if HIV testing is nearly 100% in the clinic, then the estimate of HIV prevalence should be comparable to unlinked anonymous testing. However, interpretation of voluntary testing data should be done very cautiously.

Unit 5 Answers

Warm-up questions

1. Which of the following factors are involved in the decision to select an HIV testing strategy?

   a. sensitivity and specificity of test being used
   b. objective of the test
   c. HIV prevalence in the population being tested
   d. all of the above

   All of the above are required in order to select an appropriate test that maximizes sensitivity and specificity while minimizing cost.

2. Match each phase of the HIV testing process with the components it includes:

   b pre-analytical
   a. interpreting results, entering data into tracking system, reviewing quality control

   c analytical
   b. training, laboratory safety, selection of test kits

   a post-analytical
   c. specimen processing and storage, analysis of testing performance, reagent preparation

3. The process by which reference specimens are tested externally to ensure accuracy of a technician’s or laboratory’s performance is known as:

   a. internal quality assurance
   b. external quality assurance
   c. quality performance
   d. none of the above

   Laboratories conducting HIV testing should work with a national or international reference laboratory to conduct proficiency testing in order to verify the accuracy of their instruments and methods.
Case study
You are the newly hired district surveillance officer for Panga district in the country of Nodesh, and are charged with coordinating HIV seroprevalence studies. You have been asked to help set up a new laboratory at an STI clinic in Datapur, a town near the border. Prevalence at other STI sentinel surveillance sites in the district has been approximately 8% for the last three years. You choose a test that has a sensitivity of 0.9995 and a specificity of 0.995.

a. What is the positive predictive value of the test?

95%. Assume 100 people in the population. Prevalence = a+c = 8 persons who truly have HIV; b+d = 92 persons who truly do not have HIV.

\[
a / (a + c) = 0.9995, \text{ so } a = 7.996
\]
\[
d / (b + d) = 0.995, \text{ so } d = 91.54 \text{ and } b = 0.46
\]
positive predictive value = \( a / (a + b) = 95\% \)

b. What testing algorithm would seem most appropriate for testing for HIV as part of the next HIV sentinel surveillance round at this new laboratory?

Two test strategy, because it is used for surveillance regardless of prevalence.

c. What are five steps that you would take to ensure quality of the laboratory before the first test was run?

Establish a quality assurance programme. Pre-analytic activities include training, having a laboratory safety programme, having trained staff to perform the tests, working out specimen collection, labelling and transport, selecting test kits and checking their expiration dates, ordering HIV test kit reagents.

Unit 6 Answers

Warm-up questions
1. Which staff members should be trained prior to conducting serosurveys?

a. supervisors and managerial staff
b. laboratory staff
c. clinic staff
d. all of the above

All staff should be trained so that they know the proper procedures and their responsibilities in conducting the survey.

2. True or false? When planning for the supervision of testing facilities, the national surveillance organizers should hire an outside supervisor to staff each of the facilities where HIV testing occurs. False. This role should be assigned to someone in the existing management structure, in order to minimize conflicts, encourage a sense of ownership, and encourage effective management.
3. List three types of personnel necessary to conduct an HIV serosurvey. **Clinic staff**, laboratory technicians, supervisory staff, etc.

4. The national surveillance supervisor should be responsible for supervision of:
   
   a. specimen collection  
   b. data management  
   c. laboratory equipment  
   d. sampling  
   e. **all the above**

   At the national level, there must always be a person responsible for ensuring that all the required activities take place, and that surveillance is conducted uniformly in all sites.

Case study

As part of your duties as the Panga district HIV surveillance officer, you are charged with assisting central Ministry of Health staff in training personnel for a new ANC sentinel surveillance site. You have been asked to invite appropriate people to the training.

a. Whom do you plan to invite?

   **Trainings should include clinic supervisors, laboratory staff, clinic staff and district surveillance staff.** There will likely be a mix of persons identified that work at the clinic site or who work at the district level. The important point to emphasize is that the training (or trainings) need to encompass both the staff working at the clinic and the clinic’s laboratory and the staff responsible for supervision, data management and transfer and laboratory testing (if applicable) at the district level.

b. What elements of sentinel surveillance do you think need to be covered in this training?

   **Training should include a review of operational procedures, field protocol and previous serosurvey findings (see figure).** Please emphasize the need to communicate results during the training to motivate staff to 'own' the project. Even if sentinel surveillance has not been conducted at this site previously, results from other sites and how they have been used should be conveyed. **An important part of surveillance is the feedback of results to the people who collected them.**

c. A staff member asks a question about the difference between linked and unlinked testing and why unlinked testing is being done at the clinic. How do you respond?

   **It is important for staff to have the opportunity to discuss concerns and obtain further clarification of serosurvey operations during training.** Presumably the question refers to the choice between unlinked anonymous testing without informed consent and linked non-anonymous testing with informed consent. While unlinked non-anonymous
unlinked anonymous testing is a possibility, it would be unlikely to be used in this setting. Unlinked anonymous testing refers to HIV testing done on leftover specimens of blood drawn for other clinical reasons in which the patient’s identifying information is permanently removed; there is no way to link test results with an individual patient. This is done for surveillance purposes only. Linked non-anonymous testing with informed consent refers to standard clinical testing where patients are informed of test results and the results are recorded in their charts.

The reason the surveillance system will likely opt for unlinked anonymous HIV testing is because the prevalence estimates derived from this survey will have minimum participation bias and the costs of the survey are relatively lower because there is no cost for counselling about HIV test results. Additionally, because the testing is anonymous, the privacy of the individual is maintained, informed consent is not required and the person who is tested does not have to return to be counselled about the test result. The obvious disadvantage is that there is no opportunity to counsel HIV-infected individuals about prevention (especially important in ANC settings) and care. This can be offset somewhat by offering voluntary counselling and testing at the site or nearby.

d. You receive a report that an individual patient’s results were released inadvertently to clinic staff. You view this as a serious breach in study procedures. How would you investigate this, and what would you do?

Breaching patient confidentiality is a serious matter and one that unlinked anonymous testing was specifically designed to avoid. You need to immediately and carefully review procedures for unlinking identifiers at the clinic and laboratory levels, interview staff about where the breach may have occurred and retrain staff on how to unlink identifiers from specimens. You may choose to stop data collection altogether for a period of days during which you conduct intensive retraining of clinic and laboratory staff on the reasons, rationale and procedures for unlinked anonymous testing.

e. At the end of the surveillance cycle, you discover that the clinic did not report any data for the last month of the survey period. How do you address this problem?

You should first be certain that the data truly were not reported to the district level (that is, be sure that they were not misplaced or went to the wrong person). After you are certain that the problem does not lie at your end, you should discuss the matter with the clinic supervisor. Data may be available and just not sent yet or may have been sent mistakenly to the provincial level, bypassing the district. If you establish that this was not a simple data transmission problem, you need to ascertain if blood specimens were sent to the laboratory and if the laboratory tested them. One reason for non-reporting may be that the laboratory ran out of supplies and was holding the specimens until new test kits arrived. Another reason may be that clinic personnel changed, and the new personnel were unaware of the survey and/or the survey procedures.

You need to emphasize to clinic and laboratory staff the need to keep you informed of problems with the surveys on a real time basis. You could, for instance, have done a special training for the new personnel or assisted the laboratory with obtaining new test kits from the Ministry. You also need to accept some responsibility for this
yourself. Closer monitoring of data, for instance on a weekly basis, may have led to more rapid identification of this problem before four weeks' worth of data was lost. You should plan on emphasizing in the next cycle the need for closer communication with the clinic and laboratory and the need on your part for more frequent examination of data at the district level.

Unit 7 Answers

Warm-up questions

1. Data entry is the process of entering paper records into a computerized database. In the case of HIV surveillance, data entry involves entering merged demographic data and HIV test results into a database.

2. True or false? The best way to summarize sentinel surveillance data is by calculating a single prevalence figure for the whole survey. False. Data should be analysed by each of the variables collected (for example, by gender, risk behaviour or district).

3. True or false? Data dictionaries (electronic files that describe the basic organization of a project or database) should be developed at the local clinic level. False. Data dictionaries should be developed at a national level in order to ensure consistency across sites.

Case study

You are the newly hired district surveillance officer for Panga district in the country of Nodesh, and are charged with coordinating HIV seroprevalence studies. Unlinked, anonymous annual HIV seroprevalence studies have been conducted in all five ANCs in this district for the past seven years. You decide to examine the trends in HIV prevalence at the ANCs to assess the status of the HIV epidemic in your district. Since you have included all the ANCs in the district in your survey, it is appropriate to calculate single prevalence values for the district.

The following data are available for you to examine:

Table 7.2

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of HIV tests done</td>
<td>400</td>
<td>450</td>
<td>500</td>
<td>475</td>
<td>425</td>
<td>486</td>
<td>499</td>
</tr>
<tr>
<td>Number of tests HIV+</td>
<td>25</td>
<td>27</td>
<td>30</td>
<td>24</td>
<td>20</td>
<td>28</td>
<td>28</td>
</tr>
</tbody>
</table>

Use these data to calculate the annual HIV prevalence and develop a figure or graph that you think would explain the trends.

a. What do you observe in seroprevalence trends and what might these trends mean?

Seroprevalence declined from 19% in 1997 to approximately 11% in 2003. Seroprevalence is a function of the number of people who are becoming newly infected and the number of people who are dying. When seroprevalence declines, the number of people dying is greater than the number of people becoming newly infected. Whatever the reason, the burden of disease in the population is decreasing.

b. What additional information would be helpful in understanding these trends?

The mortality rate among persons with HIV infection (both HIV-related and non-HIV-related mortality) and the HIV incidence rate.

c. Are there additional ways to examine these data to assess the epidemic?

Yes, one of the easiest ways is to look at the youngest cohorts of adult patients (15-24 years old) who presumably would have been infected relatively recently. When divided by the time period of observation, these 'rates' can be roughly interpreted as incidence rates in this age group. Other more sophisticated analyses can examine prevalence trends over time in specific age strata and, if mortality rates are known, can estimate incidence trends.

Unit 8 Answers

Warm-up questions

1. True or false? Reading or hearing about HIV in the media strengthens basic information and prevention messages. True. This helps to give people a realistic perception of their risk for infection, and it also helps to reduce stigma.

2. List two potential audiences for surveillance data. Technical professionals, NGOs, policy-makers, journalists, etc.

3. List three potential uses of HIV surveillance data. Targeting intervention activities, programme monitoring and evaluation, resource allocation, political mobilization, etc.
4. True or false? When disseminating HIV surveillance results, a single message that can be used for all target audiences is the best way to transmit the information. **False.** Based on the target audience, the message can differ in terms of its content (for example, the level of technicality), the method of dissemination (for example, radio versus written material), etc.

**Case study**

You are the HIV seroprevalence coordinator for a province in the country of Nodesh. Annual seroprevalence surveys have been conducted at five ANCs in three districts of the province for the past four years. You are in the process of analysing your province’s local data and preparing the information for dissemination. The following table summarizes your analysis so far:

<table>
<thead>
<tr>
<th>Table 8.2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of women (total and HIV+) at ANC sites</strong></td>
</tr>
<tr>
<td><strong>Women</strong></td>
</tr>
<tr>
<td>All women, all sites</td>
</tr>
<tr>
<td>All HIV+ women, all sites</td>
</tr>
<tr>
<td>Women aged 15-24 years, all sites</td>
</tr>
<tr>
<td>HIV+ women, aged 15-24 years, all sites</td>
</tr>
</tbody>
</table>

a. At a local meeting of NGO directors, you are asked whether or not there is any indication that the money and effort spent on HIV prevention in the province has been successful. They request a brief summary of the antenatal sentinel surveillance data for their next meeting. What data would you include in this summary?

*Total numbers of women tested and prevalence overall and in 15-24 year-old age group (that is, report prevalence and not raw numbers of HIV-infected women).*

How would you present the data?

*You could either present it in a table (such as the one below) or a graph with time on the x-axis. Given that these data are being analysed for a non-governmental organization, a figure with trends over time both overall and in the 15- to 24-year-old age group may be most appropriate.*

<table>
<thead>
<tr>
<th>HIV prevalence by year</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women</strong></td>
</tr>
<tr>
<td>All women, all sites</td>
</tr>
<tr>
<td>HIV prevalence, all sites</td>
</tr>
<tr>
<td>Women age 15-24 years old, all sites</td>
</tr>
<tr>
<td>HIV+ women, age 15-24 years old, all sites</td>
</tr>
</tbody>
</table>
What data other than HIV prevalence would be useful to include?

*Year.* You may also decide to present the overall number of women tested to show that the denominator remained relatively stable year to year. However, the graph would then have three lines and would also need two y-axes (one for prevalence - a proportion - and the other for numbers tested per year). It is probably wisest to leave off the number of women tested.

What conclusion do you present to NGO directors?

While the prevalence among all women has remained relatively stable over the four-year period, there has been a steady and marked (48.1%) decrease in prevalence among 15- to 24-year-old women, suggesting a declining incidence.

b. The Ministry of Health and the NACP inform you that the budgets for HIV prevention and care for your province are going to be reduced to US$300,000 for the coming year. Their policy is that money should be concentrated in the health districts in greatest need and that half should be spent on prevention and half on care programmes. They ask you to plan how you will allocate the $300,000 in the three districts within your province. You start by examining the ANC data by district and site and find the following:

<table>
<thead>
<tr>
<th>Table 8.3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of women, by district site, age group, and serostatus</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Women</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>All women</td>
<td>2,009</td>
<td>1,993</td>
<td>2,003</td>
<td>1,999</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>398</td>
<td>401</td>
<td>400</td>
<td>402</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>402</td>
<td>401</td>
<td>398</td>
<td>396</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>404</td>
<td>389</td>
<td>401</td>
<td>403</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>397</td>
<td>399</td>
<td>391</td>
<td>399</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>408</td>
<td>403</td>
<td>413</td>
<td>399</td>
</tr>
<tr>
<td>All HIV+ women</td>
<td>299</td>
<td>277</td>
<td>305</td>
<td>290</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>99</td>
<td>91</td>
<td>97</td>
<td>93</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>31</td>
<td>42</td>
<td>60</td>
<td>67</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>36</td>
<td>33</td>
<td>30</td>
<td>23</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>97</td>
<td>88</td>
<td>97</td>
<td>88</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>36</td>
<td>23</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Women age 15-24 years old</td>
<td>491</td>
<td>507</td>
<td>497</td>
<td>501</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>98</td>
<td>99</td>
<td>101</td>
<td>102</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>99</td>
<td>97</td>
<td>102</td>
<td>97</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>101</td>
<td>104</td>
<td>93</td>
<td>99</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>100</td>
<td>103</td>
<td>99</td>
<td>103</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>93</td>
<td>104</td>
<td>102</td>
<td>100</td>
</tr>
<tr>
<td>HIV+ women, age 15-24 years old</td>
<td>39</td>
<td>31</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>District A, urban site</td>
<td>10</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>District A, rural site</td>
<td>3</td>
<td>4</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>District B, rural site</td>
<td>9</td>
<td>6</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>District C, urban site</td>
<td>8</td>
<td>8</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>District C, rural site</td>
<td>9</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
Using the HIV sentinel surveillance data above, what are your recommendations on where the $150,000 for HIV prevention should be spent?

- District A (rural), because prevalence among 15- to 24-year old women is increasing.
- Districts A and C (urban), because prevalence is high.

Using the HIV sentinel surveillance data above, what are your recommendations on where the $150,000 for HIV care should be spent?

Same as above, because of high disease burden.

What other factors would you consider before making your recommendations?

You should also examine CD4 levels to decide who among the HIV-positive patients needs antiretroviral treatment.

c. You receive a call from a reporter working for your national newspaper. She says that she heard a rumour that HIV cases have gone down in your province and would like your comments. You tell her that you are on your way to a meeting right now, but promise to call her back as soon as possible and also prepare a written press release.

Using the data presented above, what would you include in the press release? What further explanation would you provide? Whom would you contact before returning the call?

Calculate the HIV prevalence in your province (without regard to district), and plot it on a graph with time on the X-axis.

1999: 299/2009 = 14.9%
2000: 277/1993 = 13.9%
2001: 305/2003 = 15.2%
2002: 290/1999 = 14.5%

HIV prevalence by year

15.5
15
14.5
14
13.5
13
1999 2000 2001 2002
year
HIV Prevalence
In your press release, you could further explain possible sources of error, the trend in prevalence (that is, varying by year but relatively stable), etc. Before returning the call, however, you need to call the provincial and district health officers to tell them what you are going to say.
Appendix B. Unlinked Testing

Collection

Staff member #1* collects specimen from patient and labels tube with a code (e.g., name, clinic identification number).

Testing

Routine clinical testing (e.g., anaemia, syphilis)

HIV test result recorded in laboratory logbook or line listing (Result cannot be traced back to patient)

Staff member #2* performs HIV test

New Result code

Patient

Blood

Staff member #1* collects specimen from patient and labels tube with a code (e.g., name, clinic identification number).

Data

Staff member #1 records code, demographic information, and routine clinical information on clinic form.

CLINIC FORM

Original Code (e.g., name, clinic identification number)

Demographic information

Routine clinical information

SURVEILLANCE FORM

New Code

Abstracted demographic information (e.g., age, marital status)

Staff member #1* records demographic information not linked to personal identifying information and new code on surveillance form.

Abstrated demographic information and HIV test results are matched by new codes and then analysed.

* Staff members #1 and #2 should not be the same person so that the patient’s anonymity is ensured.
## Appendix C. Checklist for Quality Assurance of Surveillance Activities

Supervisory surveillance staff may use the following checklist as they monitor the quality of operational activities conducted at the sentinel site during supervisory visits.

<table>
<thead>
<tr>
<th>Site name: _______________________</th>
<th>Supervisor name: ____________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site number: ____________________</td>
<td>Date (dd/mm/yy): ______________________</td>
</tr>
</tbody>
</table>

### SAMPLING

- Total no. of women visiting ANC since surveillance start: ______________________
- Total no. of women sampled since surveillance start: ______________________
- No. of women sampled on last ANC day: ______________________
- Sampling consecutive? ( )Yes ( )No: _____________
- ANC staff present: ( )Yes ( ) No: ___ Lab tech present: ( )Yes ( )No:__
- No. data forms: _________ No. blood samples:
- No. data forms without ID#: _________ No. blood samples without ID#:____
- Comments: ______________________

### EQUIPMENT

- Cryovials stored in fridge: ( )Yes ( )No: ________ Fridge temperature: ________
- Fridge working uninterrupted since last visit? ( )Yes ( ) No:____________________
- Centrifuge working? ( )Yes ( ) No:___________________
- Comments: ______________________

### SAMPLE and DATA FORM TRANSPORT:

- No. data forms taken: ______________ ID# range taken: ___________________
- No. samples taken: _______________ ID# range taken: ___________________
- Site staff name:____________________ Signature: ________________________
- COMMENTS: ______________________
This training module provides key issues in HIV sentinel surveillance and complementary surveillance techniques for tracking the epidemic, focusing on the steps to conduct unlinked anonymous HIV sero-prevalence surveys at antenatal clinics. After completing this course, participants should:

- understand the criteria for selecting sentinel populations and be able to identify specific groups and sites in their district that are suitable for sentinel surveillance
- be able to identify appropriate sampling schemes depending on the situation and the target population and create a sampling frame
- understand the considerations that determine which HIV testing approach is suited for HIV surveillance in their country and describe the advantages and disadvantages of different HIV testing options
- be able to describe the staffing, training and supervising requirements of HIV sentinel surveillance
- analyse, document and use HIV sentinel surveillance data.

This course is meant primarily for district-level surveillance officers. This module can also be used for self-study.
Module 4

Surveillance for Sexually Transmitted Infections

World Health Organization
Regional Office for South-East Asia
2007
Other HIV surveillance training modules of this series

Module 1 - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual
Module 2 - HIV clinical staging and case reporting: participant manual
Module 3 - HIV serosurveillance: participant manual
Module 5 - Surveillance of HIV risk behaviours: participant manual
Module 6 - Surveillance of populations at high risk for HIV transmission
Facilitator training guide for HIV surveillance

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of HIV, TB and STD Surveillance Section, Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health; Mr Surasak Thanaisawanyangkoon, Health Technical Officer, Bureau of AIDS, TB and STIs, Ministry of Public Health; Mrs Mattana Herber, Health Technical Officer, Office of Disease Prevention and Control;

**Timor-Leste:** Mr Virgilio Soares, HIV/AIDS Officer, Ministry of Health.

**Vietnam:** Dr Phan Thi Thu Huong, Deputy Head of HIV/AIDS/STI Surveillance, Viet Nam Administration of HIV/AIDS Control (VAAC).

United States Department of Health and Human Services, Centers for Disease Control and Prevention (HHS-CDC), Global AIDS Program (GAP) Surveillance Team.

University of California at San Francisco (UCSF), Institute for Global Health, AIDS Research Institute through the University Technical Assistance Program (UTAP) with CDC/GAP.
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How to Study this Module

What you should know before the course
This course is meant both for district-level and national-level surveillance officers. As a participant, you should have a basic understanding of HIV/AIDS and public health surveillance before taking the course.

Module structure
The module is divided into units. The units are convenient blocks of material for a single study session.

This module can also be used for self-study.

Because you already know quite a bit about HIV/AIDS, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answer may just be a guess. Answer the questions as best you can.

You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions. You can then check your work.

Module summary
This module is intended to train public health officers to develop and operate systems for sexually transmitted infection (STI) surveillance.

Appendices
At the end of this module, more information is provided:

Appendix A: Answers to Warm-Up Questions and Case Studies
Additions, Corrections, Suggestions
Do you have changes to suggest for this module? Is there other information you would like to see? Please email us. We will collect your emails, and consider your comments in the next update to this module.

Address
HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House,
Indraprastha Estate
Mahatama Gandhi Marg
New Delhi 110 002, India
Email: hiv@searo.who.int
Fax: 91 11 23370197
Overview

What this unit is about
This unit describes the general state of sexually transmitted infections (STIs) and STI surveillance in the South-East Asia Region. It also discusses the behavioural, epidemiological and biological links between STIs and HIV infection.

Warm-up questions
1. Describe three areas of inter-relationship between STIs and HIV.
2. True or false? You can reduce the risk of people transmitting and acquiring HIV infection by controlling STIs.
   True       False
3. True or false? An STI surveillance system can serve as an evaluation tool for HIV prevention programmes.
   True       False
4. Which of the following increases the risk of HIV transmission in sexual exposure?
   a. greater mucous membrane exposure
   b. the presence of white blood cells
   c. increasing the duration of exposure
   d. all of the above

Introduction

What you will learn
By the end of this unit, you should be able to:

- describe the three main areas of inter-relationship between STIs and HIV;
- explain how an STI increases susceptibility to HIV;
- explain how an STI increases the risk of transmitting HIV;
- describe how STI surveillance data can be used in understanding HIV epidemics.

STIs in South-East Asia
Sexually transmitted infections (STIs) are diseases that are spread from person to person during sexual contact. There are more than 20 pathogens that can be transmitted sexually.

STIs constitute a major public health problem worldwide. They are the primary causes of reproductive tract infections and infertility. They are also the leading cause of adverse pregnancy outcomes, including low birth weight, stillbirth and maternal mortality.
Furthermore, STIs may cause cervical cancer and primary liver cancer, the most common forms of cancer worldwide. Most STIs can be prevented through safe sexual practices such as consistent, correct use of condoms. Many STIs can be completely cured with antibiotics. Their impact is made worse by their role in spreading HIV.

There is not enough information on the status and trends of STIs in the South-East Asia Region. The World Health Organization (WHO) estimated that there were 340 million new, curable STI cases worldwide in 1999. The largest number of these (151 million) occurred in South and South-East Asia. Table 1.1 summarizes the situation.

Definitions
The following definitions will help you understand Table 1.1, as well as other parts of this module.

- **Incidence**: It is the number of new cases of a disease or condition occurring in a population over a period of time. The denominator is the population at risk. The numerator is the number of new cases during a given time period.
- **Prevalence**: It is the proportion of persons in a given population with a disease or condition at a given point in time.

Table 1.1
**Estimated prevalence and annual incidence of curable STIs by region, 1999.**

<table>
<thead>
<tr>
<th>Region</th>
<th>Population 15-49 yrs (in millions)</th>
<th>Prevalence per 1000</th>
<th>Annual incidence (in millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>South and South-East Asia</td>
<td>955</td>
<td>50</td>
<td>151</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>269</td>
<td>119</td>
<td>69</td>
</tr>
<tr>
<td>North Africa and Middle East</td>
<td>165</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td>North America</td>
<td>156</td>
<td>19</td>
<td>14</td>
</tr>
<tr>
<td>Western Europe</td>
<td>203</td>
<td>20</td>
<td>17</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>205</td>
<td>29</td>
<td>22</td>
</tr>
<tr>
<td>East Asia and Pacific</td>
<td>815</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Australia and New Zealand</td>
<td>11</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>Latin America and Caribbean</td>
<td>260</td>
<td>71</td>
<td>38</td>
</tr>
<tr>
<td>Total</td>
<td>3040</td>
<td></td>
<td>340</td>
</tr>
</tbody>
</table>

Source: WHO Global prevalence and incidence of selected curable sexually transmitted infections (www.who.int/docstore/hiv/GRSTI/002.htm)

**STI Surveillance**

STI surveillance is the ongoing and systematic collection, analysis, interpretation and dissemination of data to describe and monitor rates and trends of sexually transmitted infections. This information is needed to guide STI control efforts. Different STIs (or STI syndromes) are monitored depending on factors such as how common they are and how feasible they are to identify.
STI surveillance is also useful to HIV programmes for two reasons: 1) STIs facilitate HIV transmission and 2) STIs are markers of high-risk behaviours that also spread HIV. For these reasons, STI, HIV and behavioural surveillance are often combined. This is frequently called ‘second-generation surveillance’

WHO recommends second-generation surveillance for countries in all stages of HIV epidemics:

• Low-level: HIV prevalence has not consistently exceeded 5% in any group.
• Concentrated: HIV prevalence consistently exceeds 5% in one or more groups with high-risk behaviour. HIV prevalence is less than 1% in pregnant women in urban areas.
• Generalized: HIV prevalence is consistently greater than 1% in pregnant women.

In all three, STI surveillance serves as:

• an early warning system for HIV infection and emergence of HIV in new groups or new geographical areas;
• an evaluation tool for HIV prevention programmes.

Components of STI surveillance
There are three primary components of STI surveillance. They are:

• STI case reporting
• STI prevalence assessment and monitoring
• specific STI surveillance activities such as:
  • laboratory assessment of antimicrobial resistance
  • validation of syndromic STI management
  • other special surveys and functions

These components are complementary although how much they are used in practice varies from country to country in the Region. Which components are used depends on law, health care delivery, resources and the health care-seeking behaviour of the population, the availability of laboratory services, etc.

Types of case reporting
STI cases can be reported either by aetiologic case reporting or by syndromic case reporting.

• In aetiologic case reporting, cases are diagnosed and reported using laboratory results that identify the specific microbial organism that cause the STI.
• In syndromic case reporting, cases are diagnosed and reported according to a set of clinical signs and symptoms that correspond to a few clinical syndromes (for example, genital ulcer disease and male urethral discharge). Diagnostic laboratory tests are not used to make a diagnosis of an STI syndrome.

Most countries lack the resources and laboratory support for aetiologic diagnosis and case reporting. For this reason, syndromic case reporting is easier, cheaper and generally
more widely practised in the South-East Asia Region. If it is well implemented, syndromic case reporting can provide reliable information to guide programmes.

**STI prevalence assessment and monitoring**

The second major component of STI surveillance is prevalence assessment and monitoring in sentinel sites and population groups. The primary objective of the following activities is to measure the burden of STIs and monitor trends.

- assessing the prevalence of certain STIs in both the general population and in specific population groups;
- monitoring trends in the incidence of certain STIs in the general population and in specific groups.

STI prevalence data can be especially useful for determining patterns of spread of STIs and where risk of HIV is greatest. However, STI prevalence data, especially syphilis data, are often available but not used. For example, in many countries, antenatal clinics (ANCs) routinely screen pregnant women for syphilis. The same blood samples are often tested for HIV as part of HIV serosurveillance. However, few countries compile, analyse and report syphilis prevalence.

High syphilis prevalence in pregnancy is an important cause of spontaneous abortion, stillbirth and congenital syphilis. It is also an indicator of HIV risk in the community. If STI surveillance data show that STI transmission is occurring, then HIV transmission may be occurring as well. You can make this inference because STIs and sexually transmitted HIV are transmitted the same way.

**Specific STI surveillance activities**

These activities are used to supplement the other components of STI surveillance. Some are most useful for the management of STI control programmes, and others are useful for HIV programmes. These activities include:

- monitoring aetiologies for STI syndromes (conducting laboratory tests to find out which STI organisms are present in the most important STI syndromes)
- measuring antimicrobial resistance patterns (finding out if the organisms causing certain STIs have become resistant to antimicrobial therapies)
- Behavioural surveys and especially behavioural surveys that are combined with STI and HIV testing (finding out what behaviours are associated with STI and HIV infection in various groups)
- Research studies to address aspects of STI epidemiology that cannot be addressed by routine surveillance

**Passive and active surveillance systems**

STI data can be reported using a passive or an active surveillance system.

- In a passive surveillance system, health facilities provide case reports directly. When the facilities are understaffed or not trained, the reports may be late, incomplete or not delivered at all.
• In an active surveillance system, public health officers contact health facilities, identify and report cases.

Problems with STI surveillance
Where STI surveillance systems do not function adequately, there is not enough information available for planning, implementing and evaluating STI and HIV prevention and care programmes.

STI reporting in the Region is incomplete. When STI surveillance does occur, it may consist of either aetiologic or syndromic STI case reports or a combination of the two. These factors complicate the interpretation of STI surveillance data.

Other problems that complicate STI surveillance include:

• lack of clear national implementation guidelines;
• lack of commitment and feedback from ministries of health;
• confidentiality concerns;
• lack of symptoms in many STIs, especially in women;
• treatment of STIs in the private and informal sectors, which do not report cases;
• absence of screening programmes leading to the under-diagnosis of asymptomatic STIs.

Summary
STIs and HIV are inter-related because of behavioural, epidemiological and host factors. STIs increase susceptibility to HIV and also increase the risk of transmitting HIV. STI surveillance data can be used as an early warning of the emergence of HIV and as an evaluation tool for HIV prevention programmes.

Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion
Get into small groups by country, region or province to discuss these questions.

1. What type of STI surveillance takes place in your province, district or country?

2. What types of analysis and reports of these data are produced in your province, district or country?

3. What sort of laboratory support is available in your province, district or country for aetiologic STI testing?
Apply what you have learned/case study

Try this case study. We will discuss the answers in class.

You are a national-level public health officer in Serosia, a country with a concentrated HIV epidemic. You have reviewed the male urethral discharge surveillance data for your country. Currently, male urethral discharge is reported using a vertical reporting system. You have concluded that the reporting of this STI is incomplete in most provinces.

a. List the appropriate actions to take to improve the quality and completeness of gonorrhoea reporting for your country.

b. List two ways that surveillance for male urethral discharge can be used in understanding the HIV epidemic in Serosia.
Overview

What this unit is about

The components of STI surveillance work together to provide a more complete picture of the STI situation. This unit describes these components and how the data from surveillance can be used. Also explained are the terms and concepts of STI surveillance:

- Aetiologic and syndromic case reporting
- Passive and active surveillance
- Basic and advanced surveillance

Warm-up questions

1. True or false? Some elements of an STI surveillance system are more important for HIV surveillance activities. Others are more important for STI control programme activities.

   True   False

2. True or false? STI surveillance data can serve as an indicator of trends in HIV risk behaviours.

   True   False

3. True or false? Aetiologic reporting of syphilis (by stage), gonorrhoea, Chlamydia and congenital syphilis is considered a basic surveillance activity in the South-East Asia Region.

   True   False

4. Which of the following is not a component of an STI surveillance system?
   a. STI universal case reporting
   b. STI sentinel surveillance systems
   c. STI testing and treatment
   d. STI prevalence assessment and monitoring

5. True or false? In generalized HIV epidemics, prevalence assessments should include monitoring gonorrhoea and chlamydia.

   True   False

6. True or false? An STI surveillance system includes conditions that are newly acquired, as well as those that represent past infections.

   True   False
7. In ___________________ case reporting, STI cases are reported by the specific microbial organism that caused the STI, while in syndromic case reporting, STI cases are reported by the clinical syndrome with which the patient presents.

Introduction

What you will learn

By the end of this unit you should be able to:

- discuss the components of an STI surveillance system;
- discuss the uses of STI surveillance data;
- describe the difference between aetiologic and syndromic STI diagnosis and surveillance;
- determine the difference between basic and advanced STI surveillance activities and how these activities should be used, depending on the type of HIV epidemic;
- describe IDS case reporting.

Components and Uses of STI Surveillance Systems

Components of STI surveillance

The components of an effective STI surveillance system include routine data collection and special studies. These include the following:

- STI case reporting
  - universal case reporting, where all cases of a particular disease or syndrome are reported to health authorities. Universal case reporting can be either aetiologic or syndromic.
  - sentinel STI case reporting, which takes place at selected sites (and can be either aetiologic and syndromic)
- STI prevalence assessment and monitoring among a range of population groups sampled in various settings.
- Additional STI surveillance techniques
  - monitoring antimicrobial resistance of STI pathogens
  - assessing STI syndrome aetiologies
  - other special surveys and studies, including behavioural surveys and research studies to address aspects of STI epidemiology that cannot be addressed by routine surveillance
Figure 2.1
Components of an STI surveillance system

STI Surveillance Module 4, Units 1 and 2

Case Reporting Module 4, Units 3 and 4
- Universal Case Reporting
- Sentinel Case Reporting

Prevalence Assessment and Monitoring
- General Population Groups* Module 4, Unit 5
- High Risk Groups
- Others Groups**

Specific STD Surveillance Activities Module 4, Unit 6
- Laboratory Assessment of Microbial Resistance
- Assessment of STI Syndrome aetiologies
- Other Special Surveys and Studies
- Behavioural Surveys
- Research Studies

* Such as women in ANCs
** Such as military
Which components should be used?
The components of STI surveillance should be used together to generate a complete picture of the STI burden in a country or region.

- Some components of an STI surveillance system, such as combined STI/HIV behavioural surveillance surveys, are important for second-generation HIV surveillance activities.
- Other STI surveillance components are more important for STI control programme activities, for example:
  - assessing syndrome aetiologies
  - antimicrobial resistance monitoring.
- Some components are equally important for second-generation HIV surveillance and STI control, for example:
  - STI case reporting
  - STI prevalence assessment and monitoring

Also, different STI surveillance components are important in different situations. For example, in a concentrated epidemic, surveillance activities might focus more on high-risk groups, while in generalized epidemics, a broader picture is needed. There is more information about this later in this unit.

An example
As an example, think about the STI surveillance components that would be needed in the following situation.

Country X has a nearly perfect reporting system for STIs diagnosed syndromically (by symptoms) in public health facilities. Although the existing surveillance infrastructure provides good data on the annual burden of STI syndromes in public health facilities, additional information is necessary to understand the population burden of particular STIs.

- To better estimate the population burden of STIs and how the STIs relate to HIV, special studies could be done to establish:
  - how many people seek STI care from other providers (for example, private clinics or pharmacies) or treat themselves;
  - STI prevalence among general population or high-risk groups sampled in the community.
- To determine which organisms are causing specific STI syndromes, syndrome aetiologies would need to be studied.

Understanding STI Surveillance Data

Symptomatic and asymptomatic STIs
To accurately calculate incidence and prevalence, it is important to understand the role of symptomatic and asymptomatic presentations of STI infections. Some STIs produce symptoms rapidly after infection. Other STIs may be asymptomatic. Several STIs have both symptomatic and asymptomatic presentations.
Symptomatic STIs are usually recently acquired and represent true incident cases. STIs with largely symptomatic presentations include chancroid, early syphilis, and gonorrhoea and Chlamydia in men. *Herpes simplex* virus is an exception. Because its symptoms can recur without new infection, it is impossible to determine if the infection is newly acquired or longstanding.

Asymptomatic presentations of STI infections do not produce clinical symptoms. They can be present for a long time, often months or even years, without the patient knowing he or she is infected. For this reason, asymptomatic presentations cannot be used to measure incidence. They can, however, be used to measure prevalence. STIs that are frequently asymptomatic include latent syphilis chronic *Herpes simplex* (HSV-2) Chlamydia gonorrhoea in women. Women have symptoms less often than men, especially for gonorrhoea and Chlamydia. Their asymptomatic infections can only be detected by laboratory tests.

In general, STI case reporting of male *urethritis* (inflammation of the urethra), male and female non-vesicular genital ulcer disease and *inguinal buboes*, and scrotal swelling (due to *epididymitis*) represent recently acquired infections. Lower abdominal pain in women (syndromic PID) can be a useful marker of non-ulcerative STI (gonorrhoea/Chlamydia) in women.

The emphasis in this course is on case reporting of the most common STI syndromes—male *urethritis*, male and female non-vesicular genital ulcer disease.

**How STI surveillance data are used**

STI surveillance data can be used for a variety of purposes related to the monitoring, prevention, control and allocation of resources for STIs and HIV. For example, the data can be used to assess the overall burden of STIs and to monitor trends in recently acquired STIs. This information is important in guiding health-care workers on how to treat STI patients and their sex partners. It is also useful for planning and managing STI and HIV prevention and control programmes, for advocacy and resource mobilization and for monitoring and evaluation. STIs also serve as markers of HIV risk behaviours.

**Aetiologic versus Syndromic Case Reporting**

STI cases can be reported by one of the following strategies:

- *aetiologic case reporting*, in which the specific STI pathogen is identified by laboratory methods to make a diagnosis;
- *syndromic case reporting*, in which the symptom complex is used for diagnosis in the absence of laboratory confirmation of an STI pathogen.

**Aetiologic case reporting defined**

In aetiological case reporting, the specific STI is reported (for example, gonorrhoea). Aetiologic case reporting requires laboratory confirmation of diagnoses.

- Aetiological case reporting is only possible where well-developed systems of laboratory diagnosis are incorporated into routine STI clinical case management.
• There are wide variations in diagnostic and reporting practices. For this reason, do not base aetiologic case reporting on clinical impressions. You must have laboratory confirmation.
• In many places, the use of laboratory services for diagnosis is frequently not available in primary health-care facilities.

**Syndromic case reporting defined**

Syndromic case reporting relies on examining a patient and identifying a *syndrome* (that is, a group of symptoms reported by a patient and clinical signs detected in an examination that are characteristic of a specific condition). Recognize the following limitations of syndromic case reporting:

• The syndromes are not specific to a particular pathogen. Laboratory studies are required to determine which organisms are causing the symptoms.
• For surveillance purposes, the most useful STI syndromes are male urethral discharge and male or female genital ulcers. These common syndromes are likely to reflect recent infection and can be used to monitor *incidence* trends. Because many STIs in women are asymptomatic, syndromic case reporting may underestimate disease burden in women.
• For these reasons, STI prevalence assessment and monitoring should be undertaken as a supplement to case reporting where possible.

**Recommended case reporting**

STI case reporting based on the syndromic approach should be implemented widely in the South-East Asia Region, and supplemented by other surveillance activities.

**Case definitions**

Diagnosis of STI syndromes should be based on standard *case definitions*. A case definition is standard terminology for deciding whether a person has a particular disease using clinical and/or laboratory criteria.

• Uniform case definitions should be used throughout the country to allow data gathered from the reporting systems to be compared.
• When a clinician makes and records a diagnosis, he or she must do so according to the standard case definition. This helps record officers or other designated staff to tally correctly. If a clinician counts cases that do not meet the standard case definitions, this might overestimate STI incidence.

**Using syndromic case reporting**

Where syndromic case reporting is used, clinicians should use uniform case definitions in recording their diagnoses and reporting cases. The SEARO-recommended syndromic case definitions for surveillance are shown in Table 2.1. These syndromes are the most important for surveillance purposes (but are only a subset of syndromes identified in clinical care).
### Table 2.1

**Recommended surveillance case definitions for selected STI syndromes**

<table>
<thead>
<tr>
<th>STI syndrome</th>
<th>Case definition</th>
<th>Additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral discharge</td>
<td>• urethral discharge in men, with or without <em>dysuria</em></td>
<td>• caused by <em>Neisseria gonorrhoeae</em> and <em>Chlamydia trachomatis</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• other possible infectious agents include <em>Trichomonas vaginalis</em>, <em>Ureaplasma urealyticum</em> and <em>Mycoplasma</em> spp.</td>
</tr>
<tr>
<td>Genital ulcer (non-vesicular)</td>
<td>• ulcers (without vesicles) on the penis, scrotum or rectum in men</td>
<td>• caused by syphilis, chancroid, lymphogranuloma venereum, granuloma inguinale (donovanosis) or genital herpes</td>
</tr>
<tr>
<td></td>
<td>• ulcers (without vesicles) on the labia, vagina or rectum in women, with or without inguinal lymphadenopathy</td>
<td>• reporting non-vesicular genital ulcers excludes most herpes infections, which are most often the result of prior infection</td>
</tr>
<tr>
<td>Additional syndromes (less common)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inguinal bubo</td>
<td>• painful, often fluctuant, swelling of the lymph nodes in inguinal region of groin</td>
<td>• commonest cause lymphogranuloma venereum, chancroid or <em>Chlamydia trachomatis</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• painless bubo not uncommon with syphilis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• both lymphogranuloma venereum and chancroid are preceded by a genital ulcer, which is absent by the time the bubo develops in lymphogranuloma venereum</td>
</tr>
<tr>
<td>Scrotal swelling</td>
<td>• acute swelling of the testis</td>
<td>• caused by <em>Neisseria gonorrhoeae</em> or <em>Chlamydia trachomatis</em></td>
</tr>
<tr>
<td>Lower abdominal pain</td>
<td>• Lower abdominal and/or pelvic tenderness in women</td>
<td>• possible pelvic inflammatory disease (PID), commonly a complication of <em>Neisseria gonorrhoeae</em> or <em>Chlamydia trachomatis</em></td>
</tr>
</tbody>
</table>


Using aetiological case reporting

Where good aetiological case reporting is followed, clinicians use uniform case definitions in recording their diagnoses and reporting cases. The WHO-recommended aetiological case definitions for surveillance are shown in Table 2.2:

Table 2.2
Recommended aetiological case definitions for selected STI syndromes

<table>
<thead>
<tr>
<th>Gonorrhoea Confirmed Case Definition:</th>
<th>isolation of typical Gram-negative, oxidase-positive diplococci (presumptive <em>N. gonorrhoeae</em>) from a clinical specimen OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>demonstration of <em>N. gonorrhoeae</em> in a clinical specimen by a nucleic acid-based test OR</td>
</tr>
<tr>
<td></td>
<td>observation of Gram-negative intracellular diplococci in a urethral smear obtained from a man</td>
</tr>
<tr>
<td>Chlamydia Confirmed Case Definition:</td>
<td>positive culture OR</td>
</tr>
<tr>
<td></td>
<td>antigen detection test OR</td>
</tr>
<tr>
<td></td>
<td>nucleic acid-based test for <em>C. trachomatis</em></td>
</tr>
<tr>
<td>Syphilis (primary or secondary) Probable Case Definition:</td>
<td>illness with ulcers (primary) or muco-cutaneous lesions (secondary) AND</td>
</tr>
<tr>
<td>Confirmed Case Definition:</td>
<td>reactive serological test (non-treponemal or treponemal)</td>
</tr>
<tr>
<td></td>
<td>demonstration of <em>T. pallidum</em> in a clinical specimen by dark field microscopy, direct fluorescent antibody test for <em>T. pallidum</em>, nucleic acid-based test or equivalent methods</td>
</tr>
<tr>
<td>Syphilis (re-activation) Probable Case Definition:</td>
<td>no clinical signs or symptoms of syphilis AND</td>
</tr>
<tr>
<td></td>
<td>either a reactive non-treponemal and treponemal test in a patient with no prior syphilis diagnosis OR</td>
</tr>
<tr>
<td></td>
<td>a non-treponemal test titre demonstrating a four-fold or greater increase from the last non-treponemal test titre</td>
</tr>
<tr>
<td>Syphilis (latent) Probable Case Definition:</td>
<td>no clinical signs or symptoms of syphilis, with evidence that the infection was acquired more than 24 months ago or of unknown duration syphilis AND</td>
</tr>
<tr>
<td></td>
<td>a non-treponemal test which is reactive or non-reactive and a treponemal test which is reactive in a patient with no prior syphilis diagnosis.</td>
</tr>
<tr>
<td>Chancroid Probable Case Definition:</td>
<td>illness with genital or anal ulcers with:</td>
</tr>
<tr>
<td></td>
<td>no evidence of <em>T. pallidum</em> infection by dark field examination of ulcer exudates, or by a serological test for syphilis performed ≥7 days from ulcer onset AND</td>
</tr>
<tr>
<td></td>
<td>negative test for <em>Herpes simplex</em> virus on ulcer exudates</td>
</tr>
<tr>
<td>Confirmed Case Definition:</td>
<td>identification of <em>H. ducreyi</em> by culture or nucleic acid-based test in ulcer exudates</td>
</tr>
</tbody>
</table>
Basic and Advanced STI Surveillance

Two levels of STI surveillance activities can be planned:

- Basic STI surveillance activities should be undertaken everywhere.
- Advanced STI surveillance activities can be conducted in locations with additional laboratory capacity.

The types of activities to consider for each level are listed in Table 2.3.

Table 2.3
Comparing the approach for basic and advanced STI surveillance

<table>
<thead>
<tr>
<th>Basic Surveillance</th>
<th>Advanced Surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case reporting</strong></td>
<td><strong>Aetiologic reporting of:</strong></td>
</tr>
<tr>
<td>Sentinel or universal syndromic reporting (with minimal data elements collected) of:</td>
<td>• syphilis (by stage)</td>
</tr>
<tr>
<td>• male urethral discharge</td>
<td>• gonorrhoea</td>
</tr>
<tr>
<td>• non-vesicular genital ulcer disease in men and women</td>
<td>• Chlamydia</td>
</tr>
</tbody>
</table>

**STI prevalence assessment and monitoring**

- Focus primarily on serologic testing for syphilis.
- Test all women attending antenatal clinics for syphilis.
- Conduct periodically in high-risk populations (sex workers, STI patients).

- Conduct periodically in the general and high-risk populations:
  - women attending family planning clinics
  - military recruits
  - high-risk populations (sex workers, STI patients)
- Include urine testing for gonorrhoea and Chlamydia as well as serologic testing for syphilis
- Can be combined with behavioural surveys

**Assessment of syndrome aetiologies**

- Assess aetiology of genital ulcer disease and urethral and vaginal discharge every three years
- Assess causes of genital ulcer disease at least every three years
- Assessment of genital discharge is not needed if laboratory-based diagnoses and aetiologic case reporting is used

**Special studies**

- Monitor antimicrobial resistance for *N. gonorrhoeae* every 1-2 years.
- Conduct evaluation of STI treatment guidelines every three years.
- Investigate outbreaks of diseases with low incidence.
- Conduct special studies of:
  - serologic surveys of HSV-2 especially among adolescents and young adults
  - prevalence surveys of human papilloma virus (HPV) infections
  - prevalence studies of bacterial vaginosis
  - others as indicated
Fit STI surveillance activities to HIV epidemic state

While all countries should conduct some form of case reporting, STI assessment and monitoring activities may differ depending on the state of the HIV epidemic. Table 2.4 provides ideas on how to do this.

Table 2.4

Planning for advanced STI surveillance

<table>
<thead>
<tr>
<th>State of HIV epidemic</th>
<th>Advanced STI surveillance plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-level: HIV prevalence has not consistently exceeded 5% in any subpopulation, even among high-risk groups, such as sex workers and injection drug users.</td>
<td>• Conduct prevalence assessments in urban areas because that is where risk is initially greatest.</td>
</tr>
<tr>
<td>Concentrated: HIV prevalence consistently exceeds 5% in one or more groups with high-risk behaviour. HIV prevalence is less than 1% in pregnant women in urban areas.</td>
<td>• Conduct prevalence assessments in both rural and urban areas to monitor the spread from urban to rural areas.</td>
</tr>
<tr>
<td>Generalized: HIV prevalence is consistently greater than 1% in pregnant women. Although high-risk groups continue to contribute very greatly to the spread of HIV, transmission is also occurring in the general population.</td>
<td>• Conduct prevalence assessments in both rural and urban areas to monitor the spread from urban to rural areas. • Include monitoring gonorrhoea and Chlamydia. These conditions suggest recent high-risk behaviours.</td>
</tr>
</tbody>
</table>

Summary

An STI surveillance system includes routine data collection and special studies. STI surveillance can be based on either aetiological or syndromic case reporting or both. Syndromic case reporting is widely applicable in the South-East Asia Region.

Basic STI surveillance activities should be undertaken in all countries. Advanced STI surveillance activities can be added in countries with more extensive resources and well-developed laboratories.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. What are the most common STIs in your district, province or country?

2. Is there currently ongoing surveillance for STIs in your district, province or country?
3. If you answered yes to question 2, how does your STI surveillance system relate to the HIV and AIDS surveillance systems? How does it relate to your other communicable disease reporting systems?

Apply what you have learned/case study

You are a surveillance officer in Nodesh, a country in South-East Asia. You have received STI data from Bijarta, a district in Nodesh. Table 2.5 below provides the data. Assume that the population size has not changed between 2000 and 2003.

Table 2.5

<table>
<thead>
<tr>
<th>STI condition</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male urethral discharge</td>
<td>25 292</td>
<td>28 959</td>
<td>29 784</td>
<td>29 859</td>
</tr>
<tr>
<td>Male non-vesicular genital ulcer</td>
<td>6 429</td>
<td>7 983</td>
<td>7 497</td>
<td>7 698</td>
</tr>
<tr>
<td>Female non-vesicular genital ulcer</td>
<td>5 834</td>
<td>6 497</td>
<td>6 306</td>
<td>6 905</td>
</tr>
</tbody>
</table>

a. What do the data suggest about the trends in the incidence and prevalence of these conditions in Bijarta?

b. What do these data suggest about trends in HIV risk behaviours?

c. What additional data would you be interested in reviewing to assess burden of STI infection and incidence of STI infection in Bijarta? Why would you be interested?
Overview

What this unit is about

This unit compares and contrasts universal and sentinel case reporting for sexually transmitted infections (STIs).

Warm-up questions

1. Which of the following is an advantage of universal STI case reporting?
   a. It is relatively easy to collect from health facilities.
   b. It provides data on the burden of STIs at the health facility level.
   c. Under stable conditions and consistent reporting, data from universal STI case reporting reflect the incidence of STIs in a population.
   d. All of the above

2. True or false? Case report data collected from sentinel sites can be generalized to a broader population.
   True  False

3. In countries where information about STIs is obtained through a universal case reporting system, sentinel STI case reporting
   a. is unnecessary
   b. should replace universal case reporting as the primary method to study STIs
   c. should supplement information obtained from the universal case reporting system

4. True or false? Supervision and feedback are easier to provide for a sentinel case reporting system than for a universal system.
   True  False

Introduction

What you will learn

By the end of this unit, for STI universal case reporting and sentinel case reporting, you should be able to:

- discuss the purpose of each of these systems of surveillance;
- discuss the advantages and disadvantages of each;
- define when each should be implemented;
- define the population studied for each.
Two case reporting approaches
This unit discusses, compares and contrasts two different approaches to STI case reporting:

- **universal STI case reporting**, where all health-care facilities report basic data on STI cases to public health authorities;
- **sentinel STI case reporting**, where selected sites collect more detailed data on STI cases.

Universal STI Case Reporting

Types of reports used
In universal case reporting, basic information about STIs - including data on age group and gender - are collected from all health facilities in the country. Reporting may be either **syndromic** or **aetiologic** (see Unit 2)

Advantages and disadvantages
The advantages and disadvantages of universal case reporting for STIs are outlined in Table 3.1.

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>- It is the most readily available source of STI surveillance data.</td>
<td>- It is based on recognition of symptoms and thus provides a poor assessment of the true disease burden among women (compared with men, STIs are more often asymptomatic in women).</td>
</tr>
<tr>
<td>- It is easy to collect from health facilities.</td>
<td>- It does not provide a direct estimate of the population burden of STIs because people with asymptomatic infection do not realize they are infected so they do not seek care.</td>
</tr>
<tr>
<td>- It provides data on the burden of STIs as seen at the health facility level, important for planning health services.</td>
<td>- It is affected by fluctuations in health-seeking behaviours of the population not related to the burden of disease (for example, availability of drugs or introduction of user fees at clinics).</td>
</tr>
<tr>
<td>- When consistent, it can be used to track population-level STI trends.</td>
<td></td>
</tr>
</tbody>
</table>

STI Sentinel Case Reporting
A sentinel surveillance system is a system in which a pre-arranged sample of reporting sources (usually healthcare facilities) agrees to report all cases of one or more notifiable conditions. These sources are known as **sentinel surveillance sites**, where:

- more data on STI cases are recorded and reported;
- site trends are used to infer trends of STI case reports in other health facilities.

Health facilities that are likely to be reliable in reporting STI cases are selected and supported as sentinel surveillance sites. Quality data are obtained from a few sites. You
can collect more detailed data and use it along with the data obtained from universal case reporting system to help understand the populations affected by STIs.

STI sentinel surveillance is most effective when:

- staff at the sentinel reporting sites receive special training;
- a data system can be established so that the data are examined and used effectively.

**Sentinel site case reporting**

In sentinel site case reporting STI cases are reported from a small number of sentinel sites. Sentinel site case reporting can be based on syndromic or aetiologic diagnoses (see Unit 2) or on a combination of the two. In this unit, we will discuss primarily STI sentinel case reporting based on syndromic reporting.

- Cases are diagnosed by doctors and nurses at the sentinel sites and specific syndromes are recorded onto patients’ charts.
- It is important that the same case definition be used at all surveillance sites to enable comparison of data across sites.
- Aetiologic case reporting is also possible in sentinel sites where laboratory support is adequate. Cases may be classified as confirmed or probable, depending on the strength of the laboratory evidence of the probable causative organism.

**Advantages and disadvantages**

A major advantage of STI sentinel case reporting is that a few sites actively cooperate in systematic data collection. The result is higher quality and more consistent information at moderate cost.

Another advantage is that additional data elements can be collected and reported to provide more detail on patients’ demographic information, risk profile and treatment. The choice of which additional data to report largely depends on how the data will be used. Table 3.2 describes additional advantages and disadvantages of sentinel STI case reporting.
Table 3.2
Advantages and disadvantages of sentinel STI case reporting

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Regular supervision, feedback and logistical support can be relatively</td>
<td>• Sentinel STI surveillance cannot provide minimum population-based estimates of</td>
</tr>
<tr>
<td>easily provided because sentinel sites are located in fewer facilities.</td>
<td>disease burden. Sentinel sites are located in only a few health facilities.</td>
</tr>
<tr>
<td>• Higher quality data can be obtained from a few sites with intensive</td>
<td>Therefore, data from sentinel sites only represent the sites and their</td>
</tr>
<tr>
<td>support of training, supervision and logistics.</td>
<td>catchment populations and not the whole district, province or nation.</td>
</tr>
<tr>
<td>• A sentinel STI case reporting system is less expensive to run and</td>
<td>• Sentinel sites cannot be considered representative of other clinics due to</td>
</tr>
<tr>
<td>maintain than a universal reporting system.</td>
<td>the special attention that they receive. Information from these sites is only</td>
</tr>
<tr>
<td>• Sentinel STI case reporting is generally more flexible than universal</td>
<td>representative of the populations they serve.</td>
</tr>
<tr>
<td>case reporting. Additional studies that collect STI and/or behavioural data</td>
<td></td>
</tr>
<tr>
<td>can be added without changing the basic structure.</td>
<td></td>
</tr>
</tbody>
</table>

Selection of sentinel sites

The selection of sentinel sites can be done by *convenience sampling*. This is when sites are selected from among all health facilities based on their accessibility and availability. Using convenience sampling may affect how representative the data are that arise from the system.

Another way to sample sites is by *probability sampling*, where the sampling ensures that each site has an equal chance of being selected. Probability sampling is more difficult and inconvenient.

The selection of sentinel sites usually addresses feasibility concerns while including a wide and varied enough choice to represent conditions in different parts of the country.

Factors to consider

The system should try to include major sectors that provide STI care (for example, public and private clinics, general outpatient departments, STI clinics and special clinics like family planning). Consider these factors when you select STI sentinel surveillance sites.

Sites should be selected that:

* already are seeing a large number of STI cases and providing care;
* are varied and represent different geographic areas of the country and different population groups, including urban and rural populations;
* have qualified staff who are willing and motivated to take on the extra responsibilities of case reporting;
* include high-risk groups;
* integrate STI surveillance activities with other ongoing surveillance activities, such as HIV/AIDS sentinel surveillance to permit integrated analyses.
The national disease surveillance unit of the AIDS/STI control programme should be able to supervise the sites effectively and to provide logistic backup and support, providing training, supervisory visits and supplies.

Another less common way to select sites is to use administrative or geographic areas as sentinel areas and include all sites within the area in the sample. Surveillance in such administrative or geographic areas is enhanced to provide higher quality and more detailed data than the rest of the country.

Data elements

The following table outlines the core data elements and additional data elements that may be collected. Core data elements are those that must be collected.

Table 3.3

Core and additional data elements

<table>
<thead>
<tr>
<th>Core data elements</th>
<th>Potential additional data elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>reporting site</td>
<td>residence</td>
</tr>
<tr>
<td>date of visit</td>
<td>education or socioeconomic status</td>
</tr>
<tr>
<td>gender</td>
<td>marital status</td>
</tr>
<tr>
<td>age group, age or date of birth</td>
<td>occupation</td>
</tr>
<tr>
<td>syndrome (if using syndromic surveillance)</td>
<td>anatomic site of infection</td>
</tr>
<tr>
<td>diagnosis (if using aetiological surveillance)</td>
<td>date of symptom onset</td>
</tr>
<tr>
<td></td>
<td>risk behaviour</td>
</tr>
<tr>
<td></td>
<td>pregnancy</td>
</tr>
<tr>
<td></td>
<td>previous episodes of STI</td>
</tr>
<tr>
<td></td>
<td>treatment</td>
</tr>
<tr>
<td></td>
<td>other information deemed necessary that pertains to region or district</td>
</tr>
</tbody>
</table>

Developing reporting forms

The national surveillance unit and the national AIDS/STI control programme should develop the reporting forms.

- The same form should be used at all the sentinel sites.
- Simplified reporting forms should be developed, using as much information as possible that is normally collected as part of routine patient care whenever possible. Using an overly complex reporting form may result in incomplete reporting. It may also add heavy extra demands for data entry and analysis.
- To protect patients’ privacy, reporting forms should not have personal identifiers. Even where individual case reporting forms are transferred, they should be designed so that personal identifying information is removed before the data are reported.

Implementing surveillance

The following details are important in the implementation of sentinel surveillance at the selected sites:

- Staff members at the sites need to be trained in data collection and reporting using the standard reporting forms.
- There should be an adequate supply of forms at the sites.
There should be supervision from the national programme.

A system of regular transfer of data from the sites to the central office for analysis should be put in place.

Once a sentinel site has been chosen and is operating, it should be monitored to ensure the overall quality of data coming from the site. A site may need ongoing training of staff if there is turnover or if there is a pattern of missing and incomplete data.

Interpreting results from sentinel sites

Data from sentinel surveillance systems must be interpreted with care taking into account how sentinel sites may be similar to or different from other health care facilities in the country.

Combined Universal and Sentinel Surveillance Case Reporting

Ideally, all health facilities in a country should report through the universal system using integrated disease surveillance (IDS). A combination of universal case reporting and sentinel surveillance provides added advantages.

- Universal case reporting provides minimum estimates of incidence and prevalence of STIs.
- Sentinel site case reporting provides epidemiological and clinical detail on a subset of cases.
- In combined systems, data from sentinel sites are included in both the universal case reporting system as well as the sentinel site case reporting system.

Summary

STI case reporting can occur through universal STI case reporting, sentinel STI case reporting or a combination of the two. Universal reporting data tend to be more representative of the entire population, while sentinel case reporting produces higher quality, more detailed and more reliable surveillance data, at moderate incremental cost.

Exercises

Warm-up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. If you were to set up a sentinel site for STI case reporting in your district or province,
   a. What would be the objectives of the system?
   b. What factors would influence your location of the sentinel site?
   c. What data elements would you collect from the site?
Apply what you have learned/case study

In the nation of Malanka, an STI control programme was started in 1992. The management of STIs in Panga district, primarily carried out by doctors, nurses or midwives, is based on a syndromic approach. Cases of STI diagnosed by the syndromic approach were reported irregularly on a monthly basis to the Ministry of Health, National Health Information System (NHIS).

In 1995, in collaboration with the STI control programme, NHIS conducted a two-year pilot test of STI universal case reporting from 850 public community-based clinics and 65 public hospitals covering the 29 districts of the country. The population size of men and women was stable during this time period.

During this two-year pilot test, the NHIS received regular monthly case reporting of genital discharge, genital ulcer and genital warts from the peripheral health-care providers. Table 3.4 shows the results of this two-year case reporting for 1995-1996 for men and women.

Number of STI cases and contribution of STI (%) in utilization of health-care services for each STI syndrome by gender and year, Panga district, 1995-1996.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td></td>
<td></td>
<td>N</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urethral discharge</td>
<td>24 200</td>
<td>3.6</td>
<td>0</td>
<td>0</td>
<td>23 283</td>
<td>2.6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Vaginal discharge</td>
<td>0</td>
<td>0</td>
<td>54 000</td>
<td>6.0</td>
<td>0</td>
<td>0</td>
<td>77 321</td>
<td>5.9</td>
</tr>
<tr>
<td>Genital ulcer</td>
<td>5 834</td>
<td>0.8</td>
<td>5 800</td>
<td>0.6</td>
<td>5 800</td>
<td>0.6</td>
<td>7 042</td>
<td>0.6</td>
</tr>
<tr>
<td>Genital warts</td>
<td>1 134</td>
<td>0.2</td>
<td>2 700</td>
<td>0.3</td>
<td>986</td>
<td>0.1</td>
<td>3 060</td>
<td>0.2</td>
</tr>
</tbody>
</table>

a. Based on the scenario:
   1. To better understand the situation in Panga, what data elements would you suggest collecting on a reporting form?

   2. What are the STI syndromes that give the best information to understand the STI situation?

   3. Based on the rates of health facility utilization, which syndrome is the most prevalent in Panga?
b. How useful are the data on:
   - vaginal discharge in women in determining STI burden and trends?
   - genital warts?

c. Complete Table 3.5 below by calculating the incidence rates in cases per 100 000 of genital ulcer disease for 1995 and 1996 in both men and women.

Table 3.5
Estimated population and incidence of genital ulcer disease by sex and year, Panga district, 1995-1996

<table>
<thead>
<tr>
<th></th>
<th>Estimated population</th>
<th>Incidence*</th>
<th>Estimated population</th>
<th>Incidence*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>926 000</td>
<td>-----------</td>
<td>927 000</td>
<td>-----------</td>
</tr>
<tr>
<td>1996</td>
<td>950 000</td>
<td>-----------</td>
<td>980 000</td>
<td>-----------</td>
</tr>
</tbody>
</table>

*Incidence: cases per 100 000 per year
Overview

What this unit is about
This unit discusses STI case reporting and the information flow from health facilities to district to national level. It also reviews how to handle and analyse data.

Warm-up questions
1. Match the STI data analysis parameter with its description by putting a letter in each blank:

<table>
<thead>
<tr>
<th>Analysis by place</th>
<th>a. Analysis of data that shows by age group differences.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analysis by time</td>
<td>b. Analysis to detect if there has been an increase in STI case reports over time.</td>
</tr>
<tr>
<td>Analysis by person</td>
<td>c. Analysis to provide information about where clustering of disease might occur.</td>
</tr>
</tbody>
</table>

2. True or false? Interpretation of STI trends should be made independently from knowledge of how the STI control programmes and the health-care system operate.
   True    False

3. District surveillance officers are responsible for:
   a. checking data for inconsistencies
   b. forwarding the results to the national level
   c. following up with any health facility site that has missing or inconsistent data
   d. all of the above

4. List three ways to handle surveillance data so that patient confidentiality is protected.

Introduction

What you will learn
By the end of this unit you should be able to:

- describe how to plan your data collection and ensure confidentiality;
- describe the flow of data from health facilities to district to national level;
- discuss the roles and responsibilities of each person involved in data handling at each level;
- discuss the analysis of STI data.
Planning Your Data Collection

Initial considerations

National, district and health facility needs dictate the data elements to be collected (see units 2 and 3).

The national level should develop forms that all sites will use and coordinate training. SEARO recommends that health facilities use tally sheets to keep track of the number of patients they see and then report these data at least once a month using STI report forms. Tally sheets for STI cases based on syndromic diagnoses can be found in Annex 4.1; tally sheets for STI cases based on aetiologic diagnoses in Annex 4.2; STI reports based on syndromic diagnoses in Annex 4.3; and STI reports based on aetiologic diagnoses in Annex 4.4.

A data management system should be developed at the national level. The roles of different workers, from the health facilities or sentinel sites through to the national level, should be clearly defined. The data management system should clearly explain how surveillance officers at both the district and national levels:

- receive data
- record data
- check the data for completeness and consistency

The national level should also design a method for the submission of reports electronically, by mail, regular direct pick-up from the sites and districts or hand delivery.

Confidentiality and security

Patient confidentiality (the protection of a patient’s personal identifying information) and privacy must be ensured at every level in handling of surveillance data. Specifically:

- train staff who record, store and report surveillance data in the importance of privacy and confidentiality of patient data;
- develop a written confidentiality policy for your surveillance and STI control programmes;
- protect the integrity of STI data to ensure that they cannot be modified;
- restrict access to the data either through use of passwords or restricted access to computers;
- lock all raw data in filing cabinets;
- remove all personal identifying information before you report data from one level to another;
- keep patients’ personal identifying information only at the health facility where it was collected and do not allow unauthorized disclosure;
- Secure the data to protect it from harm or loss. Keep a backup on a floppy disk or CD-ROM every time data are added or edited.
Collecting Data

At the health facilities

STI data collection should be an integral part of STI case management. Everyone involved must have clearly defined duties.

- The data collection process should interfere as little as possible with patient care and case management.
- The data required should be information usually collected during case management.
- Data should be recorded on outpatient cards, then transferred to the patient register and the STI tally sheet.
- One individual needs to take responsibility for keeping the tally sheets and filling out the STI report forms so that reports are made on time.
- A supervisor needs to ensure that the data are ready before they are sent to the district.

Health facility process

While steps in data collection, collation and transfer from one level to another may vary from country to country, presented below is one approach:

1. The doctor, midwife or nurse who diagnoses and provides care for the patient:
   - is responsible for identifying cases and recording medical and demographic data onto patients’ charts (age and sex);
   - must record the diagnoses according to standard case definitions to help record officers or other staff to correctly tally at the end of the month.
2. Data required for reporting are often recorded in clinic registers while additional information and notes are recorded in patient charts.
3. STI cases should be recorded on the tally sheet at the end of each day and hand-tabulated and recorded on the STI reporting form on a regular basis, usually monthly. The data entry clerk or other trained staff:
   - abstracts data from the patients’ charts onto tally sheets;
   - only includes patients presenting for the first visit with a current episode of STI;
   - makes separate entries for each syndrome or each aetiologic diagnosis (some patients will have more than one STI or syndrome);
   - transfers monthly totals from tally sheets to standard reporting forms, provided as Annexes 4.3 and 4.4 of this unit;
   - makes a zero entry if there were no cases of a specific syndrome or aetiologic diagnosis during that month (do not leave the space blank) so the district level will know the report is complete.
4. In some cases, the facility will include several clinics or sites. In that case, a supervising doctor or nurse should:
   - review monthly reports from the health facility;
   - make their comments and have problems investigated before the reports are submitted to district authorities.
5. The final reporting forms should be completed in triplicate. Submit two copies to the district, and file one at the health facility.
Sentinel site case reports from health facilities will include more information than universal case reports. All case reports should indicate the source of the data, such as outpatient department, antenatal clinic, specialized STI clinic, and the total number of patients and number of new outpatients seen in the reporting department for all conditions during the reporting period.

An example of clinic-based STI register is provided in Annex 4.5.

**At the district level**

When the district level carefully reviews facility forms, the quality of data received at the national level is high. Of course, the better the data quality, the better the national level can make decisions that will affect every health facility.

District level data checking and editing should focus on:

- checking for completeness of data
- ensuring that all the variables indicated on the data collection forms are appropriately filled

District surveillance officers should check for:

- inconsistencies (for example, STIs in very young or old patients, male STI diagnoses in females)

The district surveillance officer should follow up with any health facility site that has missing or inconsistent data. Do this before forwarding the forms to the regional or national level.

The district combines the totals from all the reporting health facilities:

- If the district has computers and software, a data entry clerk will enter data into a computerized database. If these resources are not available, data entry is done at the national level.
- A copy of the health facility case reports should be kept at the district level.
- District reporting forms should state the number of health facilities with complete reports.
- The original district summary totals should be sent to the regional or national level following clear reporting lines. Annex 4.2 provides a sample form for this.

**At the national level**

Check inconsistent data with the reporting sites. At the regional and national levels (depending on your country resources), a trained data entry clerk will enter reports into a computerized database, a programme that stores all patient information, then the data are analysed. Figure 4.1 summarizes the data flow process.
**Entering Data**

**Data entry**

Data should be *double-entered* (that is, entered twice) to avoid errors. Alternatively, use software such as *Epi Info™*, which combines data entry with validation. Consider the following points regarding data entry:

- Even if you use a data entry edit program, data still need to be carefully checked before analysis.
- A simple frequency tabulation can be run after data are entered to re-check for implausible values.
- Other ways to ensure correct data entry include:
  - Place a tick or cross on forms once they have been entered.
  - Print out data in the form of a table to check whether the data are logical (for example, women should not be reported with urethral discharge).

**Analysing Data**

**Data analysis**

In *second-generation HIV surveillance*, STI case reporting is used as a proxy for HIV transmission. This is because STIs are transmitted in the same way as sexually transmitted HIV and because programmes that target prevention of sexually transmitted HIV should also prevent transmission of STIs. Several STIs cause acute symptoms and represent recently acquired infection. These may indicate trends in HIV incidence as well. Surveillance of the main STI syndromes - male urethral discharge syndrome, male and female non-vesicular genital ulcer disease - can, therefore, serve two functions:

- They indicate where HIV transmission could be occurring (for instance, a geographical area or a population group).
- They indicate where HIV prevention programmes are failing (if the rates of STIs are rising) or succeeding (if the rates of STIs are falling).
(Other STI syndromes - including female lower abdominal pain, male scrotal swelling, male and female inguinal bubo - can provide supplemental data to confirm trends of the main syndromes.)

The analysis of STI data usually takes place at the national level. At the national level, there may be an epidemiology unit for analysis of surveillance data on all priority diseases. Collaboration between this unit and the AIDS/STI control programme is essential.

Analyse data by these categories to identify the sites that are not reporting consistently:

• reporting site
• type of facility
• district
• gender
• age group

Also, analyse data separately for each syndrome (if syndromic case reporting is conducted) or for each disease (if aetiologic case reporting is conducted).

**Types of data analysis**

STI data analysis should generally focus on three parameters: person, place or time. Table 4.2 explains these parameters.

<table>
<thead>
<tr>
<th>Type of analysis</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>By person</td>
<td>Analysis of specific STIs or syndromes stratified by age group and gender</td>
</tr>
<tr>
<td>By place</td>
<td>Analysis to provide information about where clustering of disease might be occurring</td>
</tr>
<tr>
<td></td>
<td>Stratified analysis by region or geographical area to show if there are significant differences between places</td>
</tr>
<tr>
<td>By time</td>
<td>Analysis to detect if there are any trends in case reports over time (for example, incidence increasing or decreasing). Data for a specific quarter should be compared with the same quarter in the previous year</td>
</tr>
</tbody>
</table>

**Interpreting Data**

**Interpreting trends**

Be careful when you are interpreting STI trends. Interpretation of trends should not be made outside the context of STI control programmes or the health-care system. In order to accurately interpret STI trends, you must consider the following factors:

• Factors related to *health-seeking behaviour*, such as opening of additional health-care facilities, availability or unavailability of medications or introduction of user fees;
Factors affecting reporting practices, such as changes in staffing or training of the staff handling case reporting and data;

Changes in case definitions or quality of services.

If there are unexpected fluctuations, officers at the national or regional level should investigate by contacting the sites.

**Analysing universal and sentinel site data**

Analysis of sentinel site surveillance data and universal reporting data is similar with the following exceptions:

- When doing analysis by place, be cautious in interpreting clustering since sentinel sites may not be representative of other sites.
- Compared to universal reporting, it may be more difficult to calculate population-based rates of disease in a sentinel system. However, if the population from which the clinic population is drawn is known, it can serve as a denominator to calculate prevalence.

The magnitude of STIs by category and trends should help in drawing preliminary conclusions about the burden of STIs.

At all levels of analysis, the data should be clearly summarized in tables, graphs or charts, so they are easily understood. In this way, trends or patterns are identified.

**Summary**

Surveillance data collection occurs at the health facility level, while data processing takes place at the district and national levels. Analysis and use of data to improve services should take place at all levels. It is extremely important to ensure patient confidentiality. STI data analysis should generally focus on three parameters: person, place or time.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

**Small group discussion**

Get into small groups by country, region or province to discuss these questions.

1. Describe the system for forwarding STI surveillance reports from the health facility level to the national level in your country. Describe what happens to the forms at each level and indicate the responsible officers.

2. What core data elements are required for reporting a case through the STI universal reporting system? What other information would you normally report in addition to STI case reports from a health facility and from a district?
Apply what you have learned/case study

You are the national STI surveillance officer for Serosia, an Asian country. You rely primarily on syndromic surveillance using a universal reporting system. You have noticed an increase in the number of reported cases of male non-vesicular genital ulcer disease in Northern District, one of the five districts in the country.

Table 4.3

Number of reported cases of genital ulcer disease by district and year, Serosia

<table>
<thead>
<tr>
<th>District</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>40</td>
<td>42</td>
<td>38</td>
<td>54</td>
<td>45</td>
<td>38</td>
</tr>
<tr>
<td>Southern</td>
<td>60</td>
<td>70</td>
<td>72</td>
<td>84</td>
<td>65</td>
<td>58</td>
</tr>
<tr>
<td>Central</td>
<td>47</td>
<td>50</td>
<td>42</td>
<td>40</td>
<td>41</td>
<td>39</td>
</tr>
<tr>
<td>Eastern</td>
<td>53</td>
<td>87</td>
<td>76</td>
<td>95</td>
<td>107</td>
<td>197</td>
</tr>
<tr>
<td>Western</td>
<td>49</td>
<td>49</td>
<td>36</td>
<td>72</td>
<td>65</td>
<td>48</td>
</tr>
</tbody>
</table>

a. What are some possible causes of this increase?

The Eastern District is along the border. There is a larger camp for displaced persons immediately across the border. There are rumours that displaced persons have been coming to Eastern District for care since 2002. Reliable figures are unavailable.

b. Could an influx of displaced persons with STI symptoms account for the increase in STI cases in Serosia?

c. How would you investigate this?

You examine all syphilis tests done at the clinic for one month. Because this is a sentinel site for syphilis screening as well, demographic data, including nationality, are available. Table 4.4 shows your findings:

Table 4.4

Results of sentinel syphilis screening by nationality, District D

<table>
<thead>
<tr>
<th>Nationality</th>
<th>Positive syphilis tests</th>
<th>Total tested</th>
<th>Percentage positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serosian</td>
<td>10</td>
<td>1 000</td>
<td>1</td>
</tr>
<tr>
<td>Non-Serosian displaced</td>
<td>10</td>
<td>100</td>
<td>10</td>
</tr>
</tbody>
</table>

d. Calculate the prevalence among Serosia and non-Serosia persons. How could these data be used for STI control? How could they be used for HIV prevention?
### Annex 4.1 Tally Sheet for STI Cases Based on Syndromic Diagnosis

**Name of health facility:**

**Dates:** From To

<table>
<thead>
<tr>
<th>Syndromic diagnosis</th>
<th>Number of cases by sex and age group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genital ulcers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaginal discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower abdominal pain (women)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inguinal bubo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute scrotal swelling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neonatal conjunctivitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other STI</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- For every STI patient, cross one "O" vertically in the appropriate cell according to syndrome, sex and age like this Ø.
- Cross only at the first visit for the current episode. Do not cross for the follow-up visit for the current episode.
- If the patient comes for another episode of STD, cross again. The total at the end of each month, calculate the total horizontaly and vertically. One sheet is usually enough for one month. However, add more sheets if necessary.
Annex 4.2 Tally Sheet for STI Cases Based on Aetiologic Diagnosis

<table>
<thead>
<tr>
<th>Aetiologic diagnosis</th>
<th>Number of cases by sex and age group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-4</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>5-14</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>20-29</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>50+</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>0-4</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>5-14</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>20-29</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>50+</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-4</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>5-14</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>20-29</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>30-39</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>50+</td>
<td>0000</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

For every STI patient, cross one “O” vertically in the appropriate cell according to diagnosis, sex and age like this Ø.

Cross only at the first visit for the current episode. Do not cross for the follow-up visit for the current episode.

If the patient comes for another episode of STD, cross again. The total at the end of each month, calculate the total horizontally and vertically. One sheet is usually enough for one month. However, add more sheets if necessary.
Annex 4.3 STD Report Based on Syndromic Diagnosis

Country

Period of report:

Date of report:

<table>
<thead>
<tr>
<th>Syndromic diagnosis</th>
<th>Number of cases by sex and age group (years)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>Urethral discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaginal discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genital ulcer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower abdominal pain (women)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scrotal swelling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inguinal bubo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neonatal conjunctivitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. This report of STI should be based on syndromic diagnosis.
2. Only new cases diagnosed during the period should be reported.
3. The report should include data from all treatment facilities, public and private.
4. The report should be forwarded quarterly and annually.

Results of Serological Test for Syphilis

<table>
<thead>
<tr>
<th>Persons tested</th>
<th>During this period</th>
<th>Cumulative for this year</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. tested</td>
<td>No. + ve</td>
<td>No. tested</td>
</tr>
<tr>
<td>Blood donors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pregnant women</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STI patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Annex 4.4 STD Report Based on Aetiologic Diagnosis

<table>
<thead>
<tr>
<th>Aetiologic diagnosis</th>
<th>Number of cases by sex and age group (years)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>Syphilis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gonorrhoea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphogranuloma venereum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-gonococcal urethritis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chancroid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trichomoniarsis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic inflammatory disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bacterial vaginosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Candidiasis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genital herpes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Granuloma inguinale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genital wart</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neonatal conjunctivitis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other STI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. This report of STI should be based on aetiologic diagnosis.
2. Only new cases diagnosed during the period should be reported.
3. The report should include data from all treatment facilities, public and private.
4. The report should be forwarded quarterly and annually.

Results of Serological Test for Syphilis

<table>
<thead>
<tr>
<th>Persons tested</th>
<th>During this period</th>
<th>Cumulative for this year</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. tested</td>
<td>No. + ve</td>
<td>No. tested</td>
</tr>
<tr>
<td>Blood donors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pregnant women</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STI patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Annex 4.5 Clinic-Based STI Register

**SW register (to adapt)**

<table>
<thead>
<tr>
<th>Demographics (complete all)</th>
<th>Visit (tick 1 or more)</th>
<th>Syndrome (tick 1 or more)</th>
<th>Treatment (tick 1 or more)</th>
<th>Prevention/Screening (tick all performed)</th>
<th>Lab/other needs (optional)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID Number</td>
<td>Sex (M, F, T)</td>
<td>Age (years)</td>
<td>1st clinic visit</td>
<td>Check-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Partner referral</td>
<td>Syndrome</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Follow-up</td>
<td>GUD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>LAP</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>ARD</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>none</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td>Rx1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td></td>
<td></td>
<td>Rx2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td></td>
<td></td>
<td>Rx3</td>
<td></td>
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<td></td>
<td>4</td>
<td></td>
<td></td>
<td>Rx4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td></td>
<td></td>
<td>Rx5</td>
<td>Rx6</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td></td>
<td>7</td>
<td></td>
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<tr>
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<td>8</td>
<td></td>
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<td></td>
<td>9</td>
<td></td>
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<td></td>
<td>10</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Indicate if: 1st clinic visit; Check-up; Syndrome; Partner referral; Follow-up for previous STI (within 2 weeks); VCD = vaginal cervical discharge; GUD = genital ulcer; LAP = lower abdominal pain; UD = urethral discharge; ARD = anorectal discharge; Rx1 = Cervicitis, UD, ARD or presumptive treatment; Rx2 = Vaginitis treatment; Rx3 = GUD treatment; Rx4 = GUD (herpes) treatment; Rx5 = LAP treatment; Rx6 = UD 2nd line treatment (adapt if using STI packs).

Reinforce importance of condom use/risk reduction and offer condom. Treatment for regular partners should be offered for clients with GUD or LAP. Date of next visit should be marked on card.

Note additional services provided.

Fill in date once per day. Start new page each day. ID numbers from cards. Sex/gender (txxxxxx:gender).

---

| ID number | Sex (M, F, T) | Age (years) | 1st clinic visit | Check-up | Syndrome | Partner referral | Follow-up | GUD | LAP | UD | ARD | Other | none | Rx1 | Rx2 | Rx3 | Rx4 | Rx5 | Rx6 | Rx7 | Rx8 | Rx9 | Rx10 | Rx11 | Rx12 | Lab/other needs (optional) |
|-----------|---------------|-------------|------------------|----------|----------|------------------|-----------|-----|-----|-----|-----|-------|------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|                           |
| 1         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 2         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 3         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 4         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 5         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 6         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 7         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 8         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 9         |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 10        |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 11        |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |
| 12        |               |             |                  |          |          |                  |           |     |     |     |     |       |      |     |     |     |     |     |     |     |     |     |     |     |     |                 |

Fill in date once per day. Start new page each day. ID numbers from cards. Sex/gender (txxxxxx:gender).
Overview

What this unit is about
This unit describes how STI prevalence assessment and monitoring can be used as a part of second-generation HIV surveillance.

Warm-up questions

1. Prevalence__________ is the determination of prevalence among persons screened in defined populations, while prevalence monitoring is the determination of trends in prevalence over time.

2. True or false? STI prevalence data that show high rates of STIs are used to identify population sub-groups at high risk for HIV infection. Circle your answer below.
   
   True   False

3. List two purposes of STI prevalence assessment and monitoring.
   
   a.
   
   b.

4. In an STI prevalence survey of the general population, which STIs would you test for?

5. True or false? STI prevalence data are useful for monitoring the effectiveness of HIV prevention programmes.
   
   True   False

6. What does X represent in the equation below?
   
   i. total number of patients who test negative for a specific disease
   
   ii. total number of patients who test positive for all priority diseases
   
   iii. total number of patients tested

   \[
   \text{Prevalence} = \frac{\text{total number of patients who test positive for a specific disease}}{X}
   \]
Introduction

What you will learn

By the end of this unit you should be able to:

- discuss the use of prevalence assessment in a comprehensive STI surveillance system;
- discuss how STI seroprevalence studies can be linked to HIV seroprevalence studies;
- discuss the assessment of STIs in serological surveys.

Prevalence Assessments

*Prevalence assessment* is the second major component of STI surveillance. This core surveillance function is similar to HIV *seroprevalence* surveys, and includes collecting biological specimens (such as blood, urine or swabs) for identification of STIs as well as basic *demographic* information about the person tested.

Information obtained through prevalence assessments can be used to understand which groups are at greater risk for infection.

Assessments determine demographic information about populations at risk. This information is used to describe a population. When prevalence and trends are identified, appropriate treatment can be planned.

Prevalence assessments are usually planned at the national level as one of the following:

- part of a national HIV seroprevalence survey
- a stand-alone project
- part of a combined STI/HIV behavioural survey

STIs that are frequently included in surveys include:

- syphilis
- gonorrhoea
- Chlamydia
- *Herpes simplex* virus
- hepatitis B

Objectives of assessment and monitoring

The main purposes of STI prevalence assessment and *monitoring* are to:

- identify population sub-groups with high prevalence of STIs;
- monitor trends in STI *prevalence* among defined populations;
- measure the overall population burden of STIs.
Prevalence assessments are used in various situations:

- In prevalence assessment and monitoring, interventions (such as screening and treatment) are part of the surveillance activity.
- Prevalence assessment may also be performed as part of studies. These studies are designed to obtain data for programme planning.
- Often, STI prevalence is monitored in routinely screened, defined populations. For example, women are routinely screened for syphilis during antenatal care or delivery. The main purpose of testing at antenatal clinics is detection and treatment of STIs. Determination of prevalence is not the main goal.

**Definition and terms**

The following are some of the terms used in prevalence assessment and monitoring:

- **Prevalence of a disease or infection:** proportion of people in a population who have the disease or infection at a specified time
- **Prevalence monitoring:** following prevalence trends over time to see if they are increasing or decreasing
- **STI prevalence assessment and monitoring:** using surveys to determine what percentage or how many people have STIs when compared to the total population

**Uses of Prevalence Assessments**

**Programme planning**

STI prevalence data are of great use in HIV and STI programme planning, management and evaluation. They are used to:

- develop national estimates of STIs;
- identify population sub-groups at high risk for HIV infection (as evidenced by high rates of STIs);
- guide funding and resource allocation for STI and HIV prevention programmes;
- monitor effectiveness of STI and HIV prevention programmes.

**General population surveys**

Prevalence surveys can be conducted for many different STIs and several types of tests can be performed, including:

- seroprevalence surveys for syphilis and for viral STIs such as *Herpes simplex* virus and hepatitis viruses;
- urine screening for *Chlamydia* and gonorrhoea using nucleic acid-based tests.

Among the most common seroprevalence surveys are those based on syphilis screening programmes. These are similar to HIV seroprevalence surveys. But unlike HIV, these surveys are linked to individuals. In other words, the patients know their blood has been drawn for screening, and they receive the results and any needed treatment.

The two most common settings for general population serological screening for STIs are antenatal clinics (ANCs) and blood donation sites. They are especially useful in countries
where few other data on STI prevalence have been obtained and reported. The results can be used to guide HIV and STI prevention programmes.

- At ANCs, seroprevalence of syphilis among antenatal women should be conducted routinely.
- At blood donor sites, syphilis serologic tests should be conducted routinely. These data (positives and number screened) should be forwarded without personally identifying information to STI control programmes.

Other sites for routine syphilis screening
Routine syphilis screening is also done for:

- new family planning clinic patients
- prisoners at entry into detention facilities
- military recruits
- routine sex worker examinations.

There is less selection bias when the people being tested are from these sorts of facilities than when people are seeking care because they have symptoms. People with STI symptoms are more likely to be infected with STI organisms than people without symptoms. Thus, data from sites where people seek care for symptomatic STIs will overestimate the prevalence of infection.

Sentinel site surveillance
Syphilis screening can also be done at sentinel sites that are participating in the sentinel case reporting system. Data can be collected from all patients screened at the sentinel site or for specific demographic or risk groups, such as:

- pregnant women under 24 years of age screened at an ANC
- commercial sex workers screened at an STI clinic

As with sentinel case reporting, sites should be representative of facilities that provide STI care. They can be STI clinics, hospital-based clinics, primary health-care centres and/or private clinics. Participating sites should come from all geographic regions of the country and should include both urban and rural sites. The sites should have a sufficient number of samples to represent the target population in order to monitor trends.

Laboratory requirements
Assessment of prevalence is primarily based on diagnosis of infections that are frequently asymptomatic. Prevalence assessments thus require access to laboratory facilities.

- Serologic testing is used for syphilis, *H. simplex* virus, and hepatitis B.
- Urine tests are available for chlamydial and gonococcal infections.

There are several serologic tests for syphilis that can help distinguish active infection from latent or previously treated syphilis.
• Treponemal tests (such as TPHA) alone do not distinguish adequately treated syphilis from active syphilis infection. Interpretation of TPHA-positive results is ‘ever had syphilis’.
• Non-treponemal syphilis serologic tests (such as VDRL and RPR) are better markers of active infection especially when titres are high.
• Use of a non-treponemal test titre (for example, > 1:8) is a good marker for active syphilis.

Calculating Prevalence

Calculating prevalence

To calculate prevalence, take the number of patients who test positive for a specific disease (the numerator) and divide it by the total number of patients tested (the denominator) as shown below:

Figure 5.1
Calculating prevalence

\[
\text{Prevalence} = \frac{\text{total number of patients who test positive for a specific disease}}{\text{total number of patients tested}}
\]

When testing equipment is not available for prevalence assessments, you can calculate the syndromic prevalence, based on whether symptoms are present in a patient. In this case, prevalence is calculated according to the following equation:

Figure 5.2
Calculating syndromic prevalence

\[
\text{Prevalence} = \frac{\text{total number of patients symptomatic for a certain disease}}{\text{total number of patients seen}}
\]

In most cases, unless you are assured of including a person only once, positivity is only an estimate of prevalence.

Data elements

Data elements for prevalence assessment and monitoring are the same as those used for case reports. Data should be analysed by gender and age group. For instance, the prevalence of Herpes simplex virus-2 (HSV-2) among 15-24 year old women can be calculated by dividing the number of HSV-2 antibody positive women 15-24 years old by the total number of 15-24 year old women tested for HSV-2 during the assessment period.

Sample size

The minimum acceptable sample size for assessing the prevalence depends on:

• the expected prevalence of the disease in the population, based on prior estimates or similar situations in neighbouring cities and countries;
• whether the sample will be used to monitor trends in prevalence over time; to be valid, the sample size needs to be large to determine trends in prevalence over
Module 4: Surveillance for Sexually Transmitted Infections

time and identify sub-populations at high risk for infection. This means that the
sample size needs to be large enough to be able to detect the difference between
two prevalence estimates. Statistically, this is referred to as the margin of error
(for example, ±3%).

The standard statistical approach for determining the sample size requires:

- an estimate of STI prevalence in the population to be surveyed;
- the margin of error considered acceptable (for example, ±3%) (This is also called
  interval width);
- the level of confidence desired (a 95% confidence interval means that, if the survey
  were done 100 times, the prevalence in 95 surveys out of the 100 would fall within
  the 95% confidence intervals).

The STATCALC feature of Epi Info™ software provides a user-friendly sample size
calculator for setting specific target sample sizes. The Epi Info™ software is distributed
by the United States Centers for Disease Control and Prevention (CDC). You may learn
more about Epi Info™ and download the software for free at this site: http://www.cdc.
gov/epiinfo.

Practical considerations

In practice, sample sizes are balanced against the technical and financial resources
available for each collection of the survey. Very large sample sizes in a sentinel site can
provide useful information on the local epidemic. However, there may not be enough
resources to carry out surveys with very large sample sizes.

Formula to determine sample size

An exact formula to determine sample size (N) to achieve a certain pre-specified
interval (for example, ±3%, which is the same as a width of 6%) with a specified level
of confidence (for example, 95%) is shown in Figure 5.3.

Figure 5.3

Formula to determine sample size needed for pre-specified interval with
specified confidence level

\[ N = \frac{4 z^2 P (1- P)}{W^2} \]

- \( z \) is a factor that corresponds to the desired confidence interval (for a 95% confidence
  level, \( z = 1.96 \)).
- \( P \) is the expected proportion of patients with the outcome (such as syphilis
  prevalence).
- \( W \) is the width of the interval, for example the width for a margin of error of +/- 3%
  is 0.06.

Analysing Prevalence Data

Analysis of STI prevalence

Analysis of routinely collected prevalence data (for instance, data obtained from
routine screening of women in antenatal care) is similar to the analysis of universal
and sentinel case reporting data. Quarterly and annual trends in prevalence should be analysed overall and stratified by basic categories, such as disease, sex, age group and geographical location.

Prevalence trends may be altered by changes in the population being screened for several reasons:

- different types of clinics, for example, an STI clinic versus a clinic serving the general population may get different results;
- change in the population's health-seeking behaviour;
- change in criteria used to select persons for screening;
- change in diagnostic tests, especially for Chlamydia, which often vary in sensitivity and specificity.

Changes should be recorded and taken into account in the interpretation of trend data.

**Summary**

STI prevalence assessments can be used to monitor STI prevalence trends in both the general population and in specific population sub-groups and geographical sites.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

**Small group discussion**

Get into small groups by country, region or province to discuss these questions.

1. What are the main objectives of STI prevalence monitoring? How can STI prevalence data be used by an HIV control programme?

2. Are data on syphilis seroprevalence in routinely tested populations collected in your district or province? If so, what populations are being routinely tested? Are the data analysed and results disseminated?

**Apply what you have learned/case study**

Try these case studies. We will discuss the answers in class.

**Exercise 1**

You work in an STI clinic in a brothel complex that serves about 1 000 female sex workers. You conducted syphilis screening and treatment for female sex workers at the clinic every quarter as part of the intervention and monitoring activities. Table 5.1 shows the results of this STI screening and treatment programme in this high-risk population.
Table 5.1
Number of female sex workers participating in the screening and treatment programme and number with positive syphilis serologies (RPR >1:8) by quarter and age groups

<table>
<thead>
<tr>
<th>Age Group</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>15-19</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>20-24</td>
<td>8</td>
<td>9</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>25-29</td>
<td>9</td>
<td>9</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>30-34</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>&gt;34</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 5.2
Prevalence of syphilis among female sex workers participating in the screening and treatment programme and number with positive syphilis serologies (RPR >1:8) by quarter and age groups

<table>
<thead>
<tr>
<th>Age group</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>5.6%</td>
<td>6.8%</td>
<td>4.8%</td>
<td>1.6%</td>
<td>4.7%</td>
</tr>
<tr>
<td>15-19</td>
<td>7.7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>10.0%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-29</td>
<td>11.5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-34</td>
<td>13.5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;34</td>
<td>17.1%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>12.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Complete the age-specific prevalence of syphilis seroreactivity by quarter in Table 5.2.

- Does the trend in age-specific prevalence levels support your belief that you collected good quality data?

- Why is the prevalence of reactive syphilis serologies higher among older women?

- Compute test positivity of syphilis for the one-year period. What is the main use of this information?
b. There is a downward trend of STI prevalence over time that may be attributable to your intervention programme (for example, condom promotion and screening and treatment of STIs).

- List other possible reasons for this downward trend of STI prevalence in this clinic population.
- What other information do you need to collect to support your belief that this downward trend is due to your intervention?
Antimicrobial Resistance Monitoring, Assessment of STI Syndrome Aetiologies and Combined Behavioural and STI/HIV Surveys

Overview

What this unit is about

This unit describes three types of specialized surveys and defines when and how to use each:

• antimicrobial resistance monitoring;
• assessment of sexually transmitted infection (STI) syndrome aetiologies;
• combined behavioural and STI/HIV surveys.

Warm-up questions

1. For countries where syndromic STI case reporting is used, syndrome aetiologies should be reassessed every ________________ years.
   a. one to two
   b. two to three
   c. three to four

2. True or false? Monitoring antimicrobial resistance of *N. gonorrhoeae* may help to detect newly emerging resistance.
   True    False

3. Choose an item below that is not one of the main purposes of assessing syndrome aetiologies:
   a. provide data for guiding STI syndromic management
   b. assess effectiveness of HIV prevention programmes
   c. assist in the interpretation of syndromic case reports
   d. assist in the assessment of disease burden caused by specific pathogens
   e. evaluate syndromic management algorithms for urethral discharge and genital ulcers

4. List two possible uses of data obtained from monitoring antimicrobial resistance of STI pathogens.
   a. 
   b. 
5. Which of the following sampling strategies is the most difficult to use when conducting antimicrobial resistance monitoring?
   a. random
   b. systematic
   c. consecutive

6. True or false? Undertaking a combined STI/HIV and behavioural survey can identify population sub-groups at high risk for HIV infection.
   True   False

7. True or false? The choice of which STI to include in a behavioural survey is made independently of the type of population to be studied.
   True   False

8. True or false? Combining HIV/STI surveillance and behavioural surveys is more cost-effective than conducting the two surveys separately.
   True   False

**Introduction**

**What you will learn**

By the end of this unit you should be able to:

- discuss why assessment of syndrome aetiologies is a core component of a comprehensive STI surveillance system;
- discuss the objectives of antimicrobial resistance monitoring in *Neisseria gonorrhoeae* and *Haemophilus ducreyi*;
- describe the two main STI syndromes and their microbiological causes;
- discuss how data from assessments of syndrome aetiologies are used to revise syndromic treatment guidelines;
- discuss how prevalence assessment studies can be linked to behavioural surveillance surveys;
- identify the STIs most suitable for inclusion in combined STI/HIV behavioural surveillance studies.

In addition to case reporting and STI prevalence assessment and monitoring there are several activities that can supplement STI surveillance. These include:

- laboratory assessment of antimicrobial resistance;
- assessment of STI syndrome aetiologies;
- behavioural surveillance, including combined behavioural and STI/HIV surveys;
- research studies.

In this unit we will concentrate on the first three supplemental activities. Research studies are usually undertaken to address specific epidemiological situations that cannot
be explained by case reporting or by prevalence assessments. Some research activities that have been undertaken in the South-East Asia region are listed in Annex 6.1.

**Laboratory Assessment of Antimicrobial Resistance of STI Pathogens**

**Why assess resistance?**

Drugs are routinely used to treat bacterial and fungal STI infections. This has led to increasing rates of *resistance*. Resistance is the alteration of a pathogen that makes it non-responsive to a particular antimicrobial agent.

Simply put, the drug being used no longer controls or eliminates the infection.

Resistance monitoring entails examining in the laboratory the effectiveness of various antimicrobial agents in inhibiting the growth of *N. gonorrhoeae*. In resistance monitoring, various concentrations of a given antimicrobial agent are used to determine the minimum concentration of that agent that is required to stop the organism from growing. Depending on the concentration of the antimicrobial agent required to inhibit growth, the organism can be classified as sensitive, intermediate or resistant to a particular antimicrobial agent. Usually the organism is checked for sensitivity against several different antimicrobials, often from different antimicrobial classes.

As an example of how to monitor antimicrobial resistance we will discuss *N. gonorrhoeae*, the STI organism most likely to develop resistance. Resistance monitoring is done to:

- obtain the data necessary for developing and revising treatment guidelines;
- detect newly emerging resistance.

It is also important to monitor *N. gonorrhoeae* to ensure that the medication given to a patient with a gonococcal infection will cure the infection. Effective treatment for gonorrhoea:

- relieves the signs and symptoms and achieves microbiologic cure in individual patients;
- prevents complications of pelvic inflammatory disease, chronic pelvic pain and infertility in women;
- reduces the risk of HIV transmission by decreasing the presence of white blood cells at the cervix and urethra;
- interrupts transmission of *N. gonorrhoea*.

**Laboratory requirements**

Surveillance surveys for antimicrobial resistance of STI pathogens are usually organized and conducted by the national STI control programme. Sites are chosen that have health-care facilities with well-trained staff and laboratory expertise. Only selected sites will have the capacity to conduct these types of surveillance activities.

In our example of monitoring *N. gonorrhoeae* and selecting antimicrobial drugs for susceptibility testing, give priority to drugs commonly used for treating gonococcal
infections. A laboratory performing susceptibility testing for *N. gonorrhoeae* should be able to accomplish the following tasks:

- culture the organism;
- perform biochemical confirmatory tests;
- perform minimum inhibitory concentration (MIC) agar dilution testing of antimicrobial agents.

If the national reference laboratory does not have this capacity, it may send isolates to a regional laboratory in another country for testing. An isolate is a culture of bacteria or other cells.

- Regional networks supported by WHO Collaborating Centres have been established in several WHO regions to conduct antimicrobial susceptibility testing for *N. gonorrhoeae*.
- National reference laboratories are encouraged by WHO and UNAIDS to participate in these centres’ programmes of quality control and assessment.

**Planning the testing**

The minimum acceptable *sample size* for assessing the proportion of resistant organisms depends on:

- the expected proportion of the disease in the population, based on prior estimates or similar situations in neighbouring cities and countries;
- whether the sample is intended to be used to monitor trends in the proportion of resistant organisms over time.

Samples for resistance testing can be random, systematic or consecutive.

- A *random sample* of gonococcal isolates is one in which each patient submitting a specimen from which the isolate is obtained would have an equal chance of selection. This type of sampling yields the most representative sample but is too difficult to conduct in most clinic settings.
- A *systematic sample* (for instance, every tenth patient with discharge and a positive *Gram stain* during the sampling period), is an adequate sample and easier to obtain. Systematic sampling requires attention to procedural details and is subject to manipulation by clinic staff. An example of manipulation by clinic staff is a staff member excluding eligible cases that come in on busy days because of time constraints. For these reasons, systematic sampling is not feasible in some situations.
- A *consecutive sample* consists of selecting every patient that meets the inclusion criteria until you get to the required sample size or the survey period is over. Use this type of sampling if you determine that systematic sampling will not work in your setting.

A sample of 100 isolates per sentinel site during a defined time interval, such as a quarter or a year, is usually large enough to identify local patterns of resistance.
A finding of zero cases of resistant isolates among 100 isolates tested provides a probability of 95% that the true proportion of resistant isolates is <5%.

**Frequency of assessment**
The assessment of antimicrobial resistance should be performed at least once a year. When feasible, it is best to sample isolates on an ongoing basis rather than during only one month or quarter per year. For example, you can test 20 isolates per month at each sentinel site throughout the year. Ongoing sampling makes it more likely that newly emerging resistance or large changes in patterns of resistance will be detected early.

If trends in susceptibility are to be reliably monitored over time, variations in the sentinel sites and sampling procedures should be minimized.

**Recommended collection**
Sentinel sites for collection of gonococcal isolates should be representative of the major regions in the country. Urban STI clinics that have the capacity to perform cultures are usually used as sentinel sites.

- Obtain isolates from both women and men if possible.
- Obtaining samples from men who have purulent urethral discharge is easiest since a high proportion of these are due to gonorrhoea. A sample of the cervical discharge from women is necessary for isolation of the organism but it is more difficult to identify women with gonorrhoea.
- Test for Gram-negative intracellular diplococci. Using Gram stain to help in selecting specimens makes sense because the yield of culture from these patients will be high.

**Data analysis and interpretation**
Microbiologists who are familiar with the sensitivity and specificity of each of the tests used should interpret the results.

- **Sensitivity** refers to the proportion of persons with a disease who are correctly identified by a screening test or case definition as having the disease.
- **Specificity** refers to the proportion of persons without a disease who are correctly identified by a screening test or case definition as not having the disease.

Review the results of resistance testing each quarter, even if the sample size per quarter is small. Make sure the data are complete and patterns are generally consistent from quarter to quarter. If you see a big change in your quarterly review of data, investigate to determine if the change is due to:

- real shifts in resistance patterns
- problems in the laboratory

**Further investigation**
If such shifts are noted, it may be useful to:

- expand the sample beyond the number previously collected each month;
- increase the number of sites where susceptibility testing is performed until the problem is identified.

The appearance of new resistant strains should be reported as soon as possible to a WHO Collaborating Centre. The Centre will assist in confirming the finding and determine if intensive investigation is needed. Data on resistance should be reviewed carefully in preparing updated treatment guidelines and in revising the country's list of essential drugs.

Figure 6.1

**Frequency of penicillin-, tetracycline- and ciprofloxacin-resistant *N. gonorrhoeae* and frequency of penicillinase-producing *N. gonorrhoeae* by year, New Delhi, 1988-1993**

Figure 6.2
Proportion of *N. gonorrhoeae* isolates resistant to ciprofloxacin by sentinel site, South-East Asia Region, 1999-2000


Disseminating results

Distribute data on gonococcal resistance nationally at least once a year. Use charts and graphs similar to those shown in Figures 6.1 and 6.2.

Reports should summarize the proportion of isolates that were found to be resistant to the antimicrobial agents. Results should be stratified by sentinel site. It may also be useful to summarize the proportion of isolates that were of intermediate sensitivity.

Reports should include:

- the gender of patients;
- the clinic setting where the patients were tested (for example, antenatal clinic, STI clinic or clinic for female sex workers);
- changes that have occurred in the sentinel sites over time.

This information can assist in the interpretation of test results, particularly if certain sites are attended by patients whose previous therapies have failed. Such patients are more likely to have resistant strains.

Assessing STI Syndrome Aetiologies

Determining the microorganisms that cause urethral discharge, genital ulcer disease and vaginal discharge are a core STI surveillance activity. This assessment of *aetiologies* of STI syndromes is especially important in countries where STI *syndromic* management and case reporting are usually performed. Knowing the organisms that account for the STI *syndromes* allows the STI control programmes to recommend effective treatment and to interpret syndromic case reports.
The national AIDS/STI control programme typically organizes and carries out STI syndrome aetiology assessment. These surveys are conducted to assess the relative contributions of the major STI pathogens such as:

- the syndrome of urethral discharge in men (gonorrhoea, Chlamydia and others);
- the syndrome of genital ulcer disease in men and women (syphilis, chancroid and HSV-2).

Syndrome aetiologies should be reassessed every two to three years or more frequently if the need arises. For example, if there is a new outbreak of genital ulcer disease, you would reassess which microorganisms are causing the disease earlier.

**Objectives**

The main purposes of assessing syndrome aetiologies are to:

- provide data for guiding STI syndromic treatment;
- assist in the interpretation of syndromic case reports and the assessment of disease burden due to specific pathogens;
- design or modify guidelines for treating urethral discharge and genital ulcers.

**Laboratory requirements**

A microbiologist experienced in STI diagnostic tests should develop laboratory protocols for determining which organisms are causing the symptoms. Laboratories should also have quality assurance and control protocols in place.

The range of diagnostic tests that may be used is broad. Many new tests are being developed. Selection of the test to use will depend upon local availability of resources. Table 6.1 below summarizes the general types of laboratory tests that may be used for assessing syndrome aetiologies:

**Table 6.1**

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>Corresponding laboratory tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral discharge in men</td>
<td>Microscopy (Gram stain of urethral discharge to identify Gram-negative diplococci bacteria, primarily <em>N. gonorrhoeae</em>)</td>
</tr>
<tr>
<td></td>
<td>Gonorrhoea and Chlamydia testing:</td>
</tr>
<tr>
<td></td>
<td>• culture for <em>N. gonorrhoeae</em></td>
</tr>
<tr>
<td></td>
<td>• direct fluorescent antigen and enzyme-linked immunoassay (EIA) for <em>C. trachomatis</em></td>
</tr>
<tr>
<td></td>
<td>• Polymerase chain reaction (PCR) and other amplified and non-amplified nucleic-acid based tests for both pathogens</td>
</tr>
<tr>
<td>Genital ulcer disease in men and women</td>
<td>Syphilis serologic testing (non-treponemal and treponemal)</td>
</tr>
<tr>
<td></td>
<td>Dark field, direct fluorescent antibody test for syphilis</td>
</tr>
<tr>
<td></td>
<td>Culture for <em>H. ducreyi</em></td>
</tr>
<tr>
<td></td>
<td>Herpes simplex virus type 2 culture or antigen detection test</td>
</tr>
<tr>
<td></td>
<td>PCR for <em>T. pallidum</em>, <em>H. ducreyi</em> and HSV-2 available in some settings (Multiplex PCR)</td>
</tr>
</tbody>
</table>
Testing procedures

Selection of populations for assessing syndrome aetiologies depends on the number of cases available for examination at a single site. Syndrome aetiologies should ideally be assessed in:

- different types of populations
- populations with high rates of disease
- populations with low rates of disease
- different geographic locations

If your country has limited resources, begin with an assessment of urethral discharge and genital ulcer disease at a single specialized STI clinic. The clinic should:

- have well trained personnel that can perform high quality Gram stain and microscopy;
- be able to perform syphilis serologic testing.

In many countries, reliable dark field microscopy is unavailable.

Collaborate with a well-equipped laboratory to assess the contribution of Chlamydia to urethral discharge. Further assess the contribution of chancroid and herpes to genital ulcer disease. Also keep in mind that:

- Syphilis serologic testing alone provides an incomplete assessment of genital ulcer aetiology. This is because many patients with chancroid and HSV-2 ulcers can have reactive syphilis serologic tests from previously treated or untreated (latent) infections.
- A substantial proportion (10%-30%) of patients with primary syphilis will not yet have developed a serologic response to infection.

Sample size

The sample size depends on the specific aetiology and the expected prevalence of pathogens.

A minimum sample size of 50 or 100 specimens from consecutive patients with the specified syndrome (or other type of systematic sample) will provide adequate information for useful analyses.

Analysis

It is important to analyse STI data separately for each specific disease rather than reporting findings together. For example, cases of gonorrhoea should be analysed separately from cases of syphilis. The frequency of the various STI and risk behaviours should then be calculated and analysed by:

- gender
- age group
- geographic area
- marital status
- other relevant characteristics
These tests are usually performed anonymously after the patient is treated syndromically based on symptoms and examination findings. Since patients are treated for all possible pathogens causing the syndrome, there is no need to give results to individual patients.

**Combined STI/HIV Prevalence and Behavioural Surveillance Surveys**

Behavioural surveys of certain high-risk groups and of the general population are an integral part of both comprehensive STI surveillance and of second-generation HIV surveillance. Behavioural surveys can be combined with HIV seroprevalence surveys. An example of this is the Demographic and Health Survey with HIV testing (DHS+). Behavioural surveys can also be combined with STI prevalence surveys done along with HIV testing. These *combined STI/HIV behavioural surveillance surveys* collect data that compare patients’ high-risk behaviour with the presence of STIs and HIV.

Combined STI/HIV behavioural surveillance surveys combine:

- STI/HIV prevalence assessments (including blood or urine tests for HIV and STIs);
- behavioural surveys.

**Behavioural surveys**

*Behavioural surveys* use questionnaires to examine the prevalence of behaviours associated with HIV and STI transmission. In these surveys prevalence is the number of people who have a certain behaviour (usually within a specified time period) divided by the total number of people who answered the question. They are an integral part of *second-generation surveillance*. They may be conducted as part of:

- national health and demographic surveys;
- HIV behavioural surveillance or HIV serosurveillance in high-risk populations.

In behavioural surveys, you interview people about their sexual and other high-risk behaviours that are associated with an elevated risk of STI or HIV infection. Examples of high-risk behaviour include:

- having multiple casual sexual partners;
- not using condoms with casual partners;
- taking or giving gifts or money for sex;
- injecting drugs.

**Combined surveys**

In contrast to STI case reporting, combined STI/HIV and behavioural surveys allow for collecting denominator data, which in this case are the number of persons surveyed. In this way, prevalence of STIs among persons and certain behaviours can be calculated.

Combining STI/HIV prevalence assessment with behavioural surveillance surveys is more cost-effective than conducting separate surveys. The combined surveys reduce personnel costs and time.
Goals of combined surveys

Thus, the goal of combined prevalence assessment and behavioural surveys is to:

- assess the prevalence of asymptomatic STIs in surveyed populations;
- identify population sub-groups at high risk for infection; population sub-groups are groups within a population that share certain characteristics or behaviours (an example of a sub-group of the general population is unmarried men aged between 20 and 29 years, living in urban areas who have given money or gifts for sex);
- assess health-seeking behaviour for STI services; health-seeking behaviour consists of actions an individual takes to maintain or improve their health (an example of this is getting tested for STIs at a public health clinic);
- measure the effectiveness of HIV/STI prevention programmes;
- determine the need for additional prevention and health services;
- guide funding and resource allocation for STI and HIV programmes.

Use consistent data elements

Use consistent data elements to determine risk behaviour. Use behavioural survey questions, such as:

- the number of sexual partners in the past three or 12 months;
- new sexual partners in the past three months;
- condom use during the last sexual intercourse with someone other than a regular sexual partner;
- alcohol or drug use in the past 12 months;
- giving or receiving money for sex in the past 12 months.

When used with behavioural surveys, HIV and STI testing assesses risk behaviours and HIV and STI burden in high-risk and bridging populations as well as the general population. Bridging populations include people in high-risk groups who have sex with people of lower risk in the general population. An example of this might be a married truck driver having sex with a commercial sex worker and also with his wife.

Choosing STI laboratory tests for behavioural surveys

When you are choosing which STI to test for in a combined STI/HIV and behavioural survey, consider two things:

- the laboratory infrastructure development in the country
- the type of populations under study

These assessments almost always include HIV testing.

Laboratory testing for STIs

A country with strong laboratory support can conduct the following tests for STIs. Some of these infections reflect recent high-risk behaviour:

- Gonorrhoea and Chlamydia - Gonorrhoea and Chlamydia infections, identified through urine-based testing using nucleic acid amplification tests, are likely to reflect recently acquired infections. (Untreated Chlamydia and gonorrhoea can
persist for months). Consequently, the presence of these STIs reflects recent high-risk behaviour or recent exposure from a partner with high-risk behaviour.

- **Herpes simplex virus type 2 (HSV-2)** - Serologic testing for HSV-2 may be useful in adolescent populations to indicate recent high-risk behaviour. In adults, HSV-2 testing is not useful because information on the duration of infection is absent.

- **Trichomonas vaginalis** - Because trichomoniasis can persist for years with minimal symptoms, it is not a good indicator of recent infection.

- **Haemophilus ducreyi** - Culture for H. ducreyi, the causative agent for chancroid, requires sophisticated laboratory capabilities. Serologic testing is possible but results (as with HSV-2 and syphilis) indicate past infection and must be interpreted carefully. Laboratories that performed urine-based PCR testing for gonorrhoea and Chlamydia can also perform multiplex PCR for GUD for aetiologies (syphilis, chancroid, and HSV-2); this can be very important for surveillance in areas where ulcerative STIs are common.

- **Most countries in the South-East Asia Region have limits on their laboratory capacity and only test primarily for syphilis (Treponema pallidum).** Serologic testing for syphilis indicates infection but cannot determine the stage of disease or time of exposure, so is not an indication of recent high-risk behaviour. If, however, titres of non-treponemal tests are available (for example, the VDRL or RPR tests), titres of 1:8 or higher can be used as a marker of recent infection.

### Populations and STI monitoring

Table 6.2 provides a summary of populations and STIs for monitoring.

<table>
<thead>
<tr>
<th>Population</th>
<th>STI</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-risk (youth)</td>
<td>HSV-2, <em>N. gonorrhoeae</em>, <em>C. trachomatis</em></td>
<td>HSV-2 measures early sexual exposure</td>
</tr>
<tr>
<td>Bridging and high-risk:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• sex workers</td>
<td></td>
<td>Measures recent sexual exposure</td>
</tr>
<tr>
<td>• truck drivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• injection drug users</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General population</td>
<td><em>N. gonorrhoeae</em>, <em>C. trachomatis</em></td>
<td>Measures recent sexual exposure</td>
</tr>
<tr>
<td></td>
<td><em>T. pallidum</em></td>
<td>Exposure period cannot be determined unless titres are used</td>
</tr>
</tbody>
</table>

Table 6.2

**Populations and STI monitoring**
Data elements

The data elements for combined STI/HIV surveillance and behavioural surveillance are the same that are collected for routine STI surveillance. They also include the data collected regarding demographics and risk behaviours. The types of behavioural data collected will vary depending on the populations surveyed. For example:

- In high-risk population surveys, greater attention is given to specific high-risk behaviours. For example, for migrant truck drivers, questions may include those on having sex in exchange for money or goods and using condom for sex with primary partner and other partners.
- In general population surveys, questions regarding general risks along with demographic characteristics and health-related behaviours are the priority. For example, questions may cover age, marital status, sex and occupation.

Data analysis

STI data should initially be analysed separately for each specific syndrome. For example, cases of gonorrhoea should be counted separately from cases of syphilis.

Calculate separately the prevalence and risk factors for each disease. Further calculate the prevalence by:

- gender
- age group
- geographic area
- marital status
- other relevant characteristics for each disease

Combine the frequency of the various acute STIs and risk behaviours to calculate the number of persons with an acute STI in a certain time period with certain demographic characteristics or risk behaviours.

Reporting Results of Special Studies

Communicating STI surveillance data

Distribute results of these special STI surveillance activities, including antibiotic susceptibility testing, to health centres, clinicians, private providers, and laboratories that have participated. This will help increase timely, valid and complete case reporting.

National STI programmes should develop and implement a plan to effectively communicate the STI surveillance data. People experienced in health communications should design materials that concisely summarize and effectively communicate the data to each of these groups:

- National AIDS programme directors
- National STI programme directors
- District medical officers
- Health-care providers
• Non-governmental organizations (NGOs)
• Donors
• Other public health agencies

Types of reports
When communicating surveillance data, think about using the following types of reports:

• Annual STI surveillance reports, with case numbers, rates and trends by geographic area and demographic variables, and prevalence data by population;
• Fact sheets, based on the data provided by the system, with tables and graphs that can be posted at health department offices and clinics, and provided in response to ad hoc inquiries, guidelines and technical manuals;
• Regular newsletters for clinicians, laboratory personnel and others, which may include brief reports of surveillance data along with updated information on patient management;
• Press releases that highlight disease burden and trends, and can be used as part of public information campaigns;
• Educational materials such as charts and posters developed using the data provided by surveillance case reports;
• Verbal feedback during meetings and supervisory visits;
• Electronic media such as publishing summary data on a web site.

Summary
Antimicrobial resistance monitoring helps detect emerging resistance and develop treatment guidelines. Assessing syndrome aetiologies provides information on the relative contributions of different pathogens to the main STI syndromes. This guides STI syndromic treatment and assists in the interpretation of syndromic case reports.

Combined STI/HIV and behavioural surveys allow surveillance officers to calculate the prevalence of STIs among persons practising risky behaviours. Selecting an STI for inclusion in a combined STI/HIV behavioural surveillance study depends on the population surveyed and available laboratory infrastructure.

Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion
Get into small groups by country, region or province to discuss these questions.

1. What is the first-line therapy for male urethral discharge syndrome in your country?

Is there any evidence to suggest that *N. gonorrhoeae* isolates are resistant to that therapy?
If there were evidence of widespread resistance, what would you advise your provincial or national STI control programme to do?

2. How could knowing STI syndrome aetiologies be useful in designing HIV prevention programmes?

For instance, what approaches would you consider if 80% of genital ulcer disease were due to syphilis or chancroid?

What if 80% of genital ulcer disease were due to HSV-2?

Apply what you have learned/case study
Try this case study. We will discuss the answers in class.

You are the HIV/STI surveillance coordinator in a health district in Malanka, a South-East Asian country. STIs in your country are routinely managed and reported using the WHO syndromic approach. The national STI control programme will be conducting a national assessment of antimicrobial resistance in *N. gonorrhoeae*. Your district, Topinagar, has been asked to participate.

a. What are the reasons for conducting an assessment of antimicrobial resistant *N. gonorrhoeae*?
b. What factors will you need to consider in order to conduct this assessment in your district?
c. How would you select your sample?
d. Given the results in the figure below, what recommendations would you make regarding the treatment of *N. gonorrhoeae* in Malanka?

Figure 6.3
**Percentage of gonococcal isolates that were resistant to selected antimicrobial agents, Malanka**

Note: PENI, penicillin; TETR, tetracycline; SPEC, spectinomycin; CEFT, ceftriaxone; CIPR, ciprofloxacin; CEFI, cefixime
Annex 6.1 STI Research Studies

- Outbreak investigations of some selected STI syndromes or conditions
- Evaluation of STI syndromic management algorithms
- Rapid assessment of STI prevalence using new diagnostic tests
- Assessment of antimicrobial resistance in *H. ducreyi*
- Incidence and prevalence of STI-related complications
  - Pelvic inflammatory disease
  - Ectopic pregnancy
  - Cervical cancer
- Prevalence of viral STIs, such as Herpes simplex virus type 2 and human papilloma virus
- Prevalence of bacterial vaginosis and associated sequelae in defined populations
- Assessment of STI incidence and prevalence among persons who are HIV-infected and of HIV prevalence among persons with other STIs
- Development and evaluation of STI screening criteria
Your country has a concentrated HIV epidemic and high rates of other STIs, demonstrated through STI case reporting. Last year, an aid agency announced its interest in conducting a demographic and health survey of rural and urban areas. You were contacted by the provincial HIV/AIDS surveillance officer because he has decided to work with this agency to add STI testing to the HIV and behavioural survey in your province. He is asking you and the other district surveillance coordinators for your input into the survey design.

a. Which populations would you like to include in the survey in your district? Why?

b. Which STIs would you test for in addition to HIV? Why?

c. In addition to the demographic questions that the aid agency will routinely ask in the survey, what additional questions on STI/HIV risk behaviours would you want to include?
If surveillance data shows that STI transmission is occurring, then HIV transmission is likely to be occurring as well.

World Health Organization estimates that 340 million new, curable STI cases occurred globally in 1999. Of these, 151 million (44.4%) occurred in South and South-eastern Asia.

The most feasible STI surveillance system in the South-East Asia Region is STI case reporting. The STI case reporting process involves health-care providers reporting cases of STIs to public health authorities at the district, provincial or national level. In universal STI case reporting, minimum data on STI cases are collected from all the health facilities in the country.

There are two different ways to diagnose and manage STI cases. These are syndromic diagnosis and reporting, and aetiologic diagnosis and reporting. In syndromic diagnosis, three syndromes are used for STI surveillance. In aetiologic diagnosis, an exact microbiologic diagnosis is given (for example, gonorrhoea).

Diagnosis of STI syndromes should be based on standard case definitions, which use readily identifiable and consistent clinical criteria. Uniform case definitions should be used throughout the country to enable comparability of the data arising from the reporting systems.

Curable STIs with acute onset and short duration such as gonorrhoea, Chlamydia, chancroid, trichomoniasis, primary and secondary syphilis, and the syndromes they cause are priorities for STI surveillance. Simple methods can be used as to assess STI incidence and prevalence.

At sentinel surveillance sites, more data on STI cases are recorded and reported. Trends from these sites are used to infer trends of STI case reports in other health facilities. The major advantage of this system is that higher quality and more consistent information is obtained.

Prevalence assessment is the determination of prevalence of certain STIs or syndromes by laboratory testing and/or clinical examination among persons screened in defined populations. Prevalence monitoring is the monitoring of trends in prevalence over time.

In view of the increasing rates of drug-resistant pathogens worldwide, it is important for each country to monitor antimicrobial resistance in Neisseria gonorrhoeae as a component of STI surveillance.

In countries using the syndromic approach to STI treatment, it is important to monitor the actual aetiologies of urethral discharge syndrome in men, and genital ulcer diseases in men and women. These findings are used to refine national STI treatment guidelines.

Combined STI/HIV and behavioural surveys combine STI and HIV prevalence assessments with behavioural surveys. These can be done in the general population (as in DHS+) or in specific high-risk populations.
Answers are provided in italics for each unit’s warm-up questions and case study.

Answers to the questions within the unit are not included. Unit questions are designed to stimulate small group discussion among participants in the workshop or class.

Unit 1 Answers

Warm-up questions

1. Describe three areas of inter-relationship between STIs and HIV. *Behavioural (both STIs and HIV are transmitted sexually), epidemiological (populations with high rates of STIs also have high rates of sexually transmitted HIV), and biological (the presence of STIs makes it easier to acquire and spread HIV).*

2. True or false? You can reduce the risk of people transmitting and acquiring HIV infection by controlling STIs. *True. Because of the relationship between STIs and HIV (see previous question), controlling STIs can help to reduce the risk of HIV infection on an individual and population level.*

3. True or false? An STI surveillance system can serve as an evaluation tool for HIV prevention programmes. *True. HIV prevention programmes attempt to reduce risky sexual behaviours, including those that lead to STI transmission. Therefore, monitoring STIs through STI surveillance can help to evaluate the effectiveness of these prevention programmes.*

4. Which of the following increases the risk of HIV transmission in sexual exposure?
   a. greater mucous membrane exposure
   b. the presence of white blood cells
   c. increasing the duration of exposure
   d. all of the above

*Mucous membranes often contain white blood cells, which are targets of HIV. Therefore, the presence of white blood cells provides more targets for HIV to infect. Finally, increasing the duration of exposure allows HIV more time to infect.*

Case study

You are a national level public health officer in Serosia (a country with a concentrated HIV epidemic) and have reviewed the male urethral discharge surveillance data for your country. Currently, male urethral discharge is reported using a vertical reporting system. You have concluded that the reporting of this STI is incomplete in most districts.

a. List the appropriate actions to take to improve the quality and completeness of gonorrhoea reporting for your country.

   1. *Move from a vertical system to an integrated system.*
2. Establish an active reporting system in which health department staff contacts health facilities to gather the surveillance data.

b. List two ways that surveillance for male urethral discharge can be used in understanding the HIV epidemic in Serosia.

Surveillance for STI (such as male urethral discharge syndrome) can be used as a marker:

1. for the emergence of HIV in new groups
2. of how successful prevention programmes have been in high-risk populations

Unit 2 Answers

Warm-up questions

1. True or false? Some elements of an STI surveillance system are more important for HIV surveillance activities. Others are more important for STI control programme activities. True. For example, combined STI/HIV behavioural surveillance surveys are important for HIV surveillance, while antimicrobial resistance monitoring is more important for STI control programmes.

2. True or false? STI surveillance data can serve as an indicator of trends in HIV risk behaviours. True. Because STIs and sexually transmitted HIV are transmitted the same way, trends in STI data may reflect similar trends in HIV transmission.

3. True or false? Aetiologic reporting of syphilis (by stage), gonorrhoea, Chlamydia, and congenital syphilis is considered a basic surveillance activity in the South-East Asia Region. False. Aetiologic reporting is only possible where well-developed systems of laboratory diagnosis exist.

4. Which of the following is not a component of an STI surveillance system?
   a. STI universal case reporting
   b. STI sentinel surveillance systems
   c. STI testing and treatment
   d. STI prevalence assessment and monitoring

   While important to controlling the spread of STIs and HIV, treatment of STIs is not a component of STI surveillance activities.

5. True or false? In generalized HIV epidemics, prevalence assessments should include monitoring gonorrhoea and Chlamydia. True. These conditions suggest recent high-risk behaviours.

6. True or false? An STI surveillance system includes conditions that are newly acquired, as well as those that represent past infections. True. This will help to accurately calculate prevalence and incidence.
7. In aetiologic case reporting, STI cases are reported by the specific microbial organism that caused the STI, while in syndromic case reporting, STI cases are reported by the clinical syndrome with which the patient presents. Aetiologic testing requires well-developed laboratory systems and expensive diagnostic tests that are not widely available in the South-East Asia Region.

Case study
You are a surveillance officer in Nodesh, a country in South-East Asia. You have received STI data from Bijarta, a district in Nodesh. Table 2.5 below provides the data. Assume that the population size has not changed between 2000 and 2003.

Table 2.5

<table>
<thead>
<tr>
<th>STI condition</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male urethral discharge</td>
<td>25 292</td>
<td>28 959</td>
<td>29 784</td>
<td>29 859</td>
</tr>
<tr>
<td>Male non-vesicular genital ulcer</td>
<td>6 429</td>
<td>7 983</td>
<td>7 497</td>
<td>7 698</td>
</tr>
<tr>
<td>Female non-vesicular genital ulcer</td>
<td>5 834</td>
<td>6 497</td>
<td>6 306</td>
<td>6 905</td>
</tr>
</tbody>
</table>

a. What do the data suggest about the trends in the incidence and prevalence of these conditions in Bijarta?
There appears to be an increase in the number of cases of each of these STI syndromes. Because they are likely to represent new infections, it is likely that this means an increase in incidence and prevalence of these syndromes. However, this is based on an assumption of stable populations and surveillance practices.

b. What do these data suggest about trends in HIV risk behaviours?
Increases in STIs suggest increases in HIV sexual risk behaviour, such as increases in unprotected sex and/or increases in the number of sexual partners. Increases in these behaviours often correspond to increases in HIV rates.

c. What additional data would you be interested in reviewing to assess burden of STI infection and incidence of STI infection in Bijarta. Why would you be interested?
It would be worthwhile to examine HIV seroprevalence data obtained from the general population (such as from women attending antenatal clinics) as well as from high-risk populations (such as sex workers or truck drivers). If data are available from behavioural surveys of high-risk groups or the general population (as occurs with demographic health surveys), they should be examined. Also, it is always important to understand the extent to which increases in case reports may be due to changes in the population. For this reason census or other population data should be examined. Changes in surveillance practices can affect case reporting. As such, information on surveillance practices should be obtained and interpreted. Similarly, changes in the health-care system need to be understood. These would include changes in the number of health clinics or in the services provided.
Unit 3 Answers

Warm-up questions

1. Which of the following is an advantage of universal STI case reporting?
   
   a. It is relatively easy to collect from health facilities.
   
   b. It provides data on the burden of STIs at the health facility level.
   
   c. Under stable conditions and consistent reporting, data from universal STI case reporting reflect the incidence of STIs in a population.
   
   d. All of the above

2. True or false? Case report data collected from sentinel sites can be generalized to a broader population. **False.** Because sentinel sites are located in only a few health facilities, they are only representative of the populations served by those facilities, and not the broader population.

3. In countries where information about STIs is obtained through a universal case reporting system, sentinel STI case reporting
   
   a. is unnecessary
   
   b. should replace universal case reporting as the primary method to study STIs
   
   c. should supplement information obtained from the universal case reporting system

   The universal reporting system provides data that are applicable to the entire population, so it should be the priority. For more detailed information on a subset of cases, sentinel surveillance can also be used.

4. True or false? Supervision and feedback are easier to provide for a sentinel case reporting system than for a universal system. **True.** Sentinel surveillance involves activities at a smaller number of sites than in a universal system, so supervision and feedback are easier to provide.

Case study

In the nation of Malanka, an STI control programme was set up in 1992. The management of STIs in Panga district, primarily carried out by doctors, nurses or midwives, is based on a syndromic approach. Cases of STIs diagnosed by the syndromic approach were reported irregularly on a monthly basis to the Ministry of Health, National Health Information System (NHIS).

In 1995, in collaboration with the STI control programme, NHIS conducted a two-year pilot test of STI universal case reporting from 850 public community-based clinics and 65 public hospitals covering the 29 districts of the country. The population size of men and women was stable during this time period.

During this two-year pilot test, the NHIS received regular monthly case reporting of genital discharge, genital ulcer and genital warts from the peripheral healthcare providers. Table 3.4 shows the results of this two-year case reporting for 1995-1996 for men and women.
Table 3.4

Number of STI cases and contribution of STI (%) in utilization of healthcare services for each STI syndrome by gender and year, Panga district, 1995-1996

<table>
<thead>
<tr>
<th>STI syndrome</th>
<th>1995</th>
<th></th>
<th>1996</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Urethral discharge</td>
<td>24200</td>
<td>3.6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Vaginal discharge</td>
<td>0</td>
<td>0</td>
<td>54000</td>
<td>6.0</td>
</tr>
<tr>
<td>Genital ulcer</td>
<td>5834</td>
<td>0.8</td>
<td>5800</td>
<td>0.6</td>
</tr>
<tr>
<td>Genital warts</td>
<td>1134</td>
<td>0.2</td>
<td>2700</td>
<td>0.3</td>
</tr>
</tbody>
</table>

a. Based on the scenario:

1. To better understand the situation in Panga, what data elements would you suggest collecting on a reporting form?
   Information on age (age groups would be sufficient), date, and location (health facility, district, and province) should be collected.

2. What are the STI syndromes that give the best information to understand the STI situation?
   The most beneficial STI syndromes to collect would be male urethral discharge and non-vesicular genital ulcer disease in men and women. If the structure of healthcare services, health-seeking behaviour and reporting are consistent, trends in urethral discharge syndrome in men and non-vesicular genital ulcer disease in men and women will reflect trends in incidence in the population. These syndromes may provide a minimum estimate of national STI incidence.

3. Based on the rates of health facility utilization, which syndrome is the most prevalent in Panga?
   The most prevalent STI syndrome is vaginal discharge.

b. How useful are the data on:

   • vaginal discharge in women in determining STI burden and trends?
     Because vaginal discharge in women is much more non-specific than urethral discharge in men and can be due to a wide range of non-sexually transmitted pathogens, it is not useful in determining STI burden and trends.

   • genital warts? Genital warts are a chronic condition and, for this reason, are not useful for understanding trends in STI incidence.

c. Complete Table 3.5 below by calculating the incidence rates in cases per 100 000 of genital ulcer disease for 1995 and 1996 in both men and women.
Table 3.5
Estimated population and incidence of genital ulcer disease by sex and year, Panga district, 1995-1996

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimated population</td>
<td>Incidence*</td>
</tr>
<tr>
<td>1995</td>
<td>926 000</td>
<td>630</td>
</tr>
<tr>
<td>1996</td>
<td>950 000</td>
<td>611</td>
</tr>
</tbody>
</table>

*Incidence: cases per 100 000 per year

Unit 4 Answers

Warm-up questions

1. Match the STI data analysis parameter with its description by putting a letter in each blank:

   Analysis by place c. Analysis to provide information about where clustering of disease might occur.
   Analysis by time b. Analysis to detect if there has been an increase in STI case reports over time.
   Analysis by person a. Analysis of data that shows by age group differences.

2. True or false? Interpretation of STI trends should be made independently from knowledge of how the STI control programmes and the healthcare system operate.
   False. Analysis should consider the context of control programmes and the healthcare system. For example, you should think about possible changes in case definitions or quality of services, changes in staff training or handling of data, etc.

3. District surveillance officers are responsible for:
   a. checking data for inconsistencies (for example, STIs in very old or very young patients)
   b. forward the results to the national level
   c. following up with any health facility site that has missing or inconsistent data
   d. all of the above

   This should be done before data are sent to the national level, in order to ensure the accuracy of the information.

4. List three ways to handle surveillance data so that patient confidentiality is protected. Way to protect patient confidentiality include the following measures: password protected the computer hardware; limit access to as few persons as needed; provide safe cabinets for storing forms that have been entered; lock the cabinets and restrict access to authorized personnel only.
Case study

You are the national STI surveillance officer for Serosia, an Asian country. You rely primarily on syndromic surveillance using a universal reporting system. You have noticed an increase in the number of reported cases of male non-vesicular genital ulcer disease in Northern District, one of the five districts in the country.

Table 4.3

<table>
<thead>
<tr>
<th>District</th>
<th>Year</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td></td>
<td>40</td>
<td>42</td>
<td>38</td>
<td>54</td>
<td>45</td>
<td>38</td>
</tr>
<tr>
<td>Southern</td>
<td></td>
<td>60</td>
<td>70</td>
<td>72</td>
<td>84</td>
<td>65</td>
<td>58</td>
</tr>
<tr>
<td>Central</td>
<td></td>
<td>47</td>
<td>50</td>
<td>42</td>
<td>40</td>
<td>41</td>
<td>39</td>
</tr>
<tr>
<td>Eastern</td>
<td></td>
<td>53</td>
<td>87</td>
<td>76</td>
<td>95</td>
<td>107</td>
<td>197</td>
</tr>
<tr>
<td>Western</td>
<td></td>
<td>49</td>
<td>49</td>
<td>36</td>
<td>72</td>
<td>65</td>
<td>48</td>
</tr>
</tbody>
</table>

a. What are some possible causes of this increase?
   - Improved surveillance
   - Increase in health-seeking behaviour by local population
   - Increase in high-risk sexual behaviour
   - Immigration

The Eastern District is along the border. There is a larger camp for displaced persons immediately across the border. There are rumours that displaced persons have been coming to Eastern District for care since 2002. Reliable figures are unavailable.

b. Could an influx of displaced persons with STI symptoms account for the increase in STI cases in Serosia? Yes.

c. How would you investigate this?
   Do a special study to find out numerators and denominators of non-Serosians (displaced persons) visiting clinics.

You examine all syphilis tests done at the clinic for one month. Because this is a sentinel site for syphilis screening as well, demographic data, including nationality, are available. Table 4.4 shows your findings:

Table 4.4

<table>
<thead>
<tr>
<th>Nationality</th>
<th>Positive syphilis tests</th>
<th>Total tested</th>
<th>Percentage positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serosian</td>
<td>10</td>
<td>1000</td>
<td>1</td>
</tr>
<tr>
<td>Non-Serosian displaced persons</td>
<td>10</td>
<td>100</td>
<td>10</td>
</tr>
</tbody>
</table>
d. Calculate the prevalence among Serosia and non-Serosia persons. How could these data be used for STI control? How could they be used for HIV control?

Potential uses of these STI data include:

- estimating the quantity and types of drugs that are required for treatment of current and future STI cases
- developing focused interventions
- advocating for resources for STI care

Unit 5 Answers

Warm-up questions

1. Prevalence assessment is the determination of prevalence among persons screened in defined populations, while prevalence monitoring is the determination of trends in prevalence over time. Prevalence assessment is similar to HIV seroprevalence surveys, and includes collecting blood or urine for identification of STIs as well as demographic information about the person tested.

2. True or false? STI prevalence data that show high rates of STIs are used to identify population sub-groups at high risk for HIV infection. True. Because STIs and sexually transmitted HIV are similarly transmitted, and because STIs make the spread of HIV more likely, sub-groups with a high prevalence of STIs will also be at high risk for HIV infection.

3. List two purposes of STI prevalence assessment and monitoring.
   a. to identify population sub-groups with high prevalence of STIs
   b. to monitor trends in STI prevalence among defined populations
   c. to use as components of studies.

4. In an STI prevalence survey of the general population, which STIs would you test for? You should test for asymptomatic STIs, such as gonorrhoea, Chlamydia, syphilis, etc. These assessments almost always include HIV testing also.

5. True or false? STI prevalence data are useful for monitoring the effectiveness of HIV prevention programmes. True. Especially when combined with behavioural surveys, STI prevalence data can help monitor the effectiveness of HIV prevention programmes. This is because STIs and HIV are transmitted through similar routes. Therefore, those who have STIs are also at high risk of acquiring sexually transmitted HIV.

6. What does X represent in the equation below?
   a. total number of patients who test negative for a specific disease
   b. total number of patients who test positive for all priority diseases
   c. total number of patients tested

   \[
   \text{Prevalence} = \frac{\text{total number of patients who test positive for a specific disease}}{X}
   \]

   This equation estimates the prevalence (that is, the proportion of people in a particular population who have a specific disease).
Case study

Exercise 1

You work in an STI clinic in a brothel complex that serves about 1000 female sex workers. You conducted syphilis screening and treatment for female sex workers at the clinic every quarter as part of the intervention and monitoring activities. Table 5.1 shows the results of this STI screening and treatment programme in this high-risk population.

Table 5.1

Number of female sex workers participating in the screening and treatment programme and number with positive syphilis serologies (RPR >1:8) by quarter and age groups

<table>
<thead>
<tr>
<th>Age Group</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>3</td>
<td>54</td>
<td>4</td>
<td>59</td>
</tr>
<tr>
<td>15-19</td>
<td>4</td>
<td>52</td>
<td>4</td>
<td>60</td>
</tr>
<tr>
<td>20-24</td>
<td>8</td>
<td>80</td>
<td>9</td>
<td>88</td>
</tr>
<tr>
<td>25-29</td>
<td>9</td>
<td>78</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td>30-34</td>
<td>7</td>
<td>52</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>&gt;34</td>
<td>7</td>
<td>41</td>
<td>7</td>
<td>45</td>
</tr>
</tbody>
</table>

a. Complete the age-specific prevalence of syphilis seroreactivity by quarter in Table 5.2.

• Does the trend in age-specific prevalence levels support your belief that you collected good quality data?

• Why is the prevalence of reactive syphilis serologies higher among older women?

• Compute test positivity of syphilis for the one-year period. What is the main use of this information?
Table 5.2
Prevalence of syphilis among female sex workers participating in the screening and treatment programme and number with positive syphilis serologies (RPR >1:8) by quarter and age groups

<table>
<thead>
<tr>
<th>Age group</th>
<th>Quarter I</th>
<th>Quarter II</th>
<th>Quarter III</th>
<th>Quarter IV</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>5.6%</td>
<td>6.8%</td>
<td>4.8%</td>
<td>1.6%</td>
<td>4.7%</td>
</tr>
<tr>
<td>15-19</td>
<td>7.7%</td>
<td>6.7%</td>
<td>6.3%</td>
<td>4.4%</td>
<td>6.0%</td>
</tr>
<tr>
<td>20-24</td>
<td>10.0%</td>
<td>10.2%</td>
<td>7.8%</td>
<td>6.3%</td>
<td>9.6%</td>
</tr>
<tr>
<td>25-29</td>
<td>11.5%</td>
<td>11.0%</td>
<td>9.3%</td>
<td>7.8%</td>
<td>9.8%</td>
</tr>
<tr>
<td>30-34</td>
<td>13.5%</td>
<td>12.0%</td>
<td>11.7%</td>
<td>9.7%</td>
<td>11.6%</td>
</tr>
<tr>
<td>&gt;34</td>
<td>17.1%</td>
<td>15.6%</td>
<td>13.5%</td>
<td>11.1%</td>
<td>14.0%</td>
</tr>
<tr>
<td>Total</td>
<td>12.4%</td>
<td>10.2%</td>
<td>8.7%</td>
<td>6.7%</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

- The increasing trend of syphilis seropositivity by age groups supports the belief that the quality of laboratory (RPR test) data may be good.

- The prevalence of syphilis seropositivity in older groups is higher than in younger groups due to several factors
  - Longer exposure to syphilis infections for older groups.
  - Syphilis seropositivity (RPR) remains positive unless adequate treatment is given.
  - Even with adequate treatment about 10-30% remain positive (serofast reaction).

- Lower condom use in older female sex workers than in younger sex workers. Older sex workers often have less room for condom use negotiation with their clients because they are less desirable.

Test positivity in one year = total number of positive tests divided by total number of valid tests during one year period = 142/1585x100%= 9.0%. These numbers are useful for programme planning and management.

b. There is a downward trend of STI prevalence over time that you can say is attributable to your intervention programme (condom promotion and screening and treatment of STIs).

- List other possible reasons for this downward trend of STI prevalence in this clinic population.

Possible reasons for this down trend of STI prevalence include:

- Changing health-seeking behaviour of the clinic population. Those at high-risk for STIs would seek screening and treatment somewhere else
- Changing of case definition of STI or laboratory test used in the diagnosis
- Changes in the mobility of the clinic populations (for example, more sex workers with low risk for STI move into the site where the clinic is located)
• What other information do you need to collect to support your belief that this downward trend is due to your intervention?

In CSW, measure:

Exposure of CSW to programme
Uptake of condoms
STI recognition and treatment seeking
If CSW are seeking treatment elsewhere

Unit 6 Answers

Warm-up questions
1. For countries where syndromic STI case reporting is used, syndrome aetiologies should be reassessed every _______ years.
   a. one to two
   b. two to three
   c. three to four

   This is the average amount of time. If, however, there is a new outbreak of a particular syndrome (such as genital ulcer disease), you should reassess earlier.

2. True or false? Monitoring antimicrobial resistance of *N. gonorrhoeae* may help to detect newly emerging resistance. True.

3. Choose an item below that is not one of the main purposes of assessing syndrome aetiologies:
   a. provide data for guiding STI syndromic management
   b. assess effectiveness of HIV prevention programmes
   c. assist in the interpretation of syndromic case reports
   d. assist in the assessment of disease burden caused by specific pathogens
   e. evaluate syndromic management algorithms for urethral discharge and genital ulcers

   Assessing syndrome aetiologies helps to identify the particular microbes that are causing urethral discharge and genital ulcer disease. This information is not helpful in evaluating HIV prevention programmes.

4. List two possible uses for data obtained from monitoring antimicrobial resistance of STI pathogens. Two of the main uses for data obtained through monitoring antimicrobial resistance include: acquiring the data necessary for developing and revising treatment guidelines; and detecting newly emerging resistance.

5. Which of the following sampling strategies is the most difficult to use when conducting antimicrobial resistance monitoring?
   a. random
   b. systematic
c. consecutive

A random sample involves a complicated sampling scheme that, while providing the most representative sample (because each patient has an equal chance of being selected), is too difficult and expensive to conduct for resistance monitoring.

6. True or false? Undertaking a combined STI/HIV and behavioural survey can identify population sub-groups at high risk for HIV infection.

   True   False

True. One of the goals of combined prevalence assessment and behavioural surveys is to identify population sub-groups at high risk for infection. Population sub-groups are groups within a population that share certain characteristics or behaviours.

7. True or false? The choice of which STI to include in a behavioural survey is made independently of the type of population to be studied.

   True   False

False. When choosing which STI to test for, you should consider the laboratory infrastructure development in the country as well as the type of population you are studying.

8. True or false? Combining HIV/STI surveillance and behavioural surveys is more cost-effective than conducting the two surveys separately.

   True   False

True. Combining HIV/STI prevalence assessments with behavioural surveillance surveys is more cost-effective than conducting separate surveys. The combined surveys reduce personnel costs and time.

Case study

You are the HIV/STI surveillance coordinator in a health district in Malanka, a South-East Asian country. STIs in your country are routinely managed and reported using the WHO syndromic approach. The national STI control programme will be conducting a national assessment of antimicrobial resistance in N. gonorrhoeae. Your district, Topinigar, has been asked to participate.

a. What are the reasons for conducting an assessment of antimicrobial resistant N. gonorrhoeae?

You should understand that in those regions in which STI treatment is done using the syndromic approach, verification that N. gonorrhoeae is sensitive to the antimicrobial agent recommended in syndromic treatment is necessary, for treatment to be effective. Events that prompt assessment include reports on clinical failure of the treatment
for gonococcal infection and increased resistance in the neighbouring countries or regions.

b. What factors will you need to consider in order to conduct this assessment in your district?

Factors that should be mentioned include:

1) what site/populations to collect specimens from and identify the commonly used antimicrobial for the treatment of gonorrhoea in this population
2) prevalence of syndromes related to N. gonorrhoeae infection (that is, urethral discharge) and sample size of N. gonorrhoeae isolates,
3) laboratory tests to be used (that is, laboratory methods to culture N. gonorrhoeae and measure the antimicrobial resistance for N. gonorrhoeae such as agar dilution and E-test)
4) data management
5) interpretation of the data (it would be useful to obtain information on the clinical failure of gonorrhoea treatment to supplement the information collected from this in-vitro study)

c. How would you select your sample?

Systematic sampling is preferable to consecutive sampling because it is a probabilistic sampling scheme that produces a random sample. However, it requires a large number of high-risk populations to collect a sufficient number of N. gonorrhoeae isolates. If a large number of high-risk populations could not be easily obtained, consecutive sampling is sufficient.

To increase yield in detecting N. gonorrhoeae by culture in urethral and cervical specimens, only consecutive men and women with symptoms will be recruited. For selecting urethral samples from men, it is more efficient to perform a Gram stain of urethral discharge prior to culture. Only those men whose Gram stain indicates the presence of Gram-negative intracellular diplococci should be cultured.

d. Given the results in Figure 6.3, what recommendations would you make regarding the treatment of N. gonorrhoeae in Malanka?

The treatment recommendations should be changed to one of the following antimicrobial agents: ceftriaxone, ciprofloxacin, or cefixime. Because ciprofloxacin is the most inexpensive drug of the three and is given in a single oral dose, the national recommendation for the treatment of uncomplicated gonococcal infection should be ciprofloxacin. Because about 18% of the isolates are resistant to Spectinomycin, this antimicrobial should not be used as the alternative treatment for gonococcal infection. Continue to conduct surveillance for antimicrobial resistance.
Note: There are no real ‘answers’ to this exercise. The purpose is to think through what you might do and share your thoughts with other participants.

Your country has a concentrated HIV epidemic and high rates of other STIs, demonstrated through STI case reporting. Last year, an aid agency announced its interest in conducting a demographic and health survey of rural and urban areas. You were contacted by the provincial HIV/AIDS surveillance officer because he has decided to work with this agency to add STI testing to the HIV and behavioural survey in your province. He is asking you and the other district surveillance coordinators for your input into the survey design.

a. Which populations would you like to include in the survey in your district? Why?

b. Which STIs would you test for in addition to HIV? Why?

c. In addition to the demographic questions that the aid agency will routinely ask in the survey, what additional questions on STI/HIV risk behaviours would you want to include?
This training module describes the interaction between HIV infection and sexually transmitted infections (STIs) and describes how to develop and operate systems for STI surveillance. After completing this course, participants should:

- understand the inter-relationship between HIV and STIs
- be able to explain the difference between aetiologic and syndromic case reporting
- understand the advantages and disadvantages of STI universal case reporting and sentinel surveillance and when each should be implemented
- know how to ensure confidentiality when collecting, archiving and reporting STI data
- be able to identify the STIs most suitable for inclusion in combined STI/HIV biological and behavioural surveillance.

This course is meant primarily for district-level surveillance officers. This module can also be used for self-study.
Module 5

Surveillance of HIV Risk Behaviours

Participant Manual

2007
Other HIV surveillance training modules of this series

*Module 1* - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual

*Module 2* - HIV clinical staging and case reporting: participant manual

*Module 3* - HIV serosurveillance: participant manual

*Module 4* - Surveillance for sexually transmitted infections: participant manual

*Module 6* - Surveillance of populations at high risk for HIV transmission

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**Bangladesh:** Dr Motiur Rahman, Associate Scientist & Head of RTI/STI Laboratory, ICDDR, B; Dr Md Hanif Uddin, Deputy Programme Manager, National AIDS/STD Programme; Dr Khondoker Mahbuba Jamil, Senior Scientific Officer, Department of Virology, Institute of Epidemiology, Disease Control and Research;

**Bhutan:** Ms Neyzang Wangmo, Associate Lecturer of Royal Institute of Health Sciences

**China:** Ms Wang Lan, National Center for AIDS/STD Control and Prevention;

**Cambodia:** Dr Ly Penh Sun, Deputy Director, National Center for HIV/AIDS, Dermatology and STD.

**India:** Dr Shashi Kant, Additional Professor, Centre for Community Medicine, All India Institute of Medical Sciences (AIIMS); Dr A.S. Rathore, Joint Director (Training), National AIDS Control Organisation; Dr B.S.N. Reddy, Head, Dermatology Department, Maulana Azad Medical College; Dr Madhulekha Bhattacharya, Professor and Head Department of CHA National Institute of Health & Family Welfare; Dr Jagadeeshan, Tamil Nadu State AIDS Control Society.

**Indonesia:** Ms Naning Nugrahini, Technical Officer for STI and Surveillance, Monitoring and Evaluation, Directorate of Direct Transmitted Disease Control; Dr Dicky Budiman, Sub-Directorate of AIDS & STI; Dr Dyah Erti Mustikawati, Head of Section for Evaluation and Reporting, Sub-Directorate of AIDS/STI.

**Maldives:** Mr Mohammed Rameez, Programme Coordinator, Department of Public Health.

**Myanmar:** Dr Min Thwe, National AIDS Programme Manager, Ministry of Health, Government of the Union of Myanmar; Dr Tun Myint, Divisional AIDS Officer, Mandalay AIDS/STD Prevention and Control Programme; Dr Htay Naing, Medical Officer, National AIDS Control Programme.

**Nepal:** Dr K. N. Thakur, Dermatologist, Koshi Zonal Hospital; Dr Devi Prasad Bhusal, Teku Hospital.

**Srilanka:** Dr N. Punchihewa, National STD/AIDS Control Programme; Dr K.A.M. Ariyaratne, National STD/AIDS Control Programme; Dr Sriyakanthi Beneragama, Epidemiologist, National STD/AIDS Control Programme.

**Thailand:** Ms Thanapan Fongsiri, AIDS Cluster, Bureau of AIDS, TB and STI, Department of Disease Control, Ministry of Public Health; Dr Tanarak Plipat, Medical Officer, Head of HIV, TB and STD Surveillance Section, Bureau of Epidemiology, Department of Disease Control.
Control, Ministry of Public Health; Mr Surasak Thanaisawanyangkoon, Health Technical Officer, Bureau of AIDS, TB and STIs, Ministry of Public Health; Mrs Mattana Herber, Health Technical Officer, Office of Disease Prevention and Control;

**Timor-Leste:** Mr Virgilio Soares, HIV/AIDS Officer, Ministry of Health.

**Vietnam:** Dr Phan Thi Thu Huong, Deputy Head of HIV/AIDS/STI Surveillance, Vietnam Administration of HIV/AIDS Control (VAAC).

United States Department of Health and Human Services, Centers for Disease Control and Prevention (HHS-CDC), Global AIDS Program (GAP) Surveillance Team.

University of California at San Francisco (UCSF), Institute for Global Health, AIDS Research Institute through the University Technical Assistance Program (UTAP) with CDC/GAP.

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AIDS Institute of Family Health International, USA
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How to Study this Module

What you should know before the course
This course is meant primarily for those involved in the planning and implementation of behavioural surveillance. As a participant, you should understand the basic epidemiology of HIV/AIDS and public health surveillance.

Module structure
The module is divided into units. The units are convenient blocks of material for a single study session.

This module can also be used for self-study.

Because you already know quite a bit about HIV/AIDS, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answer may just be a guess. Answer the questions as best you can.

You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions. You can then check your work.

As you study this module, you may come across italicized terms that are unfamiliar. In Appendix B, you will find a glossary that defines these words.

Summary
The HIV/AIDS epidemic continues to grow worldwide and to have a devastating impact on individuals, communities and entire countries and regions. Behavioural surveillance measures trends in the behaviours that can lead to HIV infection and has been shown to make an important and useful contribution to informing national responses to HIV. Conducting behavioural surveillance requires coordination among many partners and multiple skills. Although there are many useful reference materials available for behavioural surveillance, there has not yet been a comprehensive effort to train or improve the capacity of in-country surveillance teams. This module aims to help reduce this training gap.

Appendices
More information is provided:

Appendix A: References and Further Reading Material

Appendix B: Glossary and Acronyms

Appendix C: Answers to Warm-Up Questions and Case Studies
Additions, Corrections, Suggestions

Do you want to suggest changes in this module? Is there other information you would like to see? Please email us. We will collect your letters and emails and consider your comments in the next update to this module.

Address

HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House,
Indraprastha Estate
Mahatama Gandhi Marg
New Delhi 110 002, India
Email: hiv@searo.who.int
Fax: 91 11 23370197
Overview

What this unit is about
In this unit, you will learn basic information about surveillance, its purpose, history and key considerations.

Warm-up questions
1. True or false? One-time cross-sectional surveys can be considered surveillance.
   - True
   - False

2. __________ surveillance involves regular, repeated cross-sectional surveys collecting data that can be compared over time on HIV risk behaviours and other relevant issues.
   - Behavioural
   - Biological

3. Which of the following can be a use of behavioural surveillance?
   - to explain changes in HIV prevalence over time
   - to provide information for prevention programmes
   - to raise the awareness of HIV among policy-makers
   - to provide an early warning of which groups and areas infection is likely to spread in and between
   - all of the above

4. True or false? Surveillance is a useful tool for evaluating specific HIV/AIDS interventions.
   - True
   - False

5. True or false? In a generalized epidemic everyone is at equal risk of infection.
   - True
   - False

6. _________ sites are facilities such as STD clinics, antenatal care clinics, blood donation centres, drug treatment programmes, prisons and needle exchange programmes.
   - Sentinel
   - Community

7. Which of the following is the definition of linking behavioural and biological data?
   - collecting HIV, STI and behavioural data from the same individuals at the same time
   - collecting HIV, STI and behavioural data from the same source population at different times
c. analysing HIV, STI and behavioural data from similar source population, using whatever data are available
d. reporting behavioural and biological surveillance together
e. all of the above

8. Collecting _________ level data provides more detailed information but requires larger sample sizes and thus more time and money.
   a. national
   b. sub-national

Introduction

What you will learn

By the end of this unit, you should be able to:

• define surveillance;
• outline the uses of behavioural surveillance;
• outline issues to consider when designing a surveillance system;
• outline the steps required to achieve a sustainable surveillance system.

Surveillance is the systematic, regular and ongoing collection and use of data for public health action. Although they are often the beginning of a surveillance system, one-time cross sectional surveys should not be considered as surveillance. HIV/AIDS surveillance can be divided into biological and behavioural surveillance.

Behavioural surveillance involves regular, repeated cross-sectional surveys collecting data on HIV risk behaviours and other relevant issues that can be compared over time.

Biological surveillance also involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses such as STIs and TB.

Cross-sectional surveys collect information from a selected sample of a target population at one point in time or over a short period of time. In surveillance, the same survey or a similar survey is repeated with the same target population (but a different sample of people) at regular intervals. This enables us to explore behavioural changes over time.

Uses of behavioural surveillance

Uses of behavioural surveillance include the following:

• To provide an early warning of which groups and areas infection is likely to spread in and between.
• To explain changes in HIV prevalence over time - without behavioural data, biological surveillance data are difficult to interpret. For example:
  • Does a stable or falling HIV prevalence mean there are fewer new infections? More deaths? Or that the population being tested has changed over time?
• Does a rising HIV prevalence mean prevention programmes are failing? That life expectancy is increasing because of treatment programmes?
• That the epidemic has not reached the stage when people are dying? Or that the testing population has changed over time?

• To provide information for developing prevention programmes - measuring the prevalence of HIV alone does not provide all the information needed to design effective policy and programmes. Behavioural data allows us to identify the populations and behaviours that are driving the epidemic and that should be targeted in programmes.

Note: surveillance does not provide much information about how to target the groups and behaviours. That requires purposely designed research.

• To monitor and evaluate the impact of prevention programmes. Surveillance can be a useful tool for monitoring and evaluating HIV/AIDS prevention programmes that target the populations or the geographical areas included in surveillance. The national monitoring and evaluation strategies for HIV/AIDS should, therefore, incorporate indicators derived from behavioural surveillance data. However:
  • Without adaptation, surveillance only provides evidence for the impact of HIV programmes as a whole and not for the impact of specific interventions or specific programme elements. Although surveillance can be adapted to evaluate specific interventions (by adding questions relating to exposure to the specific interventions) this must be done with care. This ensures that the focus of surveillance is not deflected away from detecting and measuring risk behaviours.
  • While surveillance is useful for evaluating programmes, like most evaluation methods, it does not provide conclusive evidence that the programme caused any observed changes in behaviour. Any observed change may have occurred even without the programme because of some other factor.

• To reinforce the findings of biological surveillance.
• To raise the awareness of HIV among policy-makers.

Designing a Behavioural Surveillance System
When designing a behavioural surveillance system, you should consider:

• whom to include in surveillance;
• where to access the surveillance populations;
• how to link biological and behavioural surveillance data;
• how to ensure that surveillance is appropriate for the context.

Whom to include
The current guidelines about whom to include in surveillance differ according to the state of the epidemic a country is in. Epidemics can be broadly classified into low-grade, concentrated and generalized epidemics.

• Low-level: Prevalence of HIV is consistently below 5% in any "high-risk groups" and below 1% in the "general population."
• **Concentrated:** Prevalence of HIV has surpassed 5% on a consistent basis in one or more "high-risk groups," but remains below 1% in the "general population."
• **Generalized:** Prevalence of HIV has surpassed 1% in the "general population."

The general guidelines for whom to include in surveillance for each epidemic state are shown in Table 1.1.

<table>
<thead>
<tr>
<th>State of the epidemic</th>
<th>Biological surveillance (annually if feasible)</th>
<th>Behavioural surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-level</td>
<td>High-risk groups</td>
<td>High-risk groups annually, general population every 3-5 years</td>
</tr>
<tr>
<td>Concentrated</td>
<td>High-risk groups, general population</td>
<td>High-risk groups annually, general population every 3-5 years</td>
</tr>
<tr>
<td>Generalized</td>
<td>High-risk groups, general population</td>
<td>High-risk groups annually, general population annually</td>
</tr>
</tbody>
</table>

**General population surveillance** measures HIV risk behaviours in a sample of people selected to represent the people living in a region or nation. The surveillance can be restricted to certain ages (for example, young people 15-24 years old) or genders.

**High-risk group surveillance** measures HIV risk behaviours in groups whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic.

Common high-risk groups considered for inclusion in behavioural surveillance are shown in Table 1.2.

<table>
<thead>
<tr>
<th>High-risk groups often considered for inclusion in behavioural surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• injecting drug users</td>
</tr>
<tr>
<td>• university students</td>
</tr>
<tr>
<td>• sex workers and their clients, for example, truck drivers or mine workers</td>
</tr>
<tr>
<td>• men who have sex with other men</td>
</tr>
<tr>
<td>• uniformed personnel (police, border personnel and military)</td>
</tr>
<tr>
<td>• migrant labourers</td>
</tr>
<tr>
<td>• young people</td>
</tr>
</tbody>
</table>

**Why include these groups?**
Here are two frequent questions asked about surveillance:

• Why should we do general population surveillance in concentrated epidemics, where the general population is at low risk?
• Why should we do high-risk group surveillance in generalized epidemics, where the whole population is at high-risk?
What are your thoughts on this?

**High-risk group surveillance in a generalized epidemic:** In a generalized epidemic, we need to conduct surveillance in sub-populations where HIV is concentrated. We also need to include their partners, because even in a generalized epidemic, not everyone in the population is at equal risk of HIV, or has an equal role in the spread or maintenance of the epidemic. The behaviours of these sub-populations may continue to drive a generalized epidemic and are therefore important to monitor and to target for interventions.

**General population surveillance in a concentrated epidemic:** In a concentrated epidemic, general population surveillance helps us understand the potential for HIV to spread beyond the groups where it is concentrated. Therefore, the surveillance acts as an early warning system by allowing us to explore the:

- size of the sub-populations in which HIV is concentrated;
- links (bridges) between the sub-populations and their partners and the ‘general’ population;
- level of risk behaviours in the ‘general’ population.

The need for general population surveillance in low-level epidemics remains controversial, as some people argue that it is not cost-effective to set up large-scale general population surveys in low-level epidemics. However, this shouldn’t prevent countries from conducting intermittent surveys.

**Where to access groups**

The populations included in surveillance can be accessed either in ‘sentinel sites’ or in the community.

*Sentinel sites* are facilities such as STI clinics, antenatal care clinics, blood donation centres, drug treatment programmes, prisons and needle exchange programmes. *Community sites* are locations in the community, such as households or brothels.

Sentinel surveillance was initially used in the 1990s, when surveillance relating to HIV/AIDS was in its early stages and focused on unlinked anonymous blood testing. Sentinel surveillance is often more convenient, cheaper and has fewer ethical implications than population-based surveillance. The main drawback of sentinel surveillance is that we do not know who the people identified through the sentinel sites represent or how they change over time. All we know is that these are people who come into contact with the sites. In contrast, when community-based surveillance uses rigorous sampling techniques, the people whom the sample represents can be clearly defined.

Note: Using antenatal clinics as sentinel sites is less problematic, as women attending antenatal care are considered to be a reasonable proxy for the general population.

In *unlinked anonymous testing*, a sample of blood originally collected for other purposes is tested for HIV. The person whose blood is taken does not know that his or her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to that person.
How to link biological and surveillance data

We have already discussed the importance of behavioural data for the interpretation of biological data over time. To ensure data are complementary and useful, behavioural and biological surveillance are best planned together.

When you are planning, decide how behavioural and biological data are best linked. This can be difficult. Linking means different things to different people. It may mean:

- collecting HIV, STI and behavioural data from the same individuals at the same time;
- collecting HIV, STI and behavioural data from the same source population at different times;
- analysing HIV, STI and behavioural data from similar source populations, using whatever data are available;
- reporting behavioural and biological surveillance together.

There are advantages and disadvantages for each type of linking. The decision on how data are best linked should be country-specific. At the very least, behavioural and biological surveillance should be presented in a single report. Table 1.3 outlines the advantages and disadvantages of each type of linking.

Whatever type of linking a country selects, linking should be done for trends over time rather than for one point in time. This is because behavioural and biological data linked at one point in time are impossible to interpret because of the temporal relationship between HIV and risk behaviours. Recent risk behaviours are not necessarily related to HIV status, as infection may have occurred some time ago. The relationship between behaviours and STIs may also be unclear.

Table 1.3
Summary of the advantages and disadvantages of different types of linking behavioural and biological data

<table>
<thead>
<tr>
<th>Type of linking</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| Collect data from same individuals | - Helps in understanding biological data over time and ensures behavioural and biological samples are alike.  
- Behavioural and biological data can be used to reinforce each other’s findings.  
- Can be cheaper if data collection activities are combined.  
- More convenient, especially where access is an issue.  
- Blood draw and longer interviews may increase refusal rates.  
- Required frequency, sample size and sampling strategies (for example, sentinel sites versus community sampling) may differ for biological and behavioural surveillance.  
- Difficult to find fieldworkers with the skills for both behavioural and biological data collection. |
### How to ensure surveillance is appropriate

There is no one-size-fits-all way of designing a surveillance system. The surveillance system needs to be designed to fit the specific features of your country’s epidemic and health system. The things that we discuss in this training are not “rules.” Everything will need adaptation to fit the needs and contexts of each country.

---

<table>
<thead>
<tr>
<th>Collect data from same source population</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps in understanding biological results over time, samples likely to be similar.</td>
<td>Temporal relationship between behaviour and HIV/AIDS/STI makes individual analysis difficult.</td>
</tr>
<tr>
<td>Behavioural and biological data can be used to reinforce each other’s findings.</td>
<td>No guarantee that behavioural and biological surveillance samples are alike.</td>
</tr>
<tr>
<td>No need to compromise on fieldworker skills, frequency of surveillance, sample size or sampling strategies.</td>
<td>No savings in cost or convenience.</td>
</tr>
<tr>
<td>Refusal rate for behavioural surveillance not increased by blood being drawn for biological surveillance.</td>
<td>Community disrupted more than once.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Analyse data for similar population</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps in understanding biological results over time.</td>
<td>Temporal relationship between behaviour and HIV/AIDS/STI makes individual analysis difficult.</td>
</tr>
<tr>
<td>Behavioural and biological data can be used to reinforce each other’s findings.</td>
<td>Using different source populations means that behavioural and biological surveillance samples may not be alike.</td>
</tr>
<tr>
<td>No need to compromise on fieldworker skills, frequency of surveillance, sample size or sampling strategies.</td>
<td>No savings in cost or convenience.</td>
</tr>
<tr>
<td>Refusal rate for behavioural surveillance not increased by blood being drawn for biological surveillance.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Produce a joint report</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides data users with all the information they need in one document.</td>
<td>Unlikely that the populations are similar so no integrated analysis.</td>
</tr>
<tr>
<td>No need to compromise on fieldworker skills, frequency of surveillance, sample size or sampling strategies.</td>
<td>No savings in cost or convenience.</td>
</tr>
<tr>
<td>Refusal rate for behavioural surveillance not increased by blood being drawn for biological surveillance.</td>
<td>Behavioural data adds little to understanding the findings of biological surveillance.</td>
</tr>
</tbody>
</table>

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(Table 1.3 Contd.)
Steps in Conducting Behavioural Surveillance

This section introduces the steps in conducting behavioural surveillance. You will learn how the different aspects of behavioural surveillance feed into each other and understand an overview of the whole surveillance process.

When you are conducting behavioural surveillance, follow these steps:

1. Identify a coordinating body.
2. Agree on the purpose of surveillance.
3. Establish criteria for selecting populations and geographic coverage areas.
4. Gather information to help with the decision about populations and geographic locations and to guide survey implementation.
5. Finalize selection of sub-populations and geographic locations for surveillance.
6. Develop a sampling design.
7. Develop survey protocol.
8. Build a sampling frame.
9. Conduct surveillance.
10. Analyse and use data.
11. Plan for next round of surveillance.

Identify a coordinating body

The purpose of the surveillance coordinating body is to provide guidance and serve as an overall decision-making committee for the surveillance system. Examples of the responsibilities of a surveillance coordinating committee include:

- defining the purpose of surveillance;
- ensuring the surveillance system is set up to meet the data needs of the country;
- identifying funding sources;
- advocating to policy-makers and stakeholders about the importance of surveillance;
- facilitating coordination between surveillance partners;
- making final decisions about the populations and geographical areas included in surveillance;
- monitoring the progress of the surveillance process;
- providing input into data interpretation and conclusions;
- maximizing data dissemination and use.

Surveillance committees may already exist in countries, but may not include all the key players or may not function appropriately. Who should be included on the committee depends on each country’s needs and experiences. Ideally, the ministry of health or national AIDS control programme should convene committees. The committees should include the various national and international bodies whose interests are served by the surveillance system, such as representatives from:

- key government ministries
- multilateral agencies
- donor agencies
- local and/or international NGOs
• members of the target population/NGOs that represent them
• agencies selected to implement surveillance

Agree on the purpose
The first task of the surveillance committee is to agree on the purpose of surveillance (outlined earlier in this module) and establish the data needs of the country.

While it is clear that consensus and coordination are important, they are often difficult to achieve, as stakeholders can have different ideas about the purpose and practicality of surveillance.

Ensuring consensus involves regular meetings and discussions among many organizations, which can be difficult to coordinate. The government should play a central role in this process.

Establish criteria for selections
Before each round of surveillance, the surveillance populations and geographical areas should be reassessed. New groups may need to be phased in if new risk groups emerge or surveillance capacity increases. Old groups may need to be phased out if data being collected from them is not useful. This should be done using set criteria:

• **Criteria for selecting populations:** The selection of surveillance populations should be based on a solid understanding of the epidemic dynamics in a country. The selected populations should be useful for monitoring and tracking the future course of the epidemic. It is not sufficient to select surveillance populations through anecdotal evidence. Often, stakeholders want to include their priority groups (for example, in order to evaluate their own interventions) or because of political pressure to include or exclude groups (for example, a government may not want to acknowledge intravenous drug use as a problem).

• **Criteria for selecting geographical coverage areas:** The geographical coverage area of surveillance should be determined based on what areas of the country and what levels of data will be most meaningful in understanding the epidemic. The main criteria for selecting geographical coverage areas are whether data is required at a national or sub-national level.

Note on national versus sub-national estimations: National level data provide estimates for the whole country. Sub-national level data provide more detailed information about different epidemics in different regions/provinces. When making decisions about geographical coverage areas, it is important to remember that you can carefully aggregate provincial figures up to get a quasi national figure, but you can rarely disaggregate a national number to get details at the provincial level. The downside of collecting sub-national level data is that it requires larger sample sizes and thus more time and money.

Gather information
Once the criteria for selecting populations and geographical areas have been established, it is time to actually make the selection. Begin the process by assessing what is currently known about the national epidemic by reviewing previous research. Once this review
has been completed and a list of potential sub-populations and geographical hotspots has been completed, a series of field assessments is required to find out:

- whether members of the proposed sub-populations do in fact engage in risky behaviours;
- whether members of the population exist in sufficient numbers to merit inclusion in the surveillance system;
- how and where members of the sub-population can be assessed and sampled in a systematic fashion;
- how the sub-population can be operationally defined and what the eligibility criteria for inclusion in surveillance should be;
- the general willingness of potential respondents to participate in surveillance surveys.

Finalize selections
All the information collected in the review of previous research and in the field assessments needs to be synthesized for final population and geographic selection by the surveillance coordinating committee.

Develop sampling design
Because we usually cannot interview all members of our chosen populations, we sample individuals and interview them. There are several ways of sampling individuals, and the most appropriate way of ensuring that unbiased and precise estimates are obtained depends on the characteristics of the population of interest.

Develop a survey protocol
Formulating and documenting the surveillance protocol is essential for the collection of high quality data that meets the needs of the country. Writing the protocol is an essential part of pre-surveillance planning. It helps to clarify the aims of the surveillance system and ensures that all of the elements of surveillance are thought out and planned for. The elements that should be included in the surveillance protocol are shown in Table 1.4.

For example, data analysis and data use are sometimes only considered once data collection is completed, but planning for these at the start of the surveillance process is the only way to ensure that appropriate data is collected and that data are used in a timely and effective manner.

Protocols also ensure that the surveillance procedures are documented so the system can use consistent methodologies and produce comparable trend data, regardless of changes in personnel between data collection rounds.
Table 1.4
Elements of a behavioural surveillance protocol

1. A brief description of the HIV/AIDS situation in the country and of the existing surveillance system
2. The objectives of the surveillance system, including how surveillance is integrated into the national monitoring and evaluation strategic plan
3. A justification of the selection of sub-populations and geographic locations for surveillance and the frequency with which the surveillance will take place
4. A description of the methodologies to be used:
   • operational definitions of the target population
   • key indicators
   • sampling approach for each target population
   • sample size calculations for each target population
   • development and validation of tools and instruments
   • selection and training of interviewers, supervisors, data entry clerks, etc.
   • data collection procedures
   • quality control
5. A data management and data analysis plan
6. The report writing and dissemination strategy and a description of how the data are expected to be used
7. A discussion of ethical considerations
8. The roles and responsibilities of collaborating partners
9. The timeline
10. The budget and available resources

Build sampling frame
Some sampling approaches require a list of units, or sampling frame, from which the sample is selected. If a sampling frame is required, it is usually necessary to map or enumerate the population of interest.

Conduct surveillance
The next step is to actually carry out the surveillance protocol. If elements of the protocol are changed during implementation, this should be documented. This ensures that data collected at the next round can be collected in a comparable manner.

As the protocol is implemented, it can be useful to collect information from fieldworkers and supervisors regarding problems they encountered during data collection and potential solutions so data collection can be improved for the next round.

Analyse and use data
An analysis plan should have been completed prior to data collection. This should include identifying personnel with appropriate data management, cleaning and analysis
skills, identifying software, defining indicators and making mock-ups of key tables and graphs. This planning helps ensure that all the required data and no unnecessary data are collected. It also helps ensure that data are analysed appropriately and are ready for dissemination in a timely manner.

Data collection and analysis is only half the battle. There is little point in collecting data that is useful but not used. Getting the data used requires that it be presented to the different users in a timely way that is easy for them to understand and interpret. As much time and planning should go into dissemination of data as into planning and conducting data collection. The results of surveillance should be shared at the national, regional and district level.

**Plan for next round**

Although the surveillance steps have been presented as if they are linear, the process should be viewed as a cycle. The purpose of surveillance is to collect trend data, and this requires that similar methods are used for each round. Surveillance systems require adaptation and modification. However, the need to adapt the surveillance system as both knowledge and the epidemic change must be balanced with the desire to collect comparable data in identical or nearly identical ways over time.

**Summary**

Surveillance is the systematic, regular and ongoing collection and use of data for public health action. Behavioural surveillance involves regular, repeated cross-sectional surveys collecting data that can be compared over time on HIV risk behaviours and other relevant issues. When designing a behavioural surveillance system, there are several issues you should consider. You should also follow the steps required to achieve a sustainable surveillance system.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

**Small group discussion**

Get into small groups by country, region or province to discuss these questions.

1. How is surveillance organized/coordinated in your settings? What works and does not work in the organizational structure?

2. Look at the diagram below. This diagram was developed using behavioural surveillance data from Asia, where the majority of epidemics are concentrated. The diagram helps us understand what behaviours are driving the HIV epidemic, the size of high-risk groups and their links to the general population. The ovals show the different population groups and their size, while the arrows show the links between the populations and the strength of the links. Describe how you could use the information shown in the diagram in your country.
Apply what you have learned/case study

Try this case study individually. We will discuss the answers in class.

1. When discussing guidelines for whom to include in surveillance for each epidemic state, what do we mean by the general population and by high-risk group surveillance?
2. Are commercial sex workers a high-risk group?
Overview

What this unit is about
In this unit, you will learn about selecting appropriate measures and indicators for behavioural surveillance.

Warm-up questions
1. What are two characteristics of a good indicator?

2. True or false? Behavioural surveillance indicators should measure aspects of behaviours that are key to the spread of HIV. Circle your answer.
   - True
   - False

3. When should behavioural surveillance indicators be selected during behavioural surveillance? Circle your answer below.
   a. during planning
   b. during analysis

4. True or false? The two most difficult issues defining behavioural surveillance indicators are defining the behaviours themselves and defining the time period to which the indicator should refer.
   - True
   - False

5. True or false? Behavioural surveillance indicators do not need to be consistent over time.
   - True
   - False

6. The time reference period of an indicator should be determined by its ________.
   a. prevalence
   b. frequency

Introduction

What you will learn
By the end of this unit, you should be able to:

- understand the characteristics of a good indicator;
- select indicators for behavioural surveillance;
- understand the main methodological difficulties with indicators for behavioural surveillance;
- discuss using standardized versus locally adapted indicators.
Good indicators

An indicator is simply a measure of something. A good indicator:

1. measures something of relevance to the topic (the measure serves some use);
2. measures the item of interest accurately;
3. is easy to interpret and is defined in clear terms, for example, if we were interested in measuring unsafe sex we would need to:
   - define unsafe sex (for example, 'sex without condom use with a commercial partner');
   - define the population to whom the measure can be generalized. (for example, 'men aged 15-49');
   - define the time period to which the measure refers (for example, 'last sex');
4. can be compared across different population groups and across time, requiring that definitions and field methodologies are consistent over time;
5. is feasible to collect in terms of effort/cost.

Selecting Indicators for Behavioural Surveillance

Behavioural surveillance indicators should measure aspects of behaviours that are key to the spread of HIV, including:

- behaviours that determine the likelihood that an uninfected person will come into contact with an infected person (number and type of sexual partners, patterns of needle exchange, etc.);
- behaviours that determine the likelihood that transmission of HIV will occur if contact with an HIV infected person comes about (level of condom use, equipment sharing practices, etc.).

Note: The likelihood of transmission is also determined by other factors, such as the presence of other STI infections.

Indicators should be selected during the planning of behavioural surveillance. This helps focus the surveillance data needs of the country. It also ensures that all the data required to construct the selected indicators are collected.

Assessing HIV

The selection of indicators should be determined by country data needs. Essential indicators for the general population, injection drug users (IDUs) and commercial sex workers (CSWs) are shown in Table 2.1. (You can learn about other common indicators at http://www.measuredhs.com/hivdata/ind_tbl.cfm).

It is also usual for data to be collected on factors that promote or reduce high-risk behaviours (for example, alcohol or drug use) and on background information so indicators can be compared across different sociodemographic profiles.
Table 2.1

**Essential indicators**

<table>
<thead>
<tr>
<th>General population</th>
<th>IDUs</th>
<th>CSWs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• proportion who had commercial sex in past year</td>
<td>• proportion who shared needles last time</td>
<td>• last time and consistent condom use with clients</td>
</tr>
<tr>
<td>• frequency of commercial sex in past year</td>
<td>• proportion who did not use clean needles consistently in past week (or other time reference period)</td>
<td>• proportion who injected drugs in past year</td>
</tr>
<tr>
<td>• proportion who had non-regular/casual partners in past year</td>
<td>• last time and consistent condom use by partner type</td>
<td></td>
</tr>
<tr>
<td>• frequency of non-regular/casual partners in past year</td>
<td>• proportion who injected drugs in past year</td>
<td></td>
</tr>
<tr>
<td>• last time and consistent condom use by partner type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• proportion who injected drugs in past year</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Methodological issues**

The two most difficult issues defining behavioural surveillance indicators are defining the behaviours themselves and defining the time period for which the indicator should refer.

**Defining behaviours**

A good indicator is easy to interpret and is defined in clear terms. What may appear to be small differences in definition can translate into large differences in what an indicator represents, how it can be used and the data required compiling it.

For example, an indicator measuring consumption of commercial sex by married men could be defined as the proportion of:

- married men who go to a sex worker;
- men who go to sex workers who are married.

The first indicator gives us an idea about the size of the link between CSWs and married men. If a large proportion of married men visit CSWs, then commercial sex could potentially be important for driving the epidemic. The second indicator does not tell us anything about the role of CSWs in driving the epidemic. We do not know if the use of CSWs is high, only that among those people who visit CSWs a certain proportion are married.

Definitions also need to be consistent across time so we can measure trends. For example, defining consistent condom use among sex workers as ‘condom use during every sex act in the last week’ in the first round of surveillance and as ‘condom use with every client in the last week’ in the second round would result in incomparable indicators.

Similarly, it would be difficult to measure trends in IDU behaviour if in the first surveillance round, an IDU is defined as someone who has ever injected drugs, and in the second round defined as someone who injected drugs in the last six months. This is because the type of people to which the information refers is different in the two rounds. The first round would include people who used drugs a long time ago and subsequently stopped. The second round refers to people who have used drugs more recently.
Time reference periods

The time period to which an indicator refers can affect how accurately it is measured. The time reference period should be determined by the frequency of a behaviour, but should be as short as possible to reduce the likelihood that respondents will not remember. If a behaviour is very common, respondents may have difficulty remembering how they behaved and a shorter reference period may be more appropriate. If the behaviour is very rare, measurement over a short reference period may not capture exposure adequately.

An example

It would be difficult for most current IDUs to remember how many times they injected in the last year. If we used this as a reference period, we would get inaccurate information. If we used a reference period that was too short (for example, in the last hour) the IDU would remember accurately how many times they had injected. But most people would respond ‘not at all’ and we would not get a good idea of the risk behaviours.

Standardized Versus Locally Adapted Indicators

We have already discussed the importance of using standardized indicators over time so countries can measure trends. It can also be important to use standardized indicators across regions or internationally to allow comparability. The UNGASS indicators at http://www.measuredhs.com/hivdata/ind_tbl.cfm are a good example of international indicators. These are designed to help monitor global progress in relation to HIV/AIDS, but their definitions and recall periods may not be so useful or meaningful at a country level. Generally, the needs of the country should come before international needs. Indicators should be locally appropriate in terms of reference periods and definitions or else they will be of little use.

Summary

Behavioural surveillance indicators should measure aspects of behaviours that are key to the spread of HIV. Indicators should be selected during the planning of behavioural surveillance. This helps focus the surveillance data needs of the country. It also ensures that all the data required to construct the selected indicators are collected. It is also important to use standardized indicators across regions or internationally to allow comparability.

Exercises

Warm-up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. What things we would need to define in order to measure high-risk sex in the general population?
2. Discuss the following questions and how well the definitions would work in your country context:
   a. How can we define a regular and non-regular sexual partners?
   b. Can single people have regular partners? What if they do not live together?
   c. What do we mean by commercial sex?

Apply what you have learned/case study

Try this case study individually. We will discuss the answers in class.

What do the following indicators measure? Which is more useful?

a. Married men who go to a sex worker

b. Men who go to sex workers who are married.
Overview

What this unit is about
In this unit, you will learn about selecting and adapting instruments and methodologies for behavioural surveillance.

Warm-up questions
1. What is measurement error?

2. In observational studies, which of the following is a source of measurement error?
   Circle your answer.
   a. interviewer error
   b. respondent error
   c. questionnaire faults
   d. all of the above

3. True or false? Bias can be controlled during data analysis.
   True   False

4. True or false? A face-to-face interview is the best data collection method.
   True   False

5. Which of the following is an advantage of using the self-administered data collection method?
   a. inexpensive to administer
   b. no literacy requirement
   c. data entry step eliminated

6. Which of the following are advantages of adapting survey questions from surveys that have already been successfully implemented?
   a. builds on current best practice of how questions can be best expressed
   b. saves time and money
   c. ensures consistency with other available data sources
   d. eliminates the need to pre-test the questionnaire
   e. all of the above

7. What is a solution to the problem of interviewer safety when working with hard-to-reach groups?

8. True or false? When having difficulty in getting members from hard-to-reach groups to show up for an interview, one solution is to use incentives.
   True   False
Introduction

What you will learn

By the end of this unit, you should be able to:

- understand measurement error and how to reduce it;
- select appropriate data collection methods;
- design and adapt survey instruments;
- anticipate potential fieldwork difficulties and identify solutions;
- select appropriate fieldworkers and supervisors.

Measurement Error

Measurement error occurs when the data collected do not accurately measure the characteristics of interest, which affects the validity of our data.

Measurement error terms

Measurement error is best illustrated with an example. Imagine that the surveillance system wants to measure how often people have unsafe sex. To do this, the respondent is asked:

'Have you had unsafe sex in the last month?'

Measurement error could occur in one of two ways:

- The person had unsafe sex but is too embarrassed to admit it, so answers 'no.' In this case, we do not measure their behaviour accurately because the respondent does not tell the truth.
- The respondent thinks of unsafe sex as sex with the risk of pregnancy. In this case, we do not measure behaviour accurately because the respondent does not interpret the question as intended.

Some measurement error is more problematic than others. Suppose we are interested in measuring the average number of sexual partners in the last month for men and women, but in our imaginary population men are more likely to over-report the number of partners, and women to under-report the number of partners. Because of this over- and under-reporting, the difference between male and female behaviour appears larger than it is. This is systematic error. Systematic error can result in biased findings.

Measurement error would be less of a problem if equal numbers of people over- and under-reported the number of partners. Because the number who over-reported the number of partners is the same as the number of people who under-report the number of people, the average number of partners calculated from the data will be the same as if everyone had told the truth.

However, the range of our measure will be larger than if everyone had told the truth. Because the over- and under-reporting balance each other out, this is non-systematic error. If measurement error is non-systematic, our finding will not be biased.

Note: Bias is a consequence of defects in the design or execution of a study. It cannot be controlled during analysis or by increasing the sample size.
**Systematic and non-systematic error example**

Table 3.1 shows three measurement error scenarios for a sample of six people. The samples are described below the table.

<table>
<thead>
<tr>
<th>Scenario 1: True answers</th>
<th>Scenario 2: Non-systematic error</th>
<th>Scenario 3: Systematic error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person 1</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Person 2</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Person 3</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Person 4</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Person 5</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Person 6</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>% unsafe sex</td>
<td>50%</td>
<td>50%</td>
</tr>
</tbody>
</table>

- **Scenario 1**: All six people in the survey tell the truth. Three had unsafe sex and three did not. The true measure of unsafe sex in our sample is 50%.
- **Scenario 2**: Persons 1, 2, 3 and 4 lie about having unsafe sex. Two people report that they had unsafe sex when they did not. Two people report that they did not have unsafe sex when they did. The error in reporting is not systematic (that is, in one direction) and our measure of unsafe sex in our sample is still 50%.
- **Scenario 3**: Persons 1 and 3 lie about having unsafe sex. Both people report that they did not have unsafe sex when they did. The error in reporting is systematic (that is, all those who lie under-report unsafe sex) and our measure of unsafe sex in our sample is only 17%, so the measure is biased.

**Measurement error factors**

In observational studies, measurement error can come from:

- questionnaire faults
- interviewer error
- respondent error

**Questionnaire faults**

The way that questions are phrased, set out and ordered can affect how accurately the data collected reflects actual behaviour. Questionnaire faults include:

- **Culturally inappropriate questions** - Some words and phrases may not be understood or may have different meanings in different cultures. For example, ‘unsafe sex’ may mean different things to different people. Such differences in meaning can result in respondents interpreting questions differently to how they were intended. It can also result in their answers, therefore, not reflecting the behaviour we are interested in. Some questions are understood, but considered objectionable in some cultures. This leads to untruthful answers. This can include questions of a personal nature or questions that convey negative implications.
- **Ambiguous wording** - Vague questions produce vague answers. For example, ‘Have you had sex without a condom recently?’ In this question, the term ‘recently’ is
too subjective and ‘sex’ is an ambiguous term. However, questions can also be so precise that people cannot answer them.

- **Leading wording** - Some questions are phrased in a way that makes the respondent more likely to choose a response category. The question may only mention some of the response options. For example, ‘*When should a condom be used: for oral sex, vaginal sex or what?*’ The questions may also be leading, emotionally charged, threaten self-esteem or indicate a socially desirable result. For example, ‘*You have had sex in the last year, haven’t you?*’

- **Too many or demanding questions** - Asking too many questions or questions that are too demanding can make respondents impatient or bored with the interview. An example of this would be asking a respondent to rank 25 factors in order of importance. In such a case, the respondent may stop listening carefully to the questions or provide answers that they think will speed up the interview process.

- **Poor ordering of questions** - Putting sensitive questions at the start of a questionnaire can put a respondent off and decrease the rapport between the interviewer and respondents. The respondent may stop listening carefully to the questions or provide answers that they think will speed up the interview process. Switching between topics or abruptly changing topic can also be confusing and cause respondents to lose concentration.

**Interviewer error**

The actions and behaviours of the interviewers can affect how accurately the data collected reflect actual behaviour. Interviewer errors include:

- **Not following the fieldwork protocols** - Interviewers not following the fieldwork protocols can affect the accuracy of data. For example, in a quantitative survey, interviewers should ask the questions exactly as they are written on the questionnaire. This ensures that fieldworkers do not phrase or interpret questions in their own way. If fieldworkers do not follow this protocol, respondents may not be asked the same questions and measurement error may occur.

- **Being judgmental** - If respondents feel that fieldworkers are judgmental and will disapprove of their behaviours, they may be less willing to report behaviours that are felt to be socially undesirable.

- **Misinterpretation of responses** - Fieldworkers can misinterpret the responses that are given. For example, the respondent may respond using slang that the interviewer does not understand.

- **Mistakes in recording answers** - Sometimes interviewers simply record the answers they are given incorrectly, or they may skip questions accidentally.

**Respondent error**

The actions and behaviours of the respondents can affect how accurately data collected reflect actual behaviour. Respondent errors include:

- **Misunderstanding the question**

- **Faulty recall** - Respondents can have difficulty remembering past behaviours correctly, or their memory of past behaviours can be influenced by behaviours or events that happened more recently.
- **Untruthful answers** - Respondents may give untruthful answers, especially if they perceive that there is a ‘correct’ answer. They may also over-report socially desirable behaviours and under-report socially undesirable behaviours. The personality, sex, race or age of the interviewer can influence the response.

Many questions essential to behavioural surveillance are sensitive. Sexual behaviour is difficult to study, owing to its private and sensitive nature. Also, doubts about the validity of reported behaviours abound. People are more likely to tell the truth in some situations than others.

Skepticism about the validity of behavioural data has been partially addressed by efforts to improve training, supervision and rapport-building with the survey populations. Results from sex surveys in the developed world are encouraging in their plausibility and consistency. The broad verdict about similar surveys in low-income countries is that the data quality is sufficiently high to merit serious analysis.

Data from large-scale surveys not specifically designed to study sexual behaviour may be less valid than data from surveys specially designed to measure sexual behaviour.

**Reducing measurement error**

Table 3.2 gives examples of ways to reduce each type of measurement error.

<table>
<thead>
<tr>
<th>Source of measurement error</th>
<th>Possible solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire faults</td>
<td></td>
</tr>
<tr>
<td>Culturally inappropriate questions</td>
<td>Tailor wording of question to the type of respondent.</td>
</tr>
<tr>
<td></td>
<td>Explore local terms with formative research and pre-test questionnaires.</td>
</tr>
<tr>
<td></td>
<td>Place sensitive questions towards the end of the questionnaire.</td>
</tr>
<tr>
<td></td>
<td>Make sure questions do not convey negative connotations.</td>
</tr>
<tr>
<td></td>
<td>Soften the impact of sensitive questions by establishing a context.</td>
</tr>
<tr>
<td></td>
<td>If translation is required, check by back translation.</td>
</tr>
<tr>
<td>Ambiguous wording</td>
<td>Keep words as simple as possible; avoid jargon and abbreviations.</td>
</tr>
<tr>
<td></td>
<td>Do not use vague questions or imprecise terms.</td>
</tr>
<tr>
<td></td>
<td>Avoid presenting more than one concept at once.</td>
</tr>
<tr>
<td></td>
<td>Make sure you do not assume too much knowledge.</td>
</tr>
<tr>
<td>Leading wording</td>
<td>Either mention all possible answers in the question or none.</td>
</tr>
<tr>
<td></td>
<td>Do not use emotionally charged words and avoid threats to self-esteem.</td>
</tr>
<tr>
<td>Issue</td>
<td>Solutions</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Too many or demanding questions</td>
<td>• Be careful with questionnaire length, exclude questions you will not use.</td>
</tr>
<tr>
<td></td>
<td>• Use screening questions with skip patterns or not options that are not applicable.</td>
</tr>
<tr>
<td></td>
<td>• Avoid demanding questions and reduce demand with formatting.</td>
</tr>
<tr>
<td>Poor ordering of questions</td>
<td>• Place questions on the same topic together.</td>
</tr>
<tr>
<td></td>
<td>• Move from general to specific questions.</td>
</tr>
<tr>
<td></td>
<td>• Use transition statements when changing subjects.</td>
</tr>
<tr>
<td></td>
<td>• Place sensitive questions towards the end of the questionnaire.</td>
</tr>
<tr>
<td>Interviewer error</td>
<td>• Select and train fieldworkers well and produce a fieldworkers’ manual.</td>
</tr>
<tr>
<td></td>
<td>• Ensure good supervision of fieldworkers.</td>
</tr>
<tr>
<td></td>
<td>• Ensure data quality check and procedures are put in place.</td>
</tr>
<tr>
<td>Misinterpretation of responses</td>
<td>• Use interviewers who understand the survey population language.</td>
</tr>
<tr>
<td></td>
<td>• Select and train fieldworkers well and produce a fieldworkers’ manual.</td>
</tr>
<tr>
<td></td>
<td>• Train fieldworkers to take notes whenever something is unclear.</td>
</tr>
<tr>
<td>Mistakes in recording answers</td>
<td>• Select and train fieldworkers well and produce a fieldworkers’ manual.</td>
</tr>
<tr>
<td></td>
<td>• Ensure good supervision of fieldworkers.</td>
</tr>
<tr>
<td></td>
<td>• Use vertical answer formats and pre-code answers.</td>
</tr>
<tr>
<td></td>
<td>• Provide instructions for interviewers on the questionnaire.</td>
</tr>
<tr>
<td></td>
<td>• Use separate typefaces for instructions and answers.</td>
</tr>
<tr>
<td>Respondent error</td>
<td>• Ensure the time reference periods are appropriate.</td>
</tr>
<tr>
<td>Faulty recall</td>
<td>• Use the appropriate data collection method.</td>
</tr>
<tr>
<td>Untruthful answers</td>
<td>• Place sensitive questions towards the end of the questionnaire.</td>
</tr>
<tr>
<td></td>
<td>• Do not use emotionally charged words and avoid threats to self-esteem.</td>
</tr>
<tr>
<td></td>
<td>• Use members of the target community as interviewers.</td>
</tr>
<tr>
<td></td>
<td>• Use interviewers of the appropriate age, sex and race.</td>
</tr>
</tbody>
</table>

**Importance of pre-testing**

Pre-testing the questionnaire is an important step in developing appropriate survey instruments. Pre-testing is essential because:

- It helps determine the most appropriate sequencing of sections and questions.
- It identifies whether the wording of questions is clear and understandable to those being interviewed, and allows ambiguities to be identified and removed before the questionnaire is finalized.
**Importance of piloting**

After the questionnaire is pre-tested, you should make further improvements during piloting. Pilots usually consist of collecting data from small samples of respondents to check how well the planned fieldwork procedures work in practice. Piloting is essential because:

- It shows how long it takes to administer the questionnaires.
- It can inform the fieldworker training process by identifying sections or questions that cause problems, ideas and issues that are not clear, and skills that need to be strengthened.
- It helps plan fieldwork by showing how well fieldworkers cope with conditions, identifying logistical constraints, and highlighting potential problems with recording or checking data. Often factors that have not been considered are revealed during piloting.

**Data Collection Methods**

The type of data collection method can influence how respondents answer questions and thus how accurately the data collected measures the behaviour of interest. This is particularly true of sensitive data where ensuring the privacy of the responses can be very important. Data collection methods you can use in behavioural surveillance include:

- **Face-to-face interviews** - An interviewer reads out the questions to the respondent. The respondent gives an oral response, which the interviewer records on the questionnaire.
- **Self-administered questionnaire** - The respondents are given or mailed the questionnaire, which they read and complete themselves.
- **Computer-assisted** - The respondent reads or hears the questions being read through a tape recorder and headphones, and completes the questionnaire on a computer.

The most appropriate method will be context-specific. Each data collection method has advantages and disadvantages. These are shown in Table 3.3. There is no conclusive evidence that any one method is better, overall, than the other.
Table 3.3
Advantages and disadvantages of various data collection methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Advantage</th>
<th>Disadvantage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face</td>
<td>• no literacy requirement</td>
<td>• labour-intensive</td>
</tr>
<tr>
<td></td>
<td>• interviewer-respondent rapport can increase truthfulness</td>
<td>• low degree of privacy and anonymity</td>
</tr>
<tr>
<td></td>
<td>• high response rate</td>
<td>• interviewers may distort answers</td>
</tr>
<tr>
<td></td>
<td>• allows flexibility in length/style of survey</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• respondent can ask for clarification</td>
<td></td>
</tr>
<tr>
<td>Self-administered</td>
<td>• higher degree of privacy and anonymity</td>
<td>• respondents must be literate</td>
</tr>
<tr>
<td></td>
<td>• inexpensive to administer</td>
<td>• no way to clarify misunderstanding</td>
</tr>
<tr>
<td></td>
<td>• higher non-response rate</td>
<td>• questionnaire must be short</td>
</tr>
<tr>
<td></td>
<td>• respondents must be literate and at ease with computers</td>
<td>• requires expensive equipment</td>
</tr>
<tr>
<td>Computer-assisted</td>
<td>• higher degree of privacy and anonymity</td>
<td>• no way to clarify misunderstandings</td>
</tr>
<tr>
<td></td>
<td>• data entry step eliminated</td>
<td></td>
</tr>
</tbody>
</table>

Survey Instruments

Available instruments

You have already learned that a characteristic of a good indicator is that it measures the behaviour of interest accurately and that accuracy can be improved by appropriate question phrasing. Luckily, we are not starting from scratch and we can adapt our questions from surveys that have already been successfully implemented. This:

- builds on current best practice of how questions can be best expressed;
- saves time and money;
- ensures consistency with other available data sources.

It is still essential to pre-test and pilot questions that have been borrowed from other surveys to adapt them for each context.

General population survey instruments that are widely used, considered to use solid sampling procedures and thorough statistical analysis, and are usually considered a reliable source of behavioural data include:

- demographic and health surveys (MACRO)
- Multiple Indicator Cluster Survey (UNICEF).

Widely used surveys for high-risk groups are behavioural surveillance surveys (FHI).
Table 3.4 shows the most common HIV/AIDS-relevant content of each survey and Internet links for accessing the questionnaires.

### Table 3.4

**Content of surveys useful for behavioural surveillance**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic and health surveys (DHS), Macro International</td>
<td>- Knowledge and source of knowledge of AIDS and other STIs</td>
</tr>
<tr>
<td></td>
<td>- Knowledge of how to avoid HIV/AIDS</td>
</tr>
<tr>
<td></td>
<td>- Condom use at last and penultimate sex</td>
</tr>
<tr>
<td></td>
<td>- Relationship to last and penultimate sexual partner</td>
</tr>
<tr>
<td></td>
<td>- Length of time known last and penultimate sexual partner</td>
</tr>
<tr>
<td></td>
<td>- Age at first sex</td>
</tr>
<tr>
<td></td>
<td>Internet link: <a href="http://www.measuredhs.com/">http://www.measuredhs.com/</a></td>
</tr>
<tr>
<td>Multiple Indicator Cluster Survey (MICS), UNICEF</td>
<td>- Knowledge and source of knowledge of AIDS</td>
</tr>
<tr>
<td></td>
<td>- Knowledge of how to avoid HIV/AIDS</td>
</tr>
<tr>
<td></td>
<td>- Knowledge of testing sites and if ever tested</td>
</tr>
<tr>
<td></td>
<td>Internet link: <a href="http://www.childinfo.org/index2.htm">http://www.childinfo.org/index2.htm</a></td>
</tr>
<tr>
<td>Behavioural surveillance surveys (BSS), FHI</td>
<td>- Surveys for CSW, MSM, IDUs, Youth, Adults on HIV-related risk behaviours</td>
</tr>
<tr>
<td></td>
<td>Internet link: <a href="http://www.fhi.org/en/topics/bss.htm">http://www.fhi.org/en/topics/bss.htm</a></td>
</tr>
</tbody>
</table>

### Fieldwork Practicalities

**Working with hard-to-reach populations**

High-risk groups that are included in surveillance are often hard to reach because:

- They engage in illegal/clandestine behaviours.
- They often do not want to be identified because of high levels of stigmatization and discrimination.
- Their existence is denied by the general population and government.
- There are restrictions on who may approach the group and how the group can be approached (gatekeepers such as brothel owners may not want sex workers interviewed, the government may not want non-military personnel interviewing military, etc.).
- Group members have little time to talk.
- Groups do not want to be found for surveillance because they fear authorities or do not want outsiders entering the group.
- Group members are difficult to differentiate from non-group members. (For example, on entering a bar known to be a place where sex is sold, how do you differentiate a sex worker from a customer of the bar?)
Examples of practical difficulties and potential solutions in working with hard-to-reach groups are outlined in Table 3.5.

### Table 3.5
**Practical problems and solutions in working with hard-to-reach groups**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to identify group members</td>
<td>• Collect information on identification of members and in the places they congregate where they may be identifiable and accessible.</td>
</tr>
<tr>
<td></td>
<td>• Use members of the group as interviewers.</td>
</tr>
<tr>
<td>Fear of persecution decreases</td>
<td>• Conduct community entry activities.</td>
</tr>
<tr>
<td>participation</td>
<td>• Work with authorities to ensure surveillance activities do not lead to police crackdowns, etc.</td>
</tr>
<tr>
<td></td>
<td>• Make sure there are some tangible benefits resulting from the surveillance activities.</td>
</tr>
<tr>
<td></td>
<td>• Use group members as interviewers or sensitize interviewers to issues.</td>
</tr>
<tr>
<td></td>
<td>• Work with NGOs who are accepted by the target population.</td>
</tr>
<tr>
<td></td>
<td>• Realize that it can take more than one surveillance round to gain a group’s trust and persevere if there are problems in initial rounds.</td>
</tr>
<tr>
<td>Gatekeeper restriction</td>
<td>• Conduct community entry activities and explain the importance of surveillance and how they will ultimately benefit the population.</td>
</tr>
<tr>
<td></td>
<td>• Receive permission from the gatekeepers for the fieldwork.</td>
</tr>
<tr>
<td></td>
<td>• Involve gatekeepers in the surveillance activities.</td>
</tr>
<tr>
<td></td>
<td>• Work with NGOs who are accepted by the target population.</td>
</tr>
<tr>
<td>Scheduling</td>
<td>• Work around groups’ schedule.</td>
</tr>
<tr>
<td>Consent and confidentiality</td>
<td>• Train fieldworkers on the importance of confidentiality and consent.</td>
</tr>
<tr>
<td>Interviewer safety</td>
<td>• Ensure that the gatekeepers know participation is voluntary.</td>
</tr>
<tr>
<td></td>
<td>• Identify potential problems with privacy and confidentiality.</td>
</tr>
<tr>
<td></td>
<td>• Select interviewers who know the area.</td>
</tr>
<tr>
<td></td>
<td>• Interviewers work in pairs.</td>
</tr>
</tbody>
</table>

### Selecting Appropriate Fieldworkers and Supervisors

**Supervisor’s role**

The supervisor’s role includes:

- representing the project at the community level;
- negotiating with and accessing communities;
- managing fieldwork and fieldwork teams;
- organizing logistics, travel, accommodation, and remuneration of fieldworkers;
- supervising and supporting fieldworkers;
- checking questionnaires and ensuring quality control;
- exercising control over sampling;
- ensuring ethical guidelines are followed;
- dealing with problems/troubleshooting.
It is common in research for supervisors to check data quality by re-interviewing a proportion of respondents. They check whether:

- the interviewers conducted the interview correctly, that is, interviewers actually conducted the interview, did not skip questions, recorded responses correctly and so forth
- questions suffered from recall bias, that is, did questions yield the same answer when re-asked?

Re-interviewing can be difficult when conducting behavioural surveillance in hidden populations because names are not recorded on the questionnaire. Trying to relocate respondents can be seen as a breach of confidentiality.

Instead, supervisors can check with people in the survey area to find out if the interviewers were there when they were supposed to be and how long they stayed. Supervisors can also perform spot checks where they re-interview the respondent straight after the interviewer has completed their interview. This makes relocating the respondent unnecessary.

**Interviewer’s role**

The interviewer is responsible for collecting and recording good quality information from respondents on the questionnaires.

To fulfill these roles, supervisors and interviewers require specific characteristics and skills. Some of these skills can be taught through training. Others, such as fluency in appropriate languages, previous experience with research and with the target populations, educational considerations, gender, age and ethnicity considerations, cannot.

**Summary**

Measurement error occurs when the data collected do not accurately measure the characteristics of interest, which affects the validity of our data. It is important to select appropriate data collection methods, since the type of data collection method can influence how respondents answer questions. You should also design and adapt survey instruments that are widely used, considered to use solid sampling procedures and thorough statistical analysis, and are usually considered a reliable source of behavioural data.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.

**Small group discussion**

Get into small groups by country, region or province to discuss these questions.
1. In your experience, what are some examples of factors that affected measurement error in observational studies?

2. What are some general population surveys that you have used that ask questions about HIV/AIDS?

Apply what you have learned/case study
Try this case study individually. We will discuss the answers in class.

1. What topics need to be taught during interviewer training?

2. What topics need to be taught during supervisor training?
Overview

What this unit is about

In this unit, you will learn the theoretical and practical knowledge required to discuss and select sampling options for behavioural surveillance.

Warm-up questions

1. The ________________ is ideal for meeting a survey’s measurement objective (for example, all commercial sex workers in a city).
   a. target population
   b. survey population

2. Is drawing names randomly out of a hat for sampling an example of probability sampling or non-probability sampling?
   a. probability sampling
   b. non-probability sampling

3. True or false? Non-probability sampling is prone to selection bias.
   True   False

4. We can increase the precision (that is, decrease standard error) of our estimate by increasing the___________.
   a. sample size
   b. quality of interviewer training

5. What is an estimate of precision that you can use to construct a range of values within which the true population measure is likely to fall?
   a. standard error
   b. systematic sample

6. Which of the following is not a type of sampling?
   a. stratified
   b. cluster
   c. respondent-driven
   d. systematic
   e. salient

7. True or false? Statistical packages assume simple random sampling when performing statistical tests.
   True   False
8. True or false? Cluster sampling provides more precise estimates of indicators than simple random sampling.

True  False

9. Which of the following is NOT a way to overcome sampling challenges for behavioural surveillance?
   a. using different sampling strategies for different groups
   b. using convenience sampling where possible
   c. using conventional sampling methods in unconventional ways
   a. using experimental sampling techniques such as respondent-driven sampling (RDS).

Introduction

What you will learn
By the end of this unit, you should be able to:

- outline the purpose of sampling;
- understand key theoretical concepts in sampling;
- understand the need for more complex sampling designs;
- understand sampling issues and options for behavioural surveillance;
- understand the criteria for choosing a sampling approach.

Sampling Approach

Definitions
We sample when we desire to measure characteristics for a specified target population, but we lack the time and resources to obtain information from every member of the target population. For example, if we want to measure condom use among commercial sex workers in a capital city, but it is not feasible to question every sex worker about their behaviour, we select a sample to question.

When we cannot measure everybody, as is usually the case, we select individuals for study from the population - a sample. We then obtain an estimate of our selected indicators for the entire population by interviewing only the people sampled. There are many different ways of selecting these individuals. These are called sampling approaches.

Concentrating survey time and resources on questioning a sample of people can also result in better quality data than spreading resources over the entire population.

The target population is the ideal population for meeting a survey’s measurement objective (for example, all commercial sex workers in a city).

The survey population is the target population modified to take into account practical considerations (for example, all commercial sex workers in a city over the age of 15, excluding those who are based at home, as these cannot be accessed).
What do we want from a sample?
We want the sample to provide:

- unbiased estimates
- precise estimates

Unbiased estimates
When we take a sample, we are not interested in the sample in its own right. Instead, we are interested in what the sample tells us about our target population. We want the sample to provide us with *unbiased* estimates of our indicators for our target population. Avoiding bias due to sampling requires a random/probability sample. This ensures that our sample is like (or can be adjusted to be like) the population it was drawn from. Most statistical software packages assume simple random sampling for their statistical tests.

A *probability sample* is one where each person in the survey population has a known, non-zero probability of selection.

If our sample is not a probability sample, or a probability sample was planned but not implemented correctly, we cannot generalize our findings beyond the sample. This is because it is unknown whether the subjects in the sample are different from those in the rest of the target population. Statistical tests are not accurate when performed on non-probability samples.

Probability sampling example
Let us imagine that the people in our class make up the population of a city. We want to find out how many people in the city practise unsafe sex. An example of a probability sample would be if we wrote each person’s name on a piece of paper and pulled a sample of names randomly from a hat, like in the game of lotto. This is called *simple random sampling*.

Everyone in the class has a chance of being sampled (a non-zero probability) and we know what that chance is. In simple random sampling, such as this, everyone has an equal chance of being selected. Therefore, if there were 10 people in the class, the probability of any individual being sampled would be 0.1 (1 out of 10). If there were 20 people in the class, the probability would be 0.05 (1 out of 20). Listing the names of the class members to draw from the hat is called developing a *sample frame*. A sample frame is a fundamental part of probability sampling.

Note: We could also have assigned each class member a number and selected numbers from a random number table.

A *sample frame* is a list of units from which a sample may be selected.

Non-probability sampling example
An example of non-probability sampling would be if we did not select people from the class at random, but instead selected those who arrived first this morning. This is easier to do than the simple random sample, as we do not have to develop a sampling frame.
The problem here is that the people who arrived first may not be the same as the rest of the class. They could be those who live closest to the class, those who own a car or those who do not have to get children ready for school before they come to class.

Whatever the reason, the early arrivers may be different from the rest of the class not just in their arrival time, but in the indicators we are interested in measuring. If we try to generalize what we find out about unsafe sex from these early birds, we could get a wrong (biased) idea about the sexual behaviour of the class as a whole.

In this type of sampling, members of the class did not have an equal probability sample. Those who arrive late have a zero probability (no chance) of being sampled. See Table 4.1 for a comparison of probability and non-probability sampling.

Table 4.1
A summary of probability and non-probability sampling

<table>
<thead>
<tr>
<th>Issue</th>
<th>Probability sample</th>
<th>Non-probability sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prone to selection bias</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Can generalize results to survey population</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Can estimate precision of survey estimates (use statistical techniques accurately)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Requires sample frame</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Requires following fixed, often costly, procedures</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Method replicable (important for measuring trends)</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Precise estimates
We want the sample to provide precise estimates. The information we get from a sample is only an estimate of the true population measure. There are many possible samples that could be selected from the population. Because of chance, each sample selected would produce a different estimate of our indicators. The variation in measurement that comes about by chance through sampling must be taken into account when using a sample to make inferences about a larger population.

When we use probability sampling, we can estimate how precisely the true population measure is estimated by the sample estimate (how large our sampling variation could be). This estimate of precision is called the *standard error*. You can use it to construct a range of values within which the true population measure is likely to fall. We usually want to be 95% sure that the true population measure lies in our range. This range is called a *confidence interval*.

We can increase the precision (that is, decrease standard error) of our estimate by increasing the sample size. Standard equations are available to calculate required sample size with the sample size, depending on:

- the initial starting level of the indicator;
- the amount of change we want to be able to measure between surveillance rounds;
• how sure we want to be that we will be able to detect this change (the power of the study);
• how sure we want to be that our true population measure falls within our confidence limits (the precision of the study).

**Simple Random Sampling Problems**

Some of the problems with simple random sampling include:

• It can require selecting a large number of random numbers from a random number table or names from a hat.
• Sampling frames for the whole population rarely exist and are too costly or impractical to compile.
• Populations can be spread over a wide area and the travel and time costs involved in covering the whole area are prohibitive.
• The population consists of distinct sub-groups that we are interested in.

**Many random Numbers**

**Problem:** Can require selecting a large number of random numbers from a random number table or names from a hat.

**Solution:** A more convenient method than having to pick names or numbers is to sample systematically from the sampling frame. In systematic sampling, we construct the sampling frame as in simple random sampling (that is, we make a list of everyone in the target population) but rather than selecting names or random numbers, we sample people at regular intervals down the list. For this scheme to work, you need to ensure that the list is not ordered in any way that would affect who is selected in the survey.

**No sampling frames for whole population**

**Problem:** Sampling frames for the whole population rarely exist and are too costly or impractical to compile.

**Solution:** When it is difficult or impossible to make a list/sampling frame of each individual in the target population, we can develop a sampling frame of some larger unit. These are called clusters or primary sampling units. We then sample in stages by first sampling clusters and then sampling people within the clusters. Cluster sampling is the most common method of sampling in surveys, as it has the advantage that the sampling frame is not required to be a list of every person in the target population. Instead, a sampling frame of clusters is required. Once the clusters are selected, we are only required to list people in the selected clusters. All members of the target population still have a chance of being sampled (a non-zero probability) as long as all the clusters within which the target population is found are included in the list of clusters.

A cluster is any aggregate of the population of interest (for example, departments, villages, health facilities).

If clusters are of unequal sizes, we need to take this into account. If we do not take size into account, people in smaller clusters will have a higher probability of being selected than those in larger clusters. If people in smaller clusters are different from those in...
larger clusters, our sample population will not be like the target population. We may get a biased estimate of our indicators.

There are two main methods of ensuring that each member of the target population has an equal chance of selection and that the required sample size is met:

- **Make the probability that a cluster is sampled dependent on its size (PPS sampling).** This requires that we know cluster size prior to cluster sampling.
- **Adjust for cluster size during data analysis.** This requires that we have the correct statistical software to adjust for cluster size during the analysis.

Cluster sampling results in a less precise estimate of our indicators than simple random sampling, as respondents within clusters may be similar to each other. We need to compensate for this by increasing the sample size.

**Populations spread out**

**Problem:** Populations can be spread over a wide area and the travel and time costs involved in covering the whole area are prohibitive.

**Solution:** Use cluster sampling as described above, as it concentrates fieldwork in specific areas/clusters and reduces the fieldwork time and travel costs.

**Distinct sub-groups**

**Problem:** The population consists of distinct sub-groups that we are interested in.

**Solution:** When the population consists of distinct sub-groups (for example, age groups or regions) we may need to make precise estimates of our indicators for each sub-group. If this is the case, we use stratified sampling.

- First, we calculate the required sample size for measuring our indicator.
- Then we define the sub-group (strata) and randomly sample the calculated sample size in each strata.

As we want to make precise estimates of our indicator for each strata, our sample size will be much larger than if we just wanted an estimate for the entire population. We can combine strata estimates to obtain a population estimate for our indicators. However, this requires that we know the proportion of the population in each strata.

*Stratification* is the classification of a survey population into sub-groups or strata on the basis of selected characteristics. *Stratified sampling* is the selection of separate (that is, independent) samples from each stratum. Stratification can result in a more precise estimate and is sometimes used purely to improve precision.
An example

The government of country Alpha desired to estimate the percentage of people in the general population who had had any unsafe sex in the last month. Alpha has three main regions: the coastal plain, the mountains and the semi-arid region. As the population is not evenly spread throughout the country, and it was thought that geography might influence the level of unsafe sex, the government chose stratified sampling. The sample size required to estimate unsafe sex was calculated as 50 people. As we required estimates for unsafe sex in each strata/region, we needed to sample 50 people in each strata/region. If we only wanted a countrywide estimate, our total sample size would be 50. Table 4.2 shows the results obtained with the estimated level of unsafe sex in each region.

Table 4.2
Results from a stratified sample carried out to estimate the level of unsafe sex in a country with three main geographical regions

<table>
<thead>
<tr>
<th>Region</th>
<th>Population</th>
<th>Sample</th>
<th>Number had unsafe sex</th>
<th>% had unsafe sex</th>
<th>Estimated total who had unsafe sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coastal plain</td>
<td>1 500 000</td>
<td>50</td>
<td>30</td>
<td>60</td>
<td>900 000</td>
</tr>
<tr>
<td>Mountains</td>
<td>150 000</td>
<td>50</td>
<td>5</td>
<td>10</td>
<td>15 000</td>
</tr>
<tr>
<td>Semi-arid region</td>
<td>300 000</td>
<td>50</td>
<td>15</td>
<td>30</td>
<td>90 000</td>
</tr>
<tr>
<td>Total</td>
<td>1 950 000</td>
<td>150</td>
<td>60</td>
<td>33</td>
<td>1 005 000</td>
</tr>
</tbody>
</table>

Table 4.2 shows how you can use stratified sampling to calculate the level of unsafe sex in each region. The level of unsafe sex for the population as a whole is calculated by estimating the total number of people in each region who had unsafe sex (for example, for the coastal plain this would be \( \frac{60}{100} \times 1 500 000 = 900 000 \)), and then adding these up to get the estimated total number of people in the country who had unsafe sex \( (1 005 000) \). The total population size is 1 950 000, so the percentage of people in the whole population who had unsafe sex is \( \frac{1005000}{1950000} \times 100 = 52\% \).

You could calculate regional estimates without using stratified sampling during the analysis. However, there would be no guarantee that the sample size would be large enough to make precise estimates for each region.

Sampling Issues in Behavioural Surveillance

Some sampling issues in behavioural surveillance include the following:

- Consistent sampling is required across survey rounds.
- General population surveys can rarely be used to access high-risk groups.
- Cluster sampling can be difficult when clusters are not stable.
- Members of high-risk groups may be difficult to identify and access.
- Cluster sampling is impossible if group members do not congregate.

Consistent sampling

Behavioural surveillance aims to measure trends over time. Therefore, it is essential that the different survey rounds define and sample a sub-population consistently over
time. If we do not do this, we do not know if any observed changes are real or just due to changes in methodology. Sometimes it is appropriate to change the sampling strategy because new and better techniques are developed. In this case, we can sample the population using both the old and new method to compare estimates.

**Accessing high-risk groups**

Household/general population surveys are rarely an appropriate method for locating members of high-risk groups. The group members may not be found in households in sufficient numbers through a household survey and may have behaviours that are too sensitive to discuss in a household setting. It is usually impossible to make a sampling frame of all the members of a high-risk group. One solution is to identify the places high-risk groups congregate, define these as clusters and sample these. Examples of possible clusters for high-risk groups are shown in Table 4.3.

<table>
<thead>
<tr>
<th>High-risk group</th>
<th>Possible cluster</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brothel-based sex workers</td>
<td>Brothel</td>
</tr>
<tr>
<td>Non-brothel-based sex workers</td>
<td>Streets, bars, hotels, guesthouses</td>
</tr>
<tr>
<td>Men who have sex with men</td>
<td>Cruising sites</td>
</tr>
<tr>
<td>Intravenous drug users</td>
<td>Shooting galleries, injecting sites</td>
</tr>
<tr>
<td>Truckers</td>
<td>Loading/unloading/halting points</td>
</tr>
<tr>
<td>Migrants</td>
<td>Households, workplaces</td>
</tr>
</tbody>
</table>

**Unstable clusters**

Unless clusters are all the same size, we need a measure of cluster size in order to ensure the sample is like the target population. It can be hard to measure the size of locations where high-risk groups congregate, as the individuals at the cluster are not fixed (for example, sex workers may move from one site to another). As well as the number of people, the type of people in a cluster may also vary (for example, sex workers who work in the afternoon may have different risk behaviours than sex workers who work in the evening). This makes it difficult to select a sample that is representative of the entire target population using conventional cluster sampling.

**Hard to reach high-risk groups**

High-risk groups can be hard to reach because members may be hidden and unwilling to be identified or acknowledge their risk behaviour. These difficulties have many implications for sampling:

- Constructing a sample frame of clusters can be difficult if people do not want to disclose the location (for example, brothels).
- Opposition from gatekeepers may cause problems in including clusters in the sample.
- Constructing sample frames within the selected clusters may be difficult, as individuals may not want to be identified as a member of the population.
High-risk groups do not congregate
Some high-risk groups do not congregate, making cluster sampling unfeasible for these groups. For example, it is difficult to think of a feasible cluster for home-based sex workers unless they all live in the same area. For other high-risk groups, only some of the population congregates. For example, it is possible to use cruising areas as clusters for some men who have sex with men. However, not all MSM frequent cruising areas, and an important section of the MSM population could be missed.

Potential solutions
There has been much debate about the best way to get around these sampling challenges. We need to:

• use different sampling strategies for different groups;
• use conventional sampling methods in unconventional ways;
• consider using experimental sampling techniques such as respondent-driven sampling (RDS).

The adaptation of conventional sampling strategies and new techniques such as respondent-driven sampling will be discussed in the following section.

Sampling Options in Behavioural Surveillance

Conventional cluster sampling
For the reasons outlined above, conventional cluster sampling is not appropriate for many high-risk groups. However, you can use it for behavioural surveillance in the general population and youth. You can also use it for a few high-risk groups such as prisoners.

Time location sampling
Time-location sampling (TLS) is like conventional cluster sampling, but it gets around the problem of clusters that are not stable (that is, clusters where the number and type of people varies by, for example, time of day). Time-location sampling allows the same site to be included in the sample frame more than once (for example, at different times of the day or different days of the week).

Thus, if the types of individuals in a cluster vary between weekday and weekends and between morning and afternoons, our clusters would be:

• Cluster 1= Site 1 weekday afternoon
• Cluster 2= Site 1 weekday evening
• Cluster 3= Site 1 weekend
• Cluster 4= Site 2 weekday afternoon
• Cluster 5= Site 2 weekday evening
• Cluster 6= Site 2 weekend, etc.

Once clusters have been selected, the most common approach is to randomly select the same number of respondents in each cluster and adjust the data during analysis for the fact that some location/time clusters will have more people associated with them than others.
This sampling scheme gets around the fact that the risk behaviour in a cluster may vary by time of day. It also means that it is not necessary to count the total number of individuals associated with a cluster, only the number of individuals in the sampling time interval. Measures are required to ensure that the same individuals are not interviewed more than once.

As for conventional cluster sampling, the sampling frame must cover the entire geographical universe of interest and include the majority of sites where group members congregate in sufficient numbers. Clusters should not consist solely of places that group members congregate for HIV prevention activities, as these locations are likely to be associated with people already concerned about HIV/AIDS.

**Respondent-driven sampling**

*Respondent-driven sampling (RDS)* is an experimental sampling technique that does not require a sampling frame. It is an adaptation of a non-probability sampling method (snowball sampling) and is based on the assumption that members of the sub-population themselves can most efficiently identify and encourage the participation in surveillance of other sub-group members.

RDS starts with initial contacts, or seeds, who are surveyed and then become recruiters. Each of these recruiters are given coupons to use to invite up to three eligible people that he or she knows in the high-risk group to be interviewed. The new recruits bring their coupon to a central place where they are interviewed. The recruits then become recruiters. This occurs for five to six waves. Both the recruits and the recruiters are given incentives to encourage participation.

Theoretically, RDS should result in a probability sample. Given sufficiently long referral chains (five to six waves), the sample composition becomes stable, regardless of the people you started with, and the final sample will be like the population from which it is recruited. Computer packages exist to assist in the entry and analysis of RDS data. We need to keep track of:

- the links between recruiters and recruits, so that we can calculate the probability of selection;
- the size of each individual’s network, so we can estimate how precisely the population measure is estimated by the sample estimate (to compensate for the fact the subjects are likely to recruit people like themselves and for difference in personal network size).

The advantages and disadvantages of time location and respondent-driven sampling are summarized in Table 4.4.
Table 4.4
Advantages and disadvantages of time location and respondent-driven sampling

<table>
<thead>
<tr>
<th>Sampling</th>
<th>Steps</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time-location sampling (TLS)</td>
<td>1. Calculate the required sample size.</td>
<td>1. Allows us to do a probability sample of populations that are hidden or floating.</td>
<td>1. Mapping and ethnographic work can be time-consuming and clusters/sites can close rapidly.</td>
</tr>
<tr>
<td></td>
<td>2. Identify clusters through ethnographic mapping.</td>
<td>2. We only need a sample frame of clusters and individuals in selected clusters.</td>
<td>2. Only reaches subset of population that come into contact with the locations where the sampling is done.</td>
</tr>
<tr>
<td></td>
<td>3. Construct a sample frame of clusters defining clusters by both location and time if the population is floating.</td>
<td>3. Samples can be concentrated in geographical areas.</td>
<td>3. It is difficult to identify and access respondents.</td>
</tr>
<tr>
<td></td>
<td>4. Select clusters and individuals in clusters using equal probability sampling.</td>
<td></td>
<td>4. It is difficult to maintain randomness while selecting respondents within clusters.</td>
</tr>
<tr>
<td>Respondent-driven sampling (RDS)</td>
<td>1. Start with initial contacts or ’seeds’ who are surveyed and then become recruiters.</td>
<td>1. Field operations are not difficult.</td>
<td>5. PPS is not often done due to difficulties estimating cluster size. Samples often require weighting. This is not always done, resulting in biased estimates.</td>
</tr>
<tr>
<td></td>
<td>2. Each recruiter invites up to three people they know in the high-risk group to be interviewed.</td>
<td>2. There is no need for ethnographic mapping or a sampling frame.</td>
<td>1. The population must be a network.</td>
</tr>
<tr>
<td></td>
<td>3. The new recruits become the recruiters.</td>
<td>3. The target population recruits for you. This is good when the group does not trust the research community.</td>
<td>2. You need to keep track of links between recruiters and recruits.</td>
</tr>
<tr>
<td></td>
<td>4. Five to six recruitment waves occur.</td>
<td>4. Less visible members of the population are reached.</td>
<td>3. Ethical issues are involved in using incentives.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. The cost is lower.</td>
<td>4. RDR is still in the experimental stages.</td>
</tr>
</tbody>
</table>
Sampling approach criteria

You should assess sampling options for each sub-population of interest. Answering the following questions can help guide the selection of sampling strategies:

1. Is the population of interest the general population or youth? If yes, conventional cluster sampling is recommended.
2. Do group members congregate in accessible locations/sites in high proportions? If no, RDS is recommended.
3. Is it possible to construct a list of all group members associated with each site? If no, TLS or RDS is recommended.
4. Are all group members on the list (not just those who happen to be present at a site) readily accessible during data collection? If no, TLS or RDS is recommended.

Only when answers to questions 2 through 4 are "yes," (as well as for the general population and youth) are conventional household or institutional survey methods feasible.

These questions are represented diagrammatically on the next page.
Sample Size Calculation

Formula for sample size calculation

The sample size needed to conduct behavioural surveys can be based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. For example, you would like enough sex workers in your survey rounds to show that condom use at last paid sex increased from 20% in the year 2006 to 30% in 2007.

The general formula for the needed sample size \( n \) is:

\[
 n = D \left[ \frac{Z_1^2 (1-P) + Z_1 P (1-P) + Z_1^2 (P_1 (1-P_1) + P_2 (1-P_1))}{(P_2 - P_1)^2} \right]
\]

Where:

- \( n \) = Sample size required per survey round (year).
- \( D \) = Design effect (see below)
- \( Z_1 \) = The z score for the desired confidence level, usually 1.96 for 95%
- \( Z_1 \) = The z score for the desired power, usually 0.83 for 80%
- \( P_1 \) = The proportion of the sample reporting indicator in year 1
- \( P_2 \) = The proportion of the sample reporting indicator in year 2
- \( P \) = \((P_1 + P_2)/2\)

Choosing the values of these numbers is based on the following considerations.

**Design effect.** The design effect can be thought of as a correction factor for how much a cluster sample differs from a simple random sample. Effectively, the design effect multiplies the sample size by the factor of \( D \). The design effect accounts for the similarities people have when they are sampled within the same cluster. For example, female sex workers within a particular brothel may be similar with respect to condom use because of the social norms, condom availability, or intervention programmes of the particular brothel. Choosing a design effect is difficult without prior survey data. Design effects from 1 (i.e., none) to 2 (moderate) cover a typical range. For RDS surveys, a small design effect of 1.25 is recommended. For cluster sampling and TLS a moderate design effect of 2.0 is recommended. The bigger the \( D \), the larger the sample size needed.

\( P_1 \) and \( P_2 \). \( P_1 \) and \( P_2 \) are the measures of interest for which you wish to see a change between survey rounds. For example, you wish to show that condom use at last paid sex for sex workers increased from 20% in 2006 \( (P_1) \) to 30% or greater in 2007 \( (P_2) \). \( P_1 \) is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be. \( P_2 \) is ideally set at the goal you would like to achieve (e.g., a 10% or greater increase in condom use). In practice, it is usually set at the smallest change you think is meaningful. For example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. The smaller the change you wish to detect, the larger the sample size you will need. Also, the closer \( P_1 \) and \( P_2 \) are to 50%, the larger the sample size you will need.
The $Z_1$ score is a statistic that corresponds to the level of significance desired. Usually, a significance level of 0.05 (or, equivalently, a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a "two-tailed" statistic). The smaller the significance level (i.e., higher confidence level), the larger the sample size you will need.

The $Z_1$ score is a statistic that corresponds to the power desired. Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a "two-tailed" statistic). The higher the power, the larger the sample size you will need.

**Example of sample size calculation**
Suppose you are planning a survey of sex workers using a two-stage cluster design. You wish to show that condom use will increase from 20% in the baseline survey (this year) to 30% or greater in the survey wave next year. How many sex workers do you need to include each year?

**Solution:**

\[ D = 2 \text{ (moderate)} \]

\[ Z_{1,1} = 1.96 \text{ (95% confidence level)} \]

\[ Z_{1,2} = 0.83 \text{ (80% power)} \]

\[ P_1 = 20\% \text{ condom use in year 1} \]

\[ P_2 = 30\% \text{ condom use in year 2} \]

\[ P = \frac{(.20 + .30)}{2} = .25 \]

\[ N = 2 \left( 1.96 \sqrt{2 \times .25(1 - .25)} + 0.83 \sqrt{.20(1-.20) + .30(1-.3))} \right)^2 / (.30 - .20)^2 \]

\[ = 582 \text{ sex workers per survey wave} \]

Table 4.5 provides pre-calculated sample size estimates over a range of possible scenarios in behavioural surveillance.
### Table 4.5

Sample size needed per survey wave to detect a change in the proportion of an indicator between survey waves, using a 95% confidence level, 80% power and a design effect of 1.25 and 2.0

<table>
<thead>
<tr>
<th>Indicator level in wave 1 (P1)</th>
<th>Indicator level in wave 2 (P2)</th>
<th>Sample size needed each wave with a design effect of 1.25</th>
<th>Sample size needed each wave with a design effect of 2.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>.10</td>
<td>.20</td>
<td>247</td>
<td>395</td>
</tr>
<tr>
<td>.10</td>
<td>.25</td>
<td>123</td>
<td>197</td>
</tr>
<tr>
<td>.20</td>
<td>.30</td>
<td>363</td>
<td>581</td>
</tr>
<tr>
<td>.20</td>
<td>.35</td>
<td>171</td>
<td>274</td>
</tr>
<tr>
<td>.30</td>
<td>.40</td>
<td>441</td>
<td>706</td>
</tr>
<tr>
<td>.30</td>
<td>.45</td>
<td>201</td>
<td>322</td>
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<tr>
<td>.40</td>
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<td>480</td>
<td>768</td>
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<td>.75</td>
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</tr>
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<td>.80</td>
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<td>581</td>
</tr>
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<td>.70</td>
<td>.85</td>
<td>149</td>
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</tr>
<tr>
<td>.80</td>
<td>.90</td>
<td>247</td>
<td>395</td>
</tr>
<tr>
<td>.80</td>
<td>.95</td>
<td>93</td>
<td>149</td>
</tr>
</tbody>
</table>

### Apply what you have learned/case study

Using Table 4.5, find the sample size you would need to do an RDS survey of IDUs in your area. Justify your answer in terms of which indicator you are using and what the level of the indicator will be in wave 1 and wave 2.

### Summary

We sample when we desire to measure characteristics for a specified target population but lack the time and resources to obtain information from every member of the target population. Concentrating survey time and resources on questioning a sample of people can also result in better quality data than spreading resources over the entire population. It is important to understand sampling issues and options for behavioural surveillance. You should also follow the criteria for choosing the most appropriate sampling approach.

### Exercises

#### Warm-up review

Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make.
Small group discussion
Get into small groups by country, region or province to discuss this question.

a. What sampling strategies have you had experience with?

b. What difficulties and successes did you have with the strategy?

Apply what you have learned/case study
Try this case study individually. We will discuss the answer in class.

1. For each of the following groups, decide what is the best sampling strategy. Why is this the best strategy? What are the strong and weak points of using this method for the group?

   a. Group 1: Youth
   b. Group 2: MSM

2. Using Table 4.5, find the sample size you would need to do a respondent-driven sampling (RDS) survey of MSM. A survey of MSM in your city found that 80% of MSM could correctly name the ways that HIV was transmitted and ways that HIV could be prevented. Health education campaigns are planned for the coming year using MSM peer educators. You wish to show that HIV/AIDS knowledge improved by at least 10% by the following year. How many MSM do you need to include in this year’s survey and next year’s survey? Assume that knowledge may increase or decrease and you wish to have 80% power. What sample size would you need if you decided to use time-location sampling (TLS) instead of RDS?
Overview

What this unit is about

In this unit, you will learn the skills required to ensure behavioural surveillance data is analysed, disseminated and used appropriately.

Warm-up questions

1. True or false? It is better to share overall responsibility between different staff for the data management.
   - True  False

2. Data management does not include which of the following?
   a. data coding
   b. data entry
   c. data cleaning and checking
   d. data framing

3. True or false? The data manager should not be involved during the questionnaire design.
   - True  False

4. Which type of behavioural surveillance analysis is performed to determine whether one variable is related to the distribution of another (for example, an association between a respondent’s age and their use of condoms)?
   a. univarite
   b. bivariate
   c. multivariate

5. Most of the indicators defined for behavioural surveillance purposes are calculated through __________ analysis.
   a. univarite
   b. bivariate
   c. multivariate

6. When data is presented, it should be packaged appropriately for the __________.
   a. different audiences
   b. data collection sequence

7. True or false? The surveillance cycle ends when the official report is published.
   - True  False
8. True or false? Data from other sources, including other countries, can be used to fill in any important gaps as long as the source is made very clear.

   True   False

Introduction

What you will learn

By the end of this unit, you should be able to:

- discuss data management issues;
- describe the types of data analysis commonly used in behavioural surveillance;
- understand the steps in ensuring appropriate data analysis and use;
- list the different audiences for behavioural surveillance data;
- interpret and package data appropriately for the different audiences.

Data Management Issues and Activities

What is data management?

Collecting data is expensive, so efficient and effective data management is critical. Data management includes:

- data coding
- data entry
- keeping the data safe
- cleaning and checking the data
- getting the data ready for analysis (merging, coding, etc.)

These activities cost time and money, and can affect the quality and usefulness of the data. Data management should be considered prior to data collection. This is when it can be useful to establish simple data management guidelines, covering issues such as coding, storing questionnaires, data entry, and database management. You should follow these guidelines from the start, and document any deviations. You also need to make sure that data management is included on the agenda of surveillance meetings, so that it is considered by the whole surveillance team.

Issues to consider in data management

Personnel: Data managers with experience and skills are required to manage large and complex data sets. It is usually better for one person to have overall responsibility for the data than to share responsibility between different staff. The data manager should be involved during the questionnaire design stage, not only to review the questions, but to review the way in which the questionnaire is organized. Make sure that data entry clerks and interviewers receive adequate training to minimize errors. You should also make sure that their work is monitored carefully.

Computer capacity: Analyse likely computer capacity requirements carefully. Databases often take up more space than anticipated, and it is important to allow enough capacity for storage of data.
**Back-up routine:** Back up regularly to prevent loss of some or all of your data files.

**Audit trail:** Document everything you do and when you do it (for example, data entry, verification, corrections). Include notes about any queries. Recording changes to the master data set on paper provides an audit trail. You can also have an electronic logging system that records all changes.

**Data checking:** Data errors can be introduced at any stage of the surveillance process and it is therefore important to be vigilant throughout. Data checks should include:

- consistency checks by supervisors after data collection;
- double data entry, as it is unlikely that two people will make the same mistake;
- data-entry programmes that can check that values stay within specified realistic ranges;
- programmes written specifically to check for inconsistencies in the data, so any errors found can be checked back to the questionnaires and, if necessary, the fieldworkers.

**Database merging:** With several data entry clerks working on the data, and several copies of the database, you need a method for merging the data at the end of the data entry phase.

**Management of paper questionnaires:** Take care of the questionnaires, making sure they are protected from the elements and kept confidential. Signing questionnaires at each stage of the data collection (data checking) is a useful way to keep track of which data should be on the database and which are still to be entered.

**Storage and archiving:** Develop a system for archiving raw data. The data management system should document data effectively, allow you to find the data you need quickly, and keep data archives and back-ups safe, up-to-date and usable.

---

**Data Analysis**

**What is data analysis?**

Data analysis is summarizing, presenting and interpreting data. Behavioural surveillance analysis can either be:

- *cross-sectional* - analysing data from one surveillance round
- *trend* - analysing data over several surveillance rounds.

If probability sampling was used, statistical tests can tell us how well the sample measure estimates the true population measure. That is, they can tell us how likely it is that our findings could have occurred by chance sampling variation or whether they really represent true population values. You need special analytical techniques if the sample was a cluster sample or if the cluster sample did not use a self-weighted design.
Types of data analysis
There are three main types of analysis conducted in behavioural surveillance:

- **Univariate analysis**: This is the most basic type of behavioural surveillance analysis. However, it is often the most important, because it shows the distribution of each variable. Most of the indicators defined for behavioural surveillance purposes are calculated through univariate analysis. They would include variables like the proportion of young men who have had sex with more than one partner during a given time period. When trends are analysed, statistical techniques are used to calculate how likely it is that changes in the proportions could have occurred by chance, or whether observed changes are likely to reflect real changes.

- **Bivariate analysis**: This analysis is performed to determine whether one variable is related to the distribution of another. For example, there might be an association between a respondent’s age (the explanatory variable) and their use of condoms (the outcome variable). Variables are associated if the value of one tells you something about the value of another. Statistical tests in bivariate analysis determine whether any observed difference reflects a true difference, or may be due to chance.

- **Multivariate analysis**: This analysis is performed to look at the influence of at least two variables on another variable, since relationships between variables are often complex and interwoven. Multivariate techniques can pinpoint the individual effects of several explanatory variables on an outcome variable that may be related to each other.

Steps in data analysis and use
Follow these four steps when performing data analysis.

1. Develop an analysis plan.
2. Explore the data.
3. Use appropriate statistical techniques.
4. Interpret data.

Develop an analysis plan
Before data collection begins, an analysis plan should be produced. This ensures that the correct data are collected, and that sufficient time and resources are allocated to data analysis. The plan should include:

- Listing the questions surveillance needs to answer. This should be done in consultation with the final data users to ensure their data needs are met.
- Defining the indicators needed to answer these questions.
- Making mock-ups of key tables and graphs to ensure you know how all the data collected will be used.
- Identifying personnel with appropriate skills, software needs, etc. It can be important to involve statisticians from the start. If they understand the purpose of the research and are familiar with the questionnaires, they will provide more useful inputs than if they are just brought in at the end to do multivariate analysis.
- Allocating sufficient funds and time for analysis. Cross-checking, recoding and the creation of indicators is often what takes time rather than doing the actual analysis.
Explore the data
Data analysis itself is usually done by a trained statistician. Once the data have been collected and cleaned, the statistician should first explore the data so they understand the data coding and detect any errors in the data. This should be followed by producing frequency distributions of the variables and recoding the data to create the required indicators.

Use appropriate techniques
Once the descriptive summaries have been carried out, the statistician should look carefully at the results (such as checking for consistency in sample sizes and missing values) to see if the data make sense. These results will focus further analysis. Most behavioural surveillance analyses will be univariate and bivariate, but whatever analysis is used, it should start with simple analyses that have a broad focus. Key findings can be missed if analysis immediately focuses on details.

Data weighting and multivariate analysis add a layer of high science to analysis. Nevertheless, significant room for error remains and complex analysis is not always appropriate, particularly if data quality is poor or sample sizes are insufficient.

Interpret data
Surveillance data, like any other data, can often be interpreted in more than one way. How indicators are defined and the selective presentation of indicators can greatly affect how the data are interpreted. People are very often driven by their own personal bias to give greater weight to one interpretation than to another. In addition, sometimes people miss the whole story simply because they focus too closely on the details. People look at pieces of data as separate entities rather than as different aspects of the same story. The importance of examining information on population size, HIV prevalence, STI prevalence and risk behaviour together cannot be overemphasized. We will use the data in Table 5.1 to explore issues around data interpretation.

The validity of self-reported data on sexual behaviour and drug use is frequently questionable. This does not mean that surveillance data are worthless. One should merely be cautious about jumping to quick conclusions about small rises or falls in infection, and surprising findings in behavioural surveillance should be investigated further.

Table 5.1
Results of surveys on sexual behaviour among high school students (1998-2002) in which an abstinence-only sexual health education curriculum was introduced in late 1998 (three months after the first surveillance round)

<table>
<thead>
<tr>
<th>Year</th>
<th>Had sex in past year (% of all)</th>
<th>Had multiple partners in the last year (% of all)</th>
<th>Always used condoms (% of those with multiple partners)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>73</td>
<td>9</td>
<td>50</td>
</tr>
<tr>
<td>1999</td>
<td>70</td>
<td>11</td>
<td>48</td>
</tr>
<tr>
<td>2000</td>
<td>68</td>
<td>15</td>
<td>41</td>
</tr>
<tr>
<td>2001</td>
<td>58</td>
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<td>38</td>
</tr>
<tr>
<td>2002</td>
<td>48</td>
<td>24</td>
<td>35</td>
</tr>
</tbody>
</table>
Using Behavioural Surveillance Data

Steps in data use
Currently, a gap remains between the collection and use of data in most surveillance systems. One reason data are not better used is that surveillance systems are often fragmented. When no single entity is responsible for compiling, analysing and presenting data cohesively, the different groups involved in surveillance often consider their job done. Before data is used, forming a surveillance committee can help resolve this issue.

There are two steps to follow in using behavioural surveillance data:

1. Develop data use plan.
2. Present data.

Develop data use plan
Before data collection begins, produce a data-use plan. This helps ensure that information gets to the right people in a timely fashion and in a way they understand.

Developing this plan should be tied to identifying the country’s data needs and consequently the data audience (that is, who will use the surveillance data).

At this stage it can be useful to identify surveillance outputs for the different audiences and how they will be disseminated. These could include a national report on HIV/AIDS, policy briefs, press releases, etc. Once outputs are identified, sufficient funds and time can be allocated for these activities. If possible, networks for future advocacy should start being built before you go ahead with surveillance activities. It is very important to establish good relationships with policy-makers and other data users.

Some common data users include:

- politicians and policy-makers
- AIDS programme managers in the health and other sectors
- international agencies
- NGOs
- researchers
- populations included in the surveillance system
- surveillance system personnel
- the private sector
- the press
- the legal profession

Present data
Presenting data appropriately and accurately helps ensure it is used. When data is presented, it should be:

- Packaged appropriately for the different audiences: The different audiences will respond to the data presented in different ways. For example, face-to-face meetings,
videos or briefing sessions are often more effective ways to interest decision-makers than producing lengthy documents that they do not have time to read. Choosing the right product for the right audience will be covered in detail later in this unit.

- **Be clear about the limitations of the data (sample size, response rates, threats to quality, etc.):** Surveillance data do not need to be perfect. They just need to be good enough to give a reliable idea of the major trends in HIV infection and related risk behaviour. Once numbers get presented as stand-alone facts, the information that would help people gauge the quality of the data is often lost. Limitations in the data in terms of sample size, response rates, etc., need to be reported and the data should not be presented as more “scientific” than is possible in the context. For example, surveillance data are sometimes presented to two decimal points of accuracy, giving an air of statistical solidity, when presenting rounded numbers is a more accurate reflection of data quality.

- **Use all data sources available:** Surveillance systems rarely produce all of the data that meets local advocacy needs. Data from other sources, including other countries, can be used to fill in any important gaps as long as the source is made very clear.

- **Take care with the physical presentation of the data:** Most people who work in public health can look at a table or graph and understand what it means, but many people in other fields cannot. If needed, headlines should be used to tell people what the data mean rather than simply describing the data. Generally, graphics should be kept as simple as possible and free of clutter.

### Choosing the right product for the right audience

Public health officials often take one-size-fits-all approach to data use, believing that surveillance work ends when the official surveillance report is published. The report may indeed contain all the important information about the levels and trends of HIV and risk behaviours. However, the same data need to be presented differently for different audiences to be able to sell the key messages and get the data acted upon.

Successful advocacy follows a number of rules:

- Define your goals.
- Define your audience.
- Find out what influences the audience’s thinking and how to get their attention.
- Use the right language.
- Get the length right.
- Choose the best messenger.
- Get the timing right.

### Define your goals

Surveillance data can meet several goals and data needs. Each goal may have to be presented to different audiences in different languages.

### Define your audience

With whom must the public health official communicate to ensure that the goals defined are obtained? Who has the potential to push things forward and who could potentially obstruct progress?
Find out how to get their attention

Once the audiences have been identified, you must determine the best way of communicating with them and the key messages for the different audiences. The best communication occurs when people have something in common. Therefore, understanding the concerns, motivation and objectives of each audience is important. Once you understand their concerns, try to use the data to address these.

Use the right language

After you identify the goal, audience, key messages that will appeal to them and the data used to make the case, language is important. For example, will confidence intervals mean anything to the group or will they confuse the picture?

Get the length right

A report or presentation has no value if no one reads it or listens. This means fitting the key information into the time that people are prepared to dedicate to it. If HIV/AIDS is the core interest of your audience, they may appreciate a full report they can read through and keep for their reference. If HIV/AIDS is not a core area of interest, the audience is more likely to digest the information if it is presented in a one-page fact sheet or short brochure.

Choose the best messenger

People listen to the people they trust. For example, the minister of health may be the best person to present surveillance data at cabinet level, whereas young people may pay more attention to a pop star acting as an AIDS ambassador.

Get the timing right

HIV/AIDS is not the only issue on people’s agendas. One way of increasing the attention the message gets is to time the release appropriately. For example, avoid clashing with important events and make use of events already scheduled, such as World AIDS Day.

Note: Guidelines for the Effective Use of Data from HIV Surveillance Systems (2004) elaborates on how to present data for different audiences and provides good examples of how HIV data can be used.

Summary

Since there are several data management issues, efficient and effective data management is critical. Behavioural surveillance data analysis can either be cross-sectional or trend. It is important to understand the steps in ensuring appropriate data analysis. You should also understand the audiences for behavioural surveillance data and how to present and package data appropriately for the different audiences.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.
Small group discussion
Get into small groups by country, region or province to discuss this question:

Discuss the strengths and weaknesses of the data management, data analysis and data use system used for behavioural surveillance in your setting.

Apply what you have learned/case study
Try this case study individually.

How do you think data would be best presented to a senior politician in terms of language, length and messenger?
Overview

What this unit is about
In this unit, you will learn about ethical considerations and requirements in behavioural surveillance.

Warm-up questions
1. Match each ethical principle with its definition.
   - Respect for persons
     a. Refers to minimizing risk to individuals—not only physical risk, but also risk of psychological harm and stigmatization.
   - Beneficence
     b. Requires investigators to see study subjects not as passive sources of data, but as persons whose rights and welfare must be protected.
   - Justice
     c. Risks and benefits from studies should be distributed fairly and evenly in populations.

2. It is important that everyone the surveillance system encounters is treated with________, from community leaders and local officials to those surveyed.

3. What is informed consent?

4. Name two pieces of information that should be provided before a person can make an informed decision to take part in a survey?
   a.

   b.

5. True or false? In surveillance, written consent forms are the most appropriate way to document that the process of informed consent has occurred.
   True False

6. What are two ways to help ensure a participant’s confidentiality?
   a.

   b.

7. Match each of the following ethical issues with a potential solution:
   - Loss of earnings
     a. Ensure fully informed consent.
   - Increases discrimination of the group
     b. Conduct interviews outside work times.
   - Participants get no direct benefit from surveillance
     c. Do not foster false expectations.
Introduction

What you will learn
By the end of this unit, you should be able to:

- understand the basic ethical principles of working with human subjects
- define informed consent and the procedures that help ensure it;
- understand the importance of confidentiality and how to ensure it;
- discuss the ethical consideration unique to behavioural surveillance.

Ethical Principles of Working with Human Subjects
Three universally accepted ethical principles of working with human subjects are respect for persons, beneficence and justice:

- **Respect for persons** requires investigators to see study subjects not as passive sources of data but persons whose rights and welfare must be protected.
- **Beneficence** refers to minimizing risk to individuals - not only physical risk but also risk of psychological harm and stigmatization.
- **Justice** means that risks and benefits from studies should be distributed fairly and evenly in populations.

It is important that everyone the surveillance system encounters is treated with respect, from community leaders and local officials to those surveyed. This is important in every aspect of the study from engaging people in the study, to the way interviews are conducted, and in the importance of providing feedback to the participants and communities involved.

Informed Consent
Before being interviewed, respondents need to decide whether they want to participate in the survey or not. **Informed consent** means that you tell the person enough about the nature of the surveillance for them to make a proper (informed) decision about whether or not to take part.

No project staff should pressurize, coerce or deceive respondents in an effort to ensure their participation, and staff should also try to ensure that respondents are not pressurized by other family or community members. Ensuring that the decision is not influenced may involve discussions around the voluntary nature of participation with gatekeepers and including sections on informed consent in the fieldworker training and manual.

Information that should be provided
A person can only make an informed decision to take part in a survey (give their consent) when he or she has information about the procedures and purpose of the interview. During informed consent, subjects are provided with information about the survey, given an opportunity to ask questions and then given the opportunity to decide whether to participate or not. This information is usually provided on an information sheet, which the fieldworker reads to the participant. Studies have shown that getting voluntary and informed consent in developing countries is difficult. You must make sure that
the information sheet uses appropriate language, is not so long that participants stop listening, and contains all the essential information.

Information that is relevant to the subject’s decision on whether or not to participate includes:

- the nature of the survey (for example, who is conducting the survey, purpose of the survey, length of interview, type of questions, etc.);
- the potential risks and benefits;
- how the information will be used;
- how their privacy will be protected (names or addresses are not written);
- that participation is voluntary;
- that participants have the right to refuse to answer any questions or stop the interview at any time, especially as they may find some of the questions sensitive.

Documenting informed consent

Written consent forms are generally required to document that the process of informed consent has occurred. In surveillance, in order to ensure total confidentiality, it is usually best to obtain verbal consent. This means that the name of the respondent does not need to be recorded. There still needs to be some way of verifying consent, but rather than the participant’s signature, interviewers can sign a statement to verify that the respondent has been given the required information and has decided to participate.

Maximizing participation

Although consent must be voluntary, we want to try and maximize participation to reduce bias. Methods include keeping interviews as short as possible, conducting fieldwork at times that are convenient to the participants and stressing the altruistic benefits of participating. Reducing refusals is important because those who refuse to be interviewed may be different from those who participate, and if there are lots of refusals, our sample may not be like the population of interest and may be biased. We need to facilitate participation, but without being coercive.

Response rates should always be reported in the analysis. Participation bias should be assessed and taken into consideration in the analysis. Recording the following for each cluster can be useful for this assessment:

- number of target group members present at the cluster at the time of interview;
- number interviewed;
- number who refused to be interviewed, their reason for refusing and basic socio-demographic information about them;
- number that were not interviewed for other reasons;
- number rejected as duplicates.

Using incentives

Incentives can consist of cash payments for participation or small gifts, such as T-shirts. In general, incentives are considered appropriate for compensating or thanking study participants for time away from work and out-of-pocket expenses, such as transportation. However, higher payments may jeopardize the voluntary nature of informed consent.
They can create a situation where an individual’s decision to participate is unduly influenced by money or gifts.

Additionally, using incentives may result in a sample that is not like the population of interest because the sample is biased towards those who have a greater need for the incentive. This needs to be balanced against the fact that not using incentives may cause the sample to be biased towards those who are more cooperative.

Respondent-driven sampling provides incentives to participants to recruit additional members of the high-risk population to the study. These incentives can be considered ‘payment’ to the participant, who in their role as recruiters act as fieldworkers. This part of the methodology may be controversial in some settings, and may require explanation to the institutional review board reviewing and overseeing the study.

Confidentiality
Confidentiality protects subjects from adverse consequences that may arise from other people knowing that they participated or their responses. For example, if information about a person’s sexual preference is disclosed, he or she may suffer discrimination, stigma or even be subject to criminal charges. Potential threats to confidentiality, as well as measures taken to minimize them, should be discussed with the participants as part of the informed consent process. The main ways to ensure confidentiality include:

- Ensure names or other means of identification are not recorded on surveys.
- Store data safely and appropriately.
- Train fieldworkers on the importance of confidentiality.
- Have clear disciplinary procedures for staff who breach confidentiality.
- Identify problems and possible solutions related to confidentiality.

Threats to confidentiality
Threats to confidentiality include finding a private place to conduct interviews and stopping other persons or gatekeepers from being present during the interview.

The presence of other people breaches confidentiality and may cause the respondent embarrassment and influence some of his/her answers. In such cases, the interviewer can explain to the respondents that some questions are confidential and ask them to suggest a place where you are unlikely to be disturbed.

Sometimes fieldworkers hear stories during interviews that make them so sad that they need to talk about it. Fieldworker training should stress that although it is important to talk through depressing issues, this should only be done with other team members and in a way that does not easily identify the respondent.

Note: Issues around maintaining confidentiality are more complicated when surveillance wishes to link individuals’ behavioural and biological surveillance data.
Ethical Considerations Unique to Behavioural Surveillance

Working with high-risk groups

Some high-risk groups such as MSM, CSWs, and IDUs participate in illegal or stigmatized behaviour and there is the potential for surveillance to make this stigmatization worse.

A list of potential harms is listed in Table 6.1 below.

Table 6.1
Potential harms caused by behavioural surveillance in high-risk groups

<table>
<thead>
<tr>
<th>Potential harms caused by behavioural surveillance in high-risk groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Physical (public attack, abuse, loss of health-care services)</td>
</tr>
<tr>
<td>• Legal (arrest, prosecution)</td>
</tr>
<tr>
<td>• Social (disclosure to family, workplace, discrimination, loss of employment, isolation)</td>
</tr>
</tbody>
</table>

If high-risk group members fear that information about their behaviour may be used against them, they may refuse to participate in the surveillance activities. Worse than this, they may participate and the results of the surveillance may lead to greater stigmatization or crackdowns by law enforcement agencies. Other potential ethical issues and potential solutions are identified in Table 6.2.

Although there are potential negative outcomes of identifying groups or behaviours in surveillance, there are also ethical issues in not including groups and individuals in prevention and treatment activities.

Table 6.2
Potential ethical issues and solutions of being included in behavioural surveillance

<table>
<thead>
<tr>
<th>Potential ethical issues</th>
<th>Potential solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increases stigmatization and discrimination of the group</td>
<td>• Ensure fully informed consent and absolute confidentiality.</td>
</tr>
<tr>
<td></td>
<td>• Reporting should be neutral.</td>
</tr>
<tr>
<td></td>
<td>• Reporting needs to be accompanied by public health communication about negative impact of stigma and discrimination on the epidemic.</td>
</tr>
<tr>
<td>Loss of earnings</td>
<td>• Keep interview as short as possible.</td>
</tr>
<tr>
<td></td>
<td>• Remunerate lost earnings.</td>
</tr>
<tr>
<td></td>
<td>• Conduct interviews outside work times.</td>
</tr>
<tr>
<td>Gatekeepers get angry at those who participate</td>
<td>• Involve and work with the gatekeepers, stress the benefits of surveillance.</td>
</tr>
<tr>
<td>Gatekeepers force participation</td>
<td>• Involve and work with the gatekeepers, stress the benefits of surveillance.</td>
</tr>
</tbody>
</table>
Illegal activities are highlighted, resulting in a police crackdown

- Involve and work with law enforcement agencies so they understand the purpose of surveillance and the damage that could result from them conducting repressive measures, such as scattering the high-risk groups or driving groups underground.

Participants get no direct benefit from surveillance

- Report findings back to survey population.
- Explain the indirect benefits during the informed consent procedure.
- Do not foster false expectations.

Working with adolescents

Different countries will have different laws and standards about when an adolescent can participate in research involving sexual behaviours, and when parental consent is required. Familiarize yourself with these laws in your country as part of your initial formative research efforts. Generally, surveillance tries to minimize the number of participants in the age range of 15-18 years, and avoid including those under 15. If it is necessary to include children under the age of 15, special guidance on research with children should be sought.

Benefits to participants

In some countries, surveillance is accompanied by an intervention. Some would argue that surveillance is unethical in the absence of an intervention. However, usually incentives (the ethical issues of which are discussed above) are the only direct benefits of participating. It is essential not to foster false expectations of direct benefits to participants. However, there are indirect benefits that should be stressed during the informed consent procedure and during community entry. These benefits are shown in Table 6.3.

Table 6.3

Potential benefits from behavioural surveillance

- Improving HIV prevention and care programmes
- Raising public awareness of burden of disease in the population, sympathy
- Reducing stigma, effecting social change, especially around HIV infection
- Feedback of results to the community
- Incentives

Fieldworkers may be asked for assistance from participants (for example, transporting a sick person to a health facility). There are limits to what is practical. Each country will need to decide this with reference to the local context. They should not make any promises they cannot keep.

Surveillance as research

Public health surveillance is usually not considered research and does not have the same requirements as research for documenting and reviewing ethical procedures. Although these ethical safeguards are not ‘required,’ they are still an essential part of surveillance, and procedures should go through local ethics committees and institutional review boards.
Summary
During behavioural surveillance, you should adhere to the universally accepted ethical principles of working with humans: respect for persons, beneficence and justice. A person can only make an informed decision to give his or her consent to participate when he or she has information about the procedures and purpose. Confidentiality protects subjects from adverse consequences that may arise from other people knowing their responses or that they participated. It is important to understand the potential ethical issues and some solutions of being included in behavioural surveillance.

Exercises

Warm-up review
Take a few minutes now to look back at your answers to the warm-up questions at the beginning of the unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion
Get into small groups by country, region or province to discuss these questions.

1. What are some of the potential social harms caused by behavioural surveillance in high-risk groups in your setting?

2. What ethical issues/difficulties have you/could you experience conducting surveillance in your country?

Apply what you have learned/case study
Try this case study individually.

Design a consent form to be used with female sex workers.
Overview

What this unit is about

In this unit, you will learn about the theoretical and practical knowledge required to plan behavioural surveillance activities. You will learn about the information that should be collected during the pre-surveillance assessment and the methods you can use to collect this information.

Warm-up questions

1. Which of the following is an example of a question you should answer in order to select appropriate geographical areas during the pre-surveillance assessment? Circle your answer.
   a. What are the regional differences in terms of HIV transmission and risk behaviour?
   b. Where are the interventions located?
   c. How much money and staff are available for surveillance?
   d. All of the above

2. Match each pre-surveillance assessment method with its description.

   _____ Assess what is currently known about the national epidemic or sub-epidemic.
   - a. This step involves reviewing existing surveillance data, published and unpublished literature, and talking to people who are knowledgeable about the epidemic.

   _____ Conduct pre-surveillance assessment using qualitative assessment methods and mapping.
   - b. You can perform this step using existing information from general population surveys or collecting the information if none exists.

   _____ Gather information on risk behaviours and HIV levels in the general populations.
   - c. This step involves fieldwork to further identify hotspots and to gather information to define populations to be included in surveillance and guide fieldwork.

3. Methods used in _____________ research include large sample size, random samples and shorter interviews. Methods used in _________ research include unstructured questionnaire, lengthy interviews and fewer well-trained fieldworkers.
   - a. qualitative
   - b. quantitative

4. Suppose you want to determine in which areas of a city street-based sex occur. Which of the following is not an appropriate method to use during a pre-surveillance assessment?
   - a. literature/data review
   - b. in-depth qualitative interviews
Introduction

What you will learn
By the end of this unit, you should be able to:

- identify and understand the purpose of the pre-surveillance process;
- understand and select the methodologies used in the pre-surveillance process.

Purpose of Pre-Surveillance Assessment

Identify populations and areas
The selection of surveillance populations should be based on a solid understanding of the epidemic dynamic in a country. The selection of geographical areas should reflect whether data is most meaningful if collected at national or sub-national level. Several questions must be answered to gain this understanding.

Key questions in order to answer to select surveillance populations:

- Should surveillance concentrate on sub-populations, the general populations or both?
- Who are the most vulnerable populations (that is, those already infected with HIV or who have high-risk behaviours)?
- For each potential group, what is their potential contribution to the epidemic (how big are they, what links do they have to other populations, what types of risky behaviours do members engage in, with whom and with what frequency)?
- How will the populations contribute to understanding the epidemic?
- What interventions have been implemented or are planned among the populations?
- Is the population accessible for surveillance?

Key questions to answer in order to select geographical areas:

- What is already known about the epidemic in different regions of the country?
- What are the regional differences in terms of HIV transmission and risk behaviour?
- Where are the highest risk populations concentrated?
- What is the estimated size of the high-risk population in each geographic area?
- Are there cross-border or internal transportation routes that could fuel transmission?
- Are the data needs at the national or sub-national level? At what level do we want to be able to generalize to?
- Can some areas serve as proxies for others?
- Where are the interventions located?
- Which locations have biological surveillance?
- How much money and staff are available for surveillance?
Determine feasibility

A successful surveillance system requires a feasible and effective data collection plan in order to enhance surveillance population participation, facilitate fieldwork and ensure appropriate sampling strategies are used. Several questions must be answered through the pre-surveillance assessment to ensure this.

Key questions to answer in order to ensure the participation of the surveillance populations and to facilitate fieldwork:

- Who are the gatekeepers of the populations?
- Whose permission is needed to conduct surveillance?
- Who can facilitate the survey process and make sure it runs smoothly and without disruption?
- In what language should the interview be conducted?
- What is the desired profile of the interviewers to ensure the most valid results?
- What are the possible locations where surveillance data could be collected where privacy will be ensured?
- What will be the best times of the day to find participants and to ensure that they will have time to complete the interviews?
- What practical problems could fieldworkers come across (for example, ensuring privacy, safety)?

Key questions to answer in order to ensure appropriate sampling strategies are used:

- Does a high proportion of the group gather at identifiable locations that can be listed and are they accessible through those locations?
- Do group members know each other? Are they part of a network?
- Can the same individuals be found at more than one location?
- Is it possible to identify the members of the sub-population at the locations where they gather?

Define groups and eligibility criteria

One of the biggest sources of error in surveillance is a failure to track populations in a consistent manner over time. This sometimes happens because a population is not defined in sufficient detail. For example, there are many ways to define female sex workers. It is thus crucial to have a clear operational definition of what a female sex worker is and to have specific eligibility criteria of who can and cannot be included in surveillance.

Key questions to answer to define populations and set eligibility criteria:

- Are the risky behaviours in a population diverse (for example, for commercial sex workers how, when and where they operate)?
- Can the group be divided by differences in their behaviours and organization?
- What characteristics can be used to identify group members?
Pre-Surveillance Assessment Methods

Three methods should be used for the pre-surveillance assessment:

1. **Assess what is currently known about the national epidemic or sub-epidemic:** This step involves reviewing existing surveillance data, published and unpublished literature, and talking to people who are knowledgeable about the epidemic to make a ‘first cut’ at identifying potential hotspots and at-risk or vulnerable populations.

2. **Conduct pre-surveillance assessment using qualitative assessment methods and mapping:** This step involves fieldwork to further identify and verify hotspots as well gathering information to clearly define populations to be included in surveillance and to guide surveillance fieldwork.

3. **Gather information on risk behaviours and HIV levels in the general populations:** This can be done using existing information from general population surveys or collecting the information if none exists. This information can be used to help validate whether the so-called high-risk populations are really at higher risk than the population at large.

Methodological Details

**Reviewing existing data**

There are several sources of information that need to be reviewed. These include the peer-reviewed scientific literature, abstracts from regional and international AIDS conferences, *grey literature* (literature that is not published in easily accessible journals or databases—for example, programme evaluations and governmental reports) and basic surveillance data.

Peer-reviewed literature can be located using internet-based search engines, such as Entrez PubMed from the U.S. National Library of Medicine. Particular care needs to be taken with specifying keywords and search terms.

- If terms are too general (for example, HIV), thousands of studies will be identified.
- If terms are too specific (for example, mentioning a specific city), nothing may be found.
- A good approach is to start with the name of your country and the keyword HIV.
- Additional search terms can be added, such as the name of the high-risk group.
- Once studies have been identified, accessed and reviewed, their bibliographies should be reviewed to identify other sources your search may not have identified.

Grey literature can also be located using the Internet. The UNAIDS website, http://www.unaids.org, is a resource for accessing this literature. UNAIDS compiles epidemiological fact sheets about each country involved in HIV/AIDS prevention programmes, as well as specific populations.

In addition, it is helpful to identify prevalence studies that report on the populations in question. A good example of this type of data can be found in the database at the United States Census website for HIV and AIDS surveillance. You will find various country
profiles that examine the patterns and trends of the epidemic, as well as maps and tables that serve to summarize the statistics for each region in a streamlined format (http://www.census.gov/ipc/www/hivaidsn.html).

Governments, donors or non-governmental organizations produce monitoring and evaluation reports. These can sometimes be accessed through the Internet. Often, you will need to contact governmental officials or representatives of the donor or non-governmental organizations to obtain copies.

**Qualitative and quantitative research**

*Qualitative research* focuses on the characteristics, or quality, of things, rather than the quantity. *Quantitative research* has powerful tools for the analysis of numbers, but researchers all know that the things counted are often qualitative categories or definitions.

For example, the number of AIDS cases a country has is dependent on the AIDS case definition. The case definition has changed several times and will probably continue to change. For the AIDS case definition, at least we can think of a way to get a standard definition: put the experts and the organizations in a room and do not let them out until they agree.

Along the spectrum of HIV disease, the point where AIDS is said to begin is completely definable by experts. However, when we talk about human behaviour, we do not have this luxury.

- If you ask someone how many sexual partners they have had in the last six months, the answer depends on what that person means by partner or means by sex. It also depends on whether they have any reluctance (or the opposite) to talk about these behaviours.
- This is in addition to the normal problems of self-reported survey research, such as recall and reporting biases or the need to meaningfully translate questionnaires.
- Luckily, these definitions and reluctances are not completely individualized. Groups tend to share these definitions and dispositions.

The questions we want to answer as part of our pre-surveillance activities do not require precise and generalizable (macro) quantitative measures of how many people have certain knowledge or perform a certain behaviour, which can be generalized on a population level. After all, the surveillance itself can do this.

Rather, it requires an in-depth (micro) knowledge of such things as:

- the performance of a behaviour (for example, sex work or injecting drugs);
- knowledge of a group’s identity if it is so organized;
- what people who are like them or in the group do;
- an understanding of how and why they do it.
This can provide a description of the:

- material circumstances of the performance of the behaviour
- how that behaviour is organized
- what the participants and larger society think about the behaviour;
- the people who perform it.

Equally, this research can help explain how people think about the risk associated with the behaviour and how they (both individually and as a group) deny or change their behaviour to accommodate the risk.

Qualitative researchers often talk of the need to present an insider’s view (an *emic* view) in order to understand what people mean when they reply to questions in an interview. Because people try to make sense of their lives and tie the way they live and how they think about it together, researchers also talk about the culture of a group.

*Culture* (as it is used here) is a kind of language that fuses the circumstances and rationales for behaviour into a logic that makes sense from that insider’s point of view. From the outside, it may not appear to make any sense. For example, street children often deny the risk of AIDS from unprotected sex because they are so preoccupied with daily survival that an illness that might strike them in ten years seems irrelevant.

**Difference between qualitative and quantitative methods**

The differences between qualitative and quantitative methods outlined above translate into practical differences in methods, as shown in Table 7.1 below.

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large sample size</td>
<td></td>
<td>Small sample size</td>
</tr>
<tr>
<td>Random sample</td>
<td></td>
<td>Purposeful sample</td>
</tr>
<tr>
<td>Calculated sample size</td>
<td></td>
<td>Theoretical sample size</td>
</tr>
<tr>
<td>Structured questionnaire</td>
<td></td>
<td>Unstructured questionnaire</td>
</tr>
<tr>
<td>No deviation for interviewers</td>
<td></td>
<td>Interviewer exploration encouraged</td>
</tr>
<tr>
<td>Shorter interviews</td>
<td></td>
<td>Lengthy interviews</td>
</tr>
<tr>
<td>More fieldworkers, but they are less skilled</td>
<td></td>
<td>Fewer fieldworkers, but they are well-trained</td>
</tr>
</tbody>
</table>

Imagine we want to determine if we need to sub-divide commercial sex workers into sub-populations. In order to define the different types of commercial sex work, there would be little point interviewing people randomly selected from the population. Instead, we need to determine who could best provide us with this information.
Informants could include:

- sex workers
- NGOs who work with CSWs
- brothel/bar owners
- clients of sex workers and pimps

Once the types of informants are determined, interviewees should be selected for their competence as an informant. A good informant is:

- knowledgeable about the topic;
- a person you can talk to easily;
- someone who understands the information you need and is willing to give it to you.

**Saturation sampling**

Unlike quantitative surveys, the sample size for qualitative research is not calculated prior to data collection.

A common way of determining sample size in qualitative research is known as *theoretical* or *saturation sampling*. This involves continuing to interview informants until no new information is learned.

We could, for example, ask informants to list all the different types of places they know where women sell sex. When the lists begin to be repetitive and informants are not providing new information, an adequate sample size has been reached. Among those involved in commercial sex work, the types of commercial sex workers can be considered common cultural knowledge and a complete list of types of workers can probably be determined from only a few good informants.

Once the different types of sex work have been identified, we need to determine if they need to be considered as separate surveillance groups. For this we need to understand how the different types of sex workers or different places where they operate affect risk and transmission. This is best explored using *open-ended semi-structured interviews*.

**Open-ended semi-structured interviews**

Open-ended questions have no answer choices from which respondents may select their response. Instead, respondents must create their own answers and state them in their own words. Using open-ended questions allows topics to be covered in more depth and can stimulate thoughtful responses, including suggestions from the respondent for the researchers, probing of people’s memories and the clarification of positions.

Probing is often necessary to avoid incomplete, uninterpretable or irrelevant answers and interviews tend to be much longer and require more skill to conduct than interviews conducted as part of large sample social science surveys.

A semi-structured interview is one that uses a written list of open-ended questions and topics that need to be covered, although not necessarily in a particular order.
Interviewers are encouraged to deviate from the guide when necessary to follow up new leads on the topic. These methods are in contrast to quantitative research, which tries to ensure that each informant is asked exactly the same questions in exactly the same way.

To continue our example, let us say we uncover two major kinds of sex workers in our discussions with expert informants and sex workers themselves: brothel-based and street-based. Before we classify one or both of them as a surveillance population we would want to know such things as:

- whether street-based sex workers worked routinely or only occasionally;
- whether they worked on the same streets or were constantly shifting in response to police or other pressure;
- whether sex workers moved back and forth between the two settings;
- whether they had many clients or only a few;
- other issues that might affect their risk profile and feasibility of selection as a surveillance population.

Certainly epidemiological risk can only be determined in risk factor studies, but these preliminary studies identify the populations and methods to apply surveillance to.

Qualitative methods useful during pre-surveillance activities include:

- key informant/expert interviews;
- focus groups and in-depth interviews;
- observation.

**Expert interviews**

You may need to interview colleagues in the local offices of the Ministry of Health, those involved in behavioural and biological surveillance, local NGOs, clinics and donor agencies in your area that work with the HIV/AIDS epidemic. These are called expert interviews because they utilize respondents who are, by virtue of special training or their work with the population, experts and have equivalent status to the researchers. These can be confused with key informant interviews. Key informants are members of the group, and often become informal assistants to the researcher. Expert interviews utilize the semi-structured open-ended interviews described in the example above.

**Focus groups and in-depth interviews**

Both in-depth interviews and focus groups use semi-structured open-ended interviews. However, in-depth interviews are less structured, and permit the respondent to talk about a wide range of issues related to the topic and themselves. These interviews can be more like conversations, and the conversations permit rapport to be developed between the researcher and the respondent. In-depth interviews can be conducted over several sessions. In-depth interviews are conducted with members of the high-risk group rather than external experts such as government officials.

Focus groups are group interviews that are designed to initiate conversations within the group so that the researchers can listen to how these ideas are expressed. They are
relatively less useful for a pre-surveillance assessment for behavioural surveillance, as their primary goal is to generate intervention ideas, to test materials and to determine social norms about things members of the group can talk about in front of other focus group participants.

Because the interviews are, in a sense, public, it may be difficult for a respondent to express private thoughts or talk about truly intimate behaviours. Similarly, the group interview can be manipulated by one or several influential members, and responses can be quite skewed.

To encourage openness in focus groups, gather together people from similar backgrounds or experiences to discuss a specific topic. A group usually consists of 8-12 people and is guided by a facilitator and a record taker who takes notes. Because of the group dynamics involved, facilitators need to have special training and be quite skilful. This is another reason why expert and in-depth interviews are the most common interviews used for pre-surveillance assessment.

**Direct observations**

This is a somewhat more advanced technique that involves passively observing the high-risk population in question to determine where and when it congregates. For instance, street-based sex workers may be observed to determine in which areas of a city they work and the times that they tend to begin and end work. Observation may be associated with discussions or conversations with respondents being observed. When this is carried out over a sufficient time to be acknowledged and accepted by the group being observed, it is called participant observation.

**PLACE**

The PLACE (Priorities for Local AIDS Control Efforts) protocol is a new rapid assessment tool used to identify high transmission areas that formalizes the collection of information on high transmission areas. PLACE uses key informants to identify sites where people meet new sex partners, then interviews people at the site to characterize the site in each area and map sites. PLACE also interviews individuals socializing at the site to describe the characteristics of the people at the site.

**Evaluating the Current State of Surveillance**

The first step in improving a country’s surveillance system is to evaluate the current system and identify what is working well and where gaps remain. As you assess your strengths and weaknesses, key issues to consider include:

- Are the goals and objectives of the surveillance system clearly stated?
- Are there standard protocols and mechanisms used to collect data?
- How effective are the various components of the surveillance system: data collection, questionnaires, etc.?
- Is the acquired information being used and adequately disseminated?
Summary

It is important to understand the theoretical and practical knowledge required to plan behavioural surveillance activities. The first step in improving a country’s surveillance system is to evaluate the current system and identify what is working well and where gaps remain. As you assess your strengths and weaknesses, consider the key issues. To collect information during the pre-surveillance assessment, there are several methods you can use.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups by country, region or province to discuss these questions.

1. Read the sections about reviewing existing data, qualitative research and the PLACE methodology. Discuss the methods and share your experiences using such methods.
2. Identify three strengths and three weaknesses in your country’s behavioural surveillance system. Keep in mind the surveillance steps as you identify their strengths and weaknesses. Key issues to consider are:
   - Are the goals and objectives of the surveillance system clearly stated?
   - Are there standard protocols and mechanisms used to collect data?
   - How effective are the various components of the surveillance system: data collection, questionnaires, etc.?
   - Is the acquired information being used and adequately disseminated?

Apply what you have learned/case study

Try this case study individually. We will discuss the answers in class.

Make a list of all the things that need to be done before data collection begins.
Notes
In this case study, answer the questions for each section before moving on and reading the section.

Part I

Global campaigns have focused on the fact that 50% of new HIV infections occur in people under the age of 24 - an age at which people are discovering their sexuality and likely to be engaging in risk behaviour.

In a country with a rapidly growing epidemic, the national surveillance data was pooled and analysed by age. It was found that some 68% of all existing infections were among young people under 25.

A front-page article in the leading newspaper reports that behavioural surveillance among secondary school children had turned up shocking indicators: over half of the students had multiple sex partners and only 20% used condoms1.

As a ministry of health official:

- What specific programme(s) might you implement in response to these data?
- To what population(s) will you target your programmes?
- What additional information do you need to make better programming decisions?

Part II

The Ministry of Health reacts rapidly, successfully lobbying for an allocation of US $4 million to develop life-skills curriculum focusing on helping young people to avoid unsafe sex. The programme is implemented quickly.

Two years later behavioural surveillance is repeated. The good news is that multiple partnerships among youth dropped from 50% to 25% and reported condom use doubles. However, the number of infections in young people reported by the HIV surveillance system has continued to grow2.

As a Ministry of Health official:

- How will you explain these data? What might account for them?
- What does this information tell you about your current HIV/AIDS programming? Would you make any changes?

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1,2 Extract from the data-use module: Using data from HIV surveillance systems: Guidance on effective use of data from second generation surveillance systems: Elizabeth Pisani.
Part III

A parliamentary committee orders an inquiry. Public health officials go back to the behavioural surveillance data. It turns out that the indicators reported in the baseline year were not inaccurate, in that half of all students who had had sex in the previous year had multiple partners and only 20% had used condoms. However, closer inspection of the data revealed that:

• Only 8% of all students had ever had sex at all, and only 4% had been sexually active in the past year;
• 10% of all secondary school students had reported injecting drugs in the previous year and by the second round of behavioural surveillance that proportion had increased to 14%.

These very high rates of injecting drug use had been overlooked because health officials, the press, and other agencies were looking for evidence of unprotected sex.

The ministry of health quickly ordered an assessment of injecting drug use and found that 85% of injectors were under the age of 25. Life-skills programmes were subsequently redesigned to focus more on helping young people stay away from drugs. Harm reduction programmes were redesigned for those already injecting drugs, and injecting drug users were added as a group to the national surveillance system.

What specific lessons can be drawn from this example?
Module 5 Summary

- Surveillance is the systematic, regular and ongoing collection and use of data for public health action. Although they are often the beginning of a surveillance system, one-time cross-sectional surveys should not be considered surveillance.

- Behavioural surveillance involves regular, repeated cross-sectional surveys collecting data that can be compared over time on HIV risk behaviours and other relevant issues. Biological surveillance also involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses such as sexually transmitted infections (STIs) and TB.

- The uses of behavioural surveillance include the following:
  - provide an early warning of which groups and areas infection is likely to spread in and between;
  - explain changes in HIV prevalence over time;
  - provide information for developing prevention programme;
  - monitor and evaluate the impact of prevention programmes;
  - reinforce the findings of biological surveillance;
  - raise the awareness of HIV among policy-makers.

- Considerations when designing a behavioural surveillance system include:
  - whom to include in surveillance;
  - where to access the surveillance populations;
  - how to link biological and behavioural surveillance data;
  - how to ensure surveillance is appropriate for the context.

- The two most difficult issues defining behavioural surveillance indicators are defining the behaviours themselves and defining the time period the indicator should refer to.

- In observational studies, measurement error can come from:
  - questionnaire faults
  - interviewer error
  - respondent error

- Data collection methods that can be used in behavioural surveillance include:
  - face-to-face interviews
  - self-administered questionnaires
  - computer-assisted method

- General population survey instruments that are widely used, considered to use solid sampling procedures and thorough statistical analysis, and are usually considered a reliable source of behavioural data include:
  - demographic and health surveys (MACRO)
  - Multiple Indicator Cluster Survey (UNICEF)
  - behavioural surveillance surveys (FHI)

- The target population is the population that is the ideal one for meeting a survey’s measurement objective. The survey population is the target population modified to take into account practical considerations. (For example, all commercial sex workers in a city over the age of 15, excluding those who are based at home, as these cannot be accessed.)

- Issues for sampling include:
  - Consistent sampling is required across survey rounds.
• General population surveys can rarely be used to access high-risk groups.
• Cluster sampling can be difficult when clusters are not stable.
• Members of high-risk groups may be difficult to identify and access.
• Cluster sampling is impossible if group members do not congregate.
• Behavioural surveillance sampling options include:
  • conventional cluster sampling
  • time-location sampling (TLS)
  • respondent-driven sampling (RDS)
• Data analysis is summarizing, presenting and interpreting data. Behavioural surveillance analysis can either be:
  • cross-sectional - analysing data from one surveillance round
  • trend - analysing data over several surveillance rounds
• Informed consent means that you tell the person enough about the nature of the surveillance for them to make a proper (informed) decision about whether or not to take part.
• Potential harms caused by behavioural surveillance in high-risk groups include:
  • physical (public attack, abuse, loss of health-care services)
  • legal (arrest, prosecution)
  • social (disclosure to family, workplace, discrimination, loss of employment, isolation)
• Potential benefits from behavioural surveillance include:
  • improving HIV prevention and care programmes;
  • raising public awareness of burden of disease in the population, sympathy;
  • reducing stigma and effecting social change, especially around HIV infection;
  • feedback of results to the community;
  • incentives.
• The purpose of pre-surveillance assessment is to:
  • identify appropriate surveillance populations and geographical areas;
  • determine feasibility of conducting surveillance in high-risk populations;
  • operationally define high-risk groups and set eligibility criteria for inclusion of population members in surveillance.
• Three methods should be used for the pre-surveillance assessment:
  • Assess what is currently known about the national epidemic or sub-epidemic.
  • Conduct pre-surveillance assessment using qualitative assessment methods and mapping.
  • Gather information on risk behaviours and HIV levels in the general populations.


Available at: http://w3.whosea.org/EN/Section10/Section18/Section348_9917.htm


ACASI: Acronym for ‘audio computerized assisted survey instruments CASI.’

Accuracy: Refers to how well the sample reflects the study population.

Acquired Immunodeficiency Syndrome (AIDS): The late stage of HIV infection that includes development of one or more opportunistic illnesses (illnesses that occur because of low levels of CD4 lymphocytes).

AIDS: See ‘Acquired Immunodeficiency Syndrome.’

BED capture-EIA test: This test detects an antibody to a small HIV protein, gp41. It was first tested in HIV types B, E and D, hence its name BED.

Behavioural surveillance: Surveys of HIV-related behaviour that involve asking a sample of people about their risk behaviours, such as their sexual and drug-injecting behaviour.

Bias: A systematic error in the collection or interpretation of data.

Biological surveillance: Surveillance that involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses, such as sexually transmitted diseases and tuberculosis.

Bivariate analysis: One of the main types of behavioural surveillance analysis that is performed to determine whether one variable is related to the distribution of another. For example, there might be an association between a respondent's age (the explanatory variable) and their use of condoms (the outcome variable). Variables are associated if the value of one tells you something about the value of another. Statistical tests in bivariate analysis determine whether any observed difference reflects a true difference, or may be due to chance.

BSS: Acronym for ‘behavioural surveillance survey.’

CASI: Acronym for ‘computerised assisted survey instruments.’

Census sampling: Every unit, or case, is measured for the entire population. A de facto census allocates persons according to their location at the time of enumeration. A de jure census assigns persons according to their usual place of residence at the time of enumeration (Last).

Chain referral sample: Any sampling method wherein participants refer other potential participants for inclusion in the sample. There are several types of chain referral sampling methods, most of which are non-probability samples. Examples of chain referrals include RDS, network sampling, random walk and snowball sampling.
**Characteristic**: A definable or measurable feature of a process, product, or variable.

**Clinic-based surveys**: Surveys that use samples that have been selected in clinical facilities, such as STI or drug treatment clinics. The most common type of the clinic-based surveys that are done using biological markers, such as HIV infection, is clinic-based sentinel serosurveillance.

**Cluster**: Any aggregate of the population of interest (for example, departments, villages, health facilities, etc.).

**Cluster sampling**: The population of interest is broken into groups or clusters and a sample of clusters is randomly selected (Levy & Lemeshow).

**Cohort studies**: Cohort studies follow a group of initially uninfected people over time, and test them repeatedly. Cohort studies follow a well-defined group of people with a common experience or exposure, who are tested repeatedly over a long period of time.

**Community-based surveys**: Surveys that use samples that have been selected from non-clinical settings. They often include high-risk groups, such as sex workers or truck drivers, who are not included in clinic-based surveys. As with clinic-based surveys, the most common type of community-based survey is called 'repeated cross-sectional community-based sentinel serosurveillance.'

**Community sites**: Locations in the community, such as households or brothels.

**Concentrated HIV epidemic**: The epidemic state in which HIV has spread to a high level in a defined subpopulation but is not well established in the general population. (HIV prevalence is consistently >5% in at least one defined subpopulation and is <1% in pregnant women in urban areas.)

**Confidence interval**: The compound interval with a given probability, for example, 95% that the true value of a variable such as mean, proportion, or rate is contained within the limits.

**Confidentiality**: Protecting information that concerns a study participant or patient from release to those who do not need to have the information.

**Consecutive sampling**: This sampling method consists of sampling every patient who meets the inclusion criteria until the required sample size is obtained or the survey period is over. While this method is not strictly a probability sample, it is easier to use and offers less occasion for sampling bias.

**Convenience sampling**: The selection of entities from a population based on accessibility and availability. Available participants may be people on the street, patients in a hospital or employees in an agency. This type of sampling does not generally represent the population of interest and is best used in the exploratory stage of research.
Coupon: Used in RDS studies to provide incentives to participants. Coupons in RDS can be used both to track participation for reimbursements and to link the recruiters to the recruits. Other methods may use coupons to encourage participation, much like the advertisements placed in popular clubs or bars. Some coupons may have two parts that can be easily separated. One part of the coupon serves as the referral coupon, which the recruiter uses to recruit a peer into the study. The other part of the coupon serves as the payment coupon. It is kept by the recruiter and he or she will use it to claim an incentive for having recruited a peer into the study. Both parts of the coupon have the unique identification number of the recruitee printed on them. The dual system eliminates the need to collect names for incentive collection.

Coupon rejecters: People who are offered a coupon by a recruiter, but decline to take it.

Cross-sectional survey: A survey that is conducted over a given period of time, such as during a single year, rather than over an extended period of time.

Cruising area: Cruising areas are public spaces, such as parks, public restrooms, bath houses, dance clubs and railway stations where MSM meet, congregate and arrange and/or engage in sexual activity.

CSW: Acronym for ‘commercial sex workers.’

Descriptive statistics: Used to describe the basic features of the data, they provide simple summaries about the sample and the measures.

DHS: Acronym for ‘demographic and health surveys.’

Differential recruitment: Recruiters successfully bring recruits in at different rates.

Emic: Refers to accounts, descriptions, and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the members of the high-risk group.

Enumeration units: The sampling units from the final stage of a multistage sampling design. See ‘Listing units.’

Epidemic: The occurrence of a disease (or other health-related event) at a level of increase to a baseline. For example, the high prevalence of HIV found in many parts of the world today, including sub-Saharan Africa, Latin America and South and South-East Asia.

Equilibrium: The point in the recruitment process where a variable is not expected to change by more than 2% with each successive wave.

Ethnographic assessments: Ethnographic assessments are written analyses of the cultural practices, beliefs and behaviours of a particular culture, network or sub-group.
**Ethnographic mapping:** Ethnographic mapping involves collecting information on the geographic location, temporal movement of and interactions among members of high-risk groups.

**External validity:** The ability to make inferences from the study sample to the population of interest.

**Gatekeepers:** Persons who can provide access to a high-risk population. Examples are a brothel owner who can provide access to female sex workers, or a prison warden who can provide access to prisoners.

**Female sex workers:** Females who engage in sex work, or the exchange of sex for money, which includes many practices and occurs in a variety of settings. These may include ‘direct’ or ‘formal’ sex workers, who are sometimes included in registries and often found in brothels, and ‘indirect’ or ‘casual’ sex workers, who do not engage in sex work full time and are unlikely to be included in registries.

**Formative research:** Research conducted before the study begins. Researchers use qualitative methods, such as focus groups, in-depth interviews, mapping or observations of the target population and the individuals who work with them to assure that the research team sufficiently understands the community.

**General population surveillance:** Surveillance that measures HIV risk behaviours in a sample of people selected to represent the people living in a region or nation. The surveillance can be restricted to certain ages (for example, young people aged 15-24) or genders.

**Generalizability:** The results from the sample are the same as the results we would have obtained had we tested every person in the study population (that is, the results from the sample are generalizable to the study population).

**Generalized HIV epidemic:** The epidemic state in which HIV is firmly established in the general population. (HIV prevalence is consistently >1% in pregnant women.)

**Grey literature:** Material that is not published in easily accessible journals or databases. Besides programme evaluations, government surveillance reports and programme planning documents mentioned earlier, it includes the abstracts of research presented at conferences, and unpublished theses and dissertations.

**Hard-to-reach populations (HTRP):** Groups of people linked by behaviours, socioeconomic situations or societal structures, who for various reasons (e.g. law, stigma) refrain from involvement in the legal economy and other aspects of the majority social institutions. Includes but is not limited to: IDUs, MSM, CSW and undocumented migrants.

**High-risk group surveillance:** Surveillance that measures HIV risk behaviours in groups whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic.
**High-risk group**: A group in the community with an elevated risk of disease, often because group members engage in some form of risky behaviour.

**High-risk heterosexuals (HRH)**: Includes but is not limited to: mobile populations, uniformed personnel and sex partners of other most-at-risk populations.

**HIV**: See ‘Human Immunodeficiency Virus’.

**Homophily**: A measure of the tendency of people to connect to other people like themselves.

**Human Immunodeficiency Virus (HIV)**: A retrovirus that causes AIDS by infecting T-cells of the immune system.

**IDU**: Acronym for ‘injection (or intravenous) drug user.’

**Incentive**: A reward or reimbursement given to participants in a study. In RDS surveys, there are typically two levels of incentive: primary incentive and secondary incentive. A participant receives the primary incentive for enrolling in the study and completing an interview. The same participant receives secondary incentive(s) for recruiting his or her peers into the study. Incentives are not absolutely necessary in every situation and should be determined during formative research.

**Incidence**: A measure of the frequency with which an event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.

**Indicator**: Specific data that are gathered to measure how well a prevention or treatment programme is doing. Defines an aspect of behaviour that is key to the spread of HIV. Indicators provide a way to track changes in behaviours over time and provide a way to compare levels of risk behaviours between different population groups.

**Information bias**: Error that results from people who have a disease being misclassified as not having the disease.

**Informed consent**: The permission granted by a patient or a participant in a research study after he or she has received comprehensive information about a research study or medical procedure. Informed consent protects the person’s freedom of choice and respects his or her autonomy with regard to decisions affecting his or her body and health.

**In-group affiliation**: What homophily measures (group similarity based on ethnicity, age, socio-economic status and so forth).

**Injection drug users**: Also called ‘intravenous drug users,’ they are persons who use or have used needles or syringes to inject drugs. Injection drug use is considered a high-risk behaviour.
Institutional sampling: Individuals in an institution, such as prison, are sampled.

Internal validity: The absence of substantial differences between groups at baseline; the absence of substantial difference of attrition rates between groups at follow-up.

Internally displaced persons (IDP): IDPs are persons who have left their homes due to civil unrest or natural disasters, but have stayed in their homeland and have not sought sanctuary in another country.

Interviewer error: Problems stemming from the actions and behaviours of the person doing the interview.

Listing units: The sampling units from the final stage of a multistage sampling design. See ’enumeration units’.

Key informants: Members of the target group, who can often become informal assistants.

Kick-off meeting: A meeting you host for community members who may in turn become seeds for the RDS survey. The purpose of the meeting is to educate seeds on study goals and process, inform seeds of their importance to the success of the study and encourage the seeds to be enthusiastic.

Lessons learned: Information from actual studies that will help you make decisions when planning your study.

Low-level epidemic: The epidemic state in which HIV has neverspread to significant levels in any sub-population, although HIV infection may have existed for many years. (HIV prevalence has not consistently exceeded 5% in any defined sub-population or in the general population.)

Markov process: A mathematical theory that provides a probabilistic description of the state of a system at any future time. The Markov process is especially relevant to RDS because of the nature of the recruitment process, whereby a chain of peers recruiting peers is monitored through a coupon mechanism.

MARP: Acronym for ’most-at-risk population’. A group within the community with an elevated risk of disease, often because group members engage in some form of high-risk behaviour.

Masking: Describes the behaviour of reclusive respondents, people who do not want to be found.

Men who have sex with men (MSM): MSM are one of the highest risk groups in the Americas, Asia, Europe and Oceania. For the purposes of this manual, we also consider male sex workers, transvestites and transgendered persons (hijra) in the MSM category.
**MICS**: See ‘Multiple Indicator Cluster Survey’.

**Monitoring and Evaluation (M&E)**: Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.

**MSC**: See ‘multi-stage cluster sampling’.

**Multi-stage cluster sampling (MSC)**: Two- or more-stage sampling. Final units from selected clusters may be randomly selected.

- Simple two-stage cluster sampling
- Probability proportional to size sampling (PPS) is used when all clusters do not have the equal probability of being selected in the sample. PPS is a class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

**Multivariate analysis**: One of the main types of analysis conducted in behavioural surveillance that is performed to look at the influence of at least two variables on another variable. Since relationships between variables are often complex and interwoven, multivariate techniques can pinpoint the individual effects of several explanatory variables on an outcome variable, which may be related to each other.

**Needs assessment**: A component of rapid assessment and response (RAR), a systematic examination of the type, depth and scope of a problem.

**Network**: This sampling method may be used for groups whose members are socially linked. Ego-centred network sampling is based on random, representative or any other form of quota sampling (Schensul). Full relational network sampling begins with identification of individuals (seeds) who act as entry points to the network.

**NGO**: Acronym for ‘non-governmental organization’.

**Non-probability sampling**: The sampling units are selected through a non-randomized process; therefore, the probability of selecting any sampling unit is not known.

**Non-random mixing**: The tendency of people to associate preferentially with others who are like themselves.

**Operational definitions of target populations**: Definitions that are operationally useful for sampling and fieldwork purposes. For example, a definition that clearly identifies what constitutes a sex worker, in terms of duration of selling sex, form of payment, type of venue where they work, etc.

**Operations manual**: A document that describes every step to be taken during the implementation of a survey or study. Ideally, it provides standard operational procedures for every foreseeable occurrence.
Over-sampling: A sample may obtain more members of a particular sub-group than their representation in the target population warrants. In some cases, over-sampling is carried on purpose to learn more about a small sub-group, such as female injection drug users in communities that are predominantly male.

p24 antigen: A protein that appears in the serum of infected individuals approximately one week before HIV antibodies appear, or about 14 days after actual infection. In very large serosurveys, persons who tested negative for HIV antibody can be retested for p24 antigen.

Parameter: The summary numerical description of variables about the target population.

Participant observation: A qualitative research method in which direct observation is carried out over a period of time, and which is understood and accepted by the group being observed.

Payment coupon: Kept by the recruiter. He/she will use it to claim an incentive for having recruited a peer into the study.

Period prevalence: Refers to prevalence over a period of time, such as a six-month period.

PLACE: See 'Priorities for local AIDS control efforts.’

PLWHA: Acronym for 'Persons living with HIV/AIDS.'

Point prevalence: Refers to prevalence at a single point in time.

Population: The entire set of individuals to which findings are to be extrapolated (Levy).

PPS: See 'Probability proportional to size sampling'.

Precision: Refers to how well the results can be reproduced each time the survey is conducted.

Pre-surveillance assessment: Describes a set of activities that occur prior to beginning formal HIV and behavioural surveillance in high-risk groups. These activities include developing detailed plans and reviewing and collecting information that will help in planning and designing surveillance activities.

Prevalence: The proportion of a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Primary incentive: The incentive a participant gets for enrolling in the study and completing an interview.
Primary sampling units: A sampling frame of a larger unit. When it is difficult or impossible to make a list/sampling frame of each individual in the target population, we can develop a sampling frame of some larger unit; that is, clusters or primary sampling units. We then sample in stages by first sampling clusters and then sampling people within the clusters.

Priorities for Local AIDS Control Efforts (PLACE): A new, rapid assessment tool used to identify high transmission areas, which formalizes the collection of information on high transmission areas. PLACE uses key informants to identify sites where people meet new sex partners, then interviews people at the site in order to characterize the site in each area and map sites, and, finally, interviews individuals socializing at the site to describe the characteristics of the people at the site.

Probability sampling: All sampling units in the study population have a known, non-zero probability of being selected in the sample, usually through a randomized process.

Probability proportional to size sampling: A class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

Protocol: The detailed plan for conducting a research study or other activities in which specific steps are required, including surveillance activities.

Purposive sampling: A non-random sampling method that involves choosing respondents with certain characteristics.

Qualitative research: Research that focuses on the characteristics or quality of things, rather than the quantity. The sample included qualitative research is usually much less used than that included in quantitative research.

Quantitative research: Research that focuses on quantity of things, rather than the quality. Quantitative research has powerful tools for the analysis of numbers, but researchers know that the things counted are often qualitative categories or definitions.

Questionnaire faults: Problems with the way questions are phrased, set out and ordered, which lead to misunderstandings of the questions.

Random walk: A variation of link-tracing sampling procedure in which the respondent is asked to give the names of other members of a hidden population. From that list, one is selected randomly, located and added to the sample. The process is repeated for a desired number of waves. (S.K. Thompson et al.)

Random error: Also called non-systematic error. This is the type of error that results from chance and leads to imprecise results.

Rapid assessment and response (RAR): A method that is used to assess the nature and extent of a public health problem and to suggest ways to address the problem. RAR is not designed as a surveillance tool, but as a way to assess a situation quickly, and bring in resources to address it.
RDS: See ‘Respondent driven sampling’.

RDSAT: Respondent driven sampling analysis tool (a freeware software package for analyzing RDS samples.)

Referral coupon: Used by the recruiter to recruit a peer into the study.

Refugees: By legal definition, refugees are persons who are outside their country of nationality and who are unable or unwilling to return to that country. They cannot return due to a well-founded fear of persecution because of race, religion, political opinion or membership in an ethnic or social group.

Reliability: Refers to how reproducible a result is from repeated applications of a measure to the same subject.

Representativeness: The degree to which the sample truly reflects the study population (that is, whether it is representative of the study population).

Resource assessment: A component of RAR, a systematic examination of the response (funds, people, buildings, knowledge) that is either available or required to solve the problem.

Respondent driven sampling (RDS): An experimental sampling technique that does not require a sampling frame. It is an adaptation of a non-probability sampling method (snowball sampling) and is based on the assumption that members of the sub-population themselves can most efficiently identify and encourage the participation in surveillance of other sub-group members. RDS starts with initial contacts or ‘seeds’, who are surveyed and then become recruiters. Each of these recruiters is given coupons to use to invite up to three eligible people that he/she knows in the high-risk group to be interviewed. The new recruits bring their coupon to a central place where they are interviewed. The recruits then become recruiters. This occurs for five to six waves. Both the recruits and the recruiters are given incentives to encourage participation.

Safety protocol: A study document that describes how to deal with field incidents or adverse events.

Sample: A selected subset of a population. There are specific types of samples used in surveillance and epidemiology such as convenience, systematic, population-based and random.

Sampling bias: Also called selection bias. This refers to errors in sampling that decrease accuracy and lead to incorrect estimates. We also use the term ‘biased samples’ to mean that errors were made in choosing the people in the sample.

Sampling element: Individual member of the population whose characteristics are to be measured. See ‘Sampling unit.’

Sampling error: The part of the total estimation error of a parameter caused by the random nature of sampling.
Sample frame: A list of units from which a sample may be selected. A sample frame is a fundamental part of probability sampling.

Sampling units: Refers to individual members of the population whose characteristics are to be measured. See ‘Sampling element’.

Sampling variation: Difference between the estimate you measure in a sample and the true value of the variable in the study population.

Second-generation surveillance: Built upon a country’s existing data collection system, second-generation HIV surveillance systems are designed to be adapted and modified to meet the specific needs of differing epidemics. This form of surveillance aims to improve the quality and diversity of information sources by developing and implementing standard and rigorous study protocols, using appropriate methods and tools. Second generation surveillance refers to activities outside of those activities generally considered to be a part of routine case surveillance such as case reporting and sentinel serosurveys and uses additional sources of data to gain additional understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spreads them.

Secondary incentive: The incentive a participant gets for recruiting his or her peers into the study.

Seeds: Non-randomly selected (by the investigators) members of the target population who will initiate the RDS recruitment process. From each seed, a recruitment chain is expected to grow.

Seroprevalence surveys: Surveys that estimate HIV prevalence by testing blood for HIV antibody.

Sentinel sites: Facilities such as STD clinics, antenatal care clinics, blood donation centres, drug treatment programmes, prisons and needle exchange programmes.

Sexually transmitted infections: Diseases that are spread by the transfer of organisms from person to person during sexual contact.

Simple random sampling (SRS): Sampling where everyone has an equal chance of being randomly selected (a non-zero probability) and we know what that chance is.

Snowball sampling: Relies on informants to identify other relevant study participants in a chain referral pattern. Informants (seeds) who meet inclusion criteria are identified. This sampling design is based on chain referral and relies on the seed(s) to identify other relevant subjects for study inclusion. Those other subjects may identify other relevant subjects for inclusion. Snowball sampling is useful for studying populations that are difficult to identify or access. Representativeness is limited.

Social influence: Mild peer pressure from the recruiter who will receive a secondary incentive for recruiting his/her peers.
Social network: Members of a peer group who know each other.

Sociometric stars: Seeds who are not only willing to recruit their peers, but are well-regarded by their peers and have a lot of them. Such seeds are more likely to influence others to be recruited into the study.

SRS: Acronym for simple random sampling.

Standard error: Estimate of precision in probability sampling that can be used to construct a range of values within which the true population measure is likely to fall. We usually want to be 95% sure that the true population measure lies in our range.

Standardized Testing Algorithm for Recent HIV Seroconversion (STARHS): A method for measuring new infection that uses a single blood test. Also called the 'detuned assay,' STARHS uses two EIA tests, one highly sensitive and another modified to be less sensitive.

Statistics: A branch of applied mathematics concerned with the collection and interpretation of quantitative data and the use of probability theory to estimate population parameters.

Steering method: Using additional methods to recruit a special sub-population of interest; for example, providing an extra coupon to be used only to recruit female IDUs.

STI: See 'Sexually transmitted infection'.

Strata: A sub-group in stratified sampling.

Strategic information (SI): Refers to any data collected with regard to the monitoring and evaluation of a program or system. Includes, but is not limited to, process indicators, output indicators and surveillance data.

Stratification: The classification of a survey population into sub-groups or strata on the basis of selected characteristics.

Stratified and constant incentives: In a study of SWs, a constant incentive level was considered too low to attract the more hidden SWs who earned a higher income. The research team considered using a stratified incentive process. The SWs received an incentive based on the type of sex work they did. For instance, a street-based SW received a $5.00 incentive, while a call-girl-type SW received a $10.00 incentive.

Stratified sampling: The selection of separate (independent) samples from each stratum. When the population consists of distinct sub-groups, (for example, age groups or regions) we may need to make precise estimates of our indicators for each sub-group. If this is the case, we use stratified sampling. First we calculate the required sample size for measuring our indicator, then define the sub-group (strata) and randomly sample the calculated sample size in each stratum. Since we want to make precise estimates of our indicator for each stratum, our sample size will be much larger than if we just wanted an estimate for the entire population. We can combine strata estimates to
obtain a population estimate for our indicators. However, this requires that we know
the proportion of the population in each strata.

**Systematic sampling**: Every \( k \)th unit is sampled from a sampling frame after a random
start. Systematic sampling is often used instead of SRS when the sampling list is long
or the desired sample size is large.

**Surveillance**: The systematic, regular and ongoing collection and use of data for public
health action.

**Surveillance sites**: The places from which case reports are obtained. This includes sites
at which universal reporting and sentinel reporting are done. These may be healthcare
facilities or other locations at which serosurveys are conducted.

**Survey population**: The target population modified to take into account practical
considerations (for example, all commercial sex workers in a city over the age of 15,
excluding those who are based at home, as they cannot be accessed).

**Systematic sampling**: When we construct the sampling frame, as in simple random
sampling (that is, we make a list of everyone in the target population) but rather than
selecting names or random numbers, we sample people at regular intervals down the
list. For this scheme to work you need to ensure that the list is not ordered in any way
that would bias those who are selected in the survey.

**Target population**: The population that is the ideal one for meeting a survey’s
measurement objective (for example, all commercial sex workers in a city).

**Targeted sampling**: Targeted sampling uses pre-existing indicator data (qualitative
and quantitative) to construct a sampling frame from which recruitment sites are then
randomly selected. Qualitative indicator data includes ethnographic data and key
informant interviews. Types of quantitative indicator data include cases of HIV/AIDS
and STIs, admissions to drug treatment and population characteristics from census data.
There are several limitations: 1) indicator data may not be useful in characterising the
target population; 2) sampling may be biased and difficult to replicate; 3) geographic
areas may not be sampled in proportion to the number of members in the population of
interest; 4) the population of interest may not be sampled in proportion to the intensity
of risk behaviour and 5) the probability of selecting a member of the population of
interest may not be known.

**TB**: Tuberculosis.

**Time location sampling (TLS)**: Similar to conventional cluster sampling, but gets around
the problem of clusters that are not stable (that is, clusters where the number and type
of people vary by, for example, time of day). Time location sampling allows the same
site to be included in the sample frame more than once (for example, at different times
of the day or different days of the week).

**Transgendered persons**: Persons who identify with or express a gender and/or sex
different from their biologic sex.
**Transition probability**: The likelihood that a person will change from one state to another, for example becoming HIV positive.

**Univariate analysis**: The most basic, yet often the most important, type of behavioural surveillance analysis, because it shows the distribution of each variable. Most of the indicators defined for behavioural surveillance purposes are calculated through univariate analysis. They would include variables like the proportion of young men who have had sex with more than one partner during a given time period. When trends are analysed, statistical techniques are used to calculate how likely it is that changes in the proportions could have occurred by chance, or whether observed changes are likely to reflect real changes.

**Universal conscription**: Military conscription in which all physically able men between certain ages (for example 17-28) must perform military service.

**Unlinked anonymous testing**: Testing that occurs when a sample of blood is originally collected for other purposes is tested for HIV. The person whose blood is taken does not know that his/her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to them.

**Unprotected sex**: Having sex without using a condom.

**Validity**: The validity of a measure is the extent to which it actually measures what it is suppose to measure.

**Values**: Magnitude of measurements (statistics).

**Variable**: Any characteristic or attribute that can be measured.

**Venue-based**: Locations in the community, such as bars or brothels.

**Venue-based sampling (brick and mortar sites)**: Recruit respondents in places and at times where they would reasonably be expected to gather. The venues act as screeners in identifying potential respondents. Venue-based sampling requires comprehensive formative research.

**Voluntary migrants**: People who temporarily work or travel away from their homes.

**Volunteerism**: A term to describe overly cooperative subjects, leading to a potential bias if such cooperative people differ from the rest of the population of interest.
Answers are provided in italics for each unit’s warm-up questions and case study.

Answers to the questions within the unit are not included. Unit questions are designed to stimulate small group discussion among participants in the workshop or class.

**Unit 1 Answers**

**Warm-up questions**

1. True or false? One-time cross-sectional surveys can be considered surveillance.  
   *False. Although they are often the beginning of a surveillance system, one-time cross-sectional surveys should not be considered surveillance.*

2. ________ surveillance involves regular, repeated cross-sectional surveys collecting data that can be compared over time on HIV risk behaviours and other relevant issues.
   a. behavioural
   b. biological

3. Which of the following is a use of behavioural surveillance?
   a. to explain changes in HIV prevalence over time
   b. to provide information for prevention programmes
   c. to raise the awareness of HIV among policy-makers
   d. to provide an early warning of which groups and areas infection is likely to spread in and between
   e. *all of the above*

4. True or false? Surveillance is a useful tool for evaluating specific HIV/AIDS interventions. *False. Without adaptation, surveillance only provides evidence for the impact of HIV programmes as a whole, and not for the impact of specific interventions or specific programme elements.*

5. True or false? In a generalized epidemic everyone is at equal risk of infection. *False. Even in a generalized epidemic, not everyone in the population is at equal risk of HIV, or has an equal role in the spread or maintenance of the epidemic.*

6. ________ sites are facilities such as STD clinics, antenatal care clinics, blood donation centres, drug treatment programmes, prisons and needle exchange programmes
   a. sentinel
   b. community

7. Which of the following is the definition of linking behavioural and biological data?
   a. collecting HIV, STI and behavioural data from the same individuals at the same time
b. collecting HIV, STI and behavioural data from the same source population at different times

c. analysing HIV, STI and behavioural data from similar source population, using whatever data are available

d. reporting behavioural and biological surveillance together

e. all of the above

8. Collecting ___________ level data provides more detailed information but requires larger sample sizes and, therefore, more time and money

a. national

b. sub-national

Case study

1. The general population is the people living in a region or nation. High-risk groups are those whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic. Remember that high-risk groups are part of the general population, that they have links with other population groups and that membership can overlap. For example, commercial sex workers (CSWs) can also be intravenous drug users (IDUs). Ultimately, what is considered a high-risk group must be based on the local context.

2. Local information must be used to determine what constitutes a risk group based on a group's importance or potential importance in the epidemic. Most people view CSW as a risk group, but one could argue that CSWs are not a actually a group. This could be argued because CSW can be sub-divided into many groups, and because individual women on the street who solicit sex do not always belong to or associate with any groups. Alternatively, people with multiple partners could be considered a 'group.'

Unit 2 Answers

Warm-up questions

1. What are two characteristics of a good indicator? A good indicator measures something of relevance to the topic (the measure serves some use), measures the item of interest accurately, is easy to interpret and is defined in clear terms. It can be compared across different population groups and across time and is feasible to collect in terms of effort/cost.

3. True or false? Behavioural surveillance indicators should measure aspects of behaviours that are key to the spread of HIV. True.

4. When should indicators be selected during behavioural surveillance?
   a. during planning
   b. during analysis

5. True or false? The two most difficult issues defining behavioural surveillance indicators are defining the behaviours themselves and defining the time period for which the indicator should refer. True.
6. True or false? Behavioural surveillance indicators do not need to be consistent over time. **False**

7. The time reference period of an indicator should be determined by its ________.
   a. prevalence
   b. frequency

Case study
The first indicator gives us an idea about the size of the link between CSWs and married men. If a large proportion of married men visit CSWs, commercial sex could potentially be important for driving the epidemic.

The second indicator does not tell us anything about the role of CSW in driving the epidemic. We do not know if the use of CSWs is high only in that, among those people who use CSW, a certain proportion are married.

Unit 3 Answers

Warm-up questions
1. What is measurement error? **When the data collected do not accurately measure the characteristics of interest, which affects the validity of our data.**

2. In observational studies, which of the following is a source of measurement error?
   a. interviewer error
   b. respondent error
   c. questionnaire faults
   d. **all of the above**

3. True or false? Bias can be controlled for during data analysis. **False.**

4. True or false? A face-to-face interview is the best data collection method. **False.** *Each data collection method has advantages and disadvantages, and there is no conclusive evidence that any one method is better, overall, than another.*

5. Which of the following is an advantage of using the self-administered data collection method?
   a. **inexpensive to administer**
   b. no literacy requirement
   c. date entry step eliminated

6. Which of the following are advantages of adapting survey questions from surveys that have already been successfully implemented?
   a. **builds on current best practice of how questions can be best expressed**
   b. saves time and money
   c. **ensures consistency with other available data sources**
   d. eliminates the need to pre-test the questionnaire
   e. all of the above
7. What are two solutions to the problem of interviewer safety when working with hard-to-reach groups?
   a. Select interviewers who know the area.
   b. Interviewers should work in pairs.

8. True or false? When having difficulty in getting members from hard-to-reach groups to show up for an interview, one solution is to use incentives. True.

Case study

Introduction to the purpose of the study
Rapport building and communication skills
Cultural sensitivity/knowledge of the target population
How to talk about sex with ease (how to be non-judgmental)
Survey protocol
Handling and tracking non-response
Controlling the interview, handling interruptions and respondent fatigue
Use of survey instruments—skip patterns, coding, phrasing and meaning, note-taking
How to respond to interviewee questions
Quality assurance within interviews
Ethics: respecting confidentiality, protecting respondents
Ability to report to supervisor
All of the interviewer training
Sampling methodology
Importance of quality control and standardisation
Awareness of falsified responses
Logistics in fieldwork
Safety of fieldworkers and respondents
Management skills
Ability to report to upper management

Unit 4 Answers

Warm-up questions

1. The ______________ is the population that is the ideal one for meeting a survey’s measurement objective. (For example, all commercial sex workers in a city.)
   a. target population
   b. survey population

2. Is drawing names randomly out of a hat for sampling an example of probability sampling or non-probability sampling?
   a. probability sampling
   b. non-probability sampling

3. True or false? Non-probability sampling is prone to selection bias. True.
4. We can increase the precision (that is, decrease standard error) of our estimate by increasing the _________.
   a. sample size
   b. quality of interviewer training

5. What is an estimate of precision that can be used to construct a range of values within which the true population measure is likely to fall?
   a. standard error
   b. systematic sample

6. Which of the following is not a type of sampling
   a. stratified
   b. cluster
   c. respondent-driven
   d. systematic
   e. salient

7. True or false? Statistical packages assume simple random sampling when performing statistical tests. True.

8. True or false? Cluster sampling provides more precise estimates of indicators than simple random sampling. False. Cluster sampling results in a less precise estimate of our indicators than simple random sampling, as respondents within clusters may be similar to each other. We need to compensate for this by increasing the sample size.

9. Which of the following is not a way to overcome sampling challenges for behavioural surveillance?
   a. using different sampling strategies for different groups
   b. using convenience sampling when possible
   c. using conventional sampling methods in unconventional ways
   d. using experimental sampling techniques such as respondent-driven sampling (RDS)

Case study
1. Group 1: Youth. Conventional cluster sampling would be appropriate in most settings.

Advantages of cluster sampling:
- only need sample frame of clusters and individuals in selected clusters;
- sample concentrated in geographical areas.

Disadvantages of cluster sampling
- decreases precision of estimate, requiring a larger sample size;
- PPS sampling or weighted sampling required for unbiased estimates.

Group 2: MSM. Either RDS or TLS would be appropriate in most settings.
Advantages of TLS:
- allows us to do a probability sample of populations that are hidden or floating;
- only need sample frame of clusters and individuals in selected clusters;
- sample can be concentrated in geographical areas.

Disadvantages of TLS:
- mapping and ethnographic work can be time consuming and clusters/sites can close rapidly;
- only reaches sub-set of population that come into contact with the locations where the sampling is done;
- difficult to identify and access respondents;
- difficult to maintain randomness while selecting respondents within clusters;
- PPS not often done due to difficulties estimating cluster size, and samples often require weighting, which if not done can result in biased estimates.

Advantages of RDS
- ease of field operations;
- no need for ethnographic mapping or sampling frame;
- target population recruits for you, which is useful when the group does not trust the research community;
- less visible members of the population reached;
- lower cost.

Disadvantage of RDS
- population must be a network;
- need to keep track of links between recruiters and recruits;
- ethical issues involved in using incentives;
- still in experimental stage.

2. For the RDS survey 247. From Table 4.5, go down to .80 in the first column and .90 in the second column. The third column of 247 is the sample size needed for each year’s survey if you use RDS. If TLS is used, then the sample size is 395 per year. The larger sample size is the result of a larger design effect anticipated in TLS.

Unit 5 Answers

Warm-up questions
1. True or false? It is better to share overall responsibility between different staff for the data management. False. It is usually better for one person to have overall responsibility for the data than to share responsibility between different staff.

2. Data management does not include which of the following?
   a. data coding
   b. data entry
   c. data cleaning and checking
   d. data framing
3. True or false? The data manager should not be involved during the questionnaire design. False. The data manager should be involved during the questionnaire design stage, not only to review the questions, but to review the way in which the questionnaire is organized.

4. Which type of behavioural surveillance analysis is performed to determine whether one variable is related to the distribution of another? (For example, an association between a respondent’s age and his or her use of condoms.)
   a. univarite
   b. bivariate
   c. multivariate

5. Most of the indicators defined for behavioural surveillance purposes are calculated through ________ analysis.
   a. univarite
   b. bivariate
   c. multivariate

6. When data are presented, they should be packaged appropriately for the different ________.
   a. audiences
   b. data collection sequence

7. True or false? The surveillance cycle ends when the official report is published. False.

8. True or false? Data from other sources, including other countries, can be used to fill in any important gaps, as long as the source is made very clear. True.

Case study

In communicating with policy-makers, pare your message to the bare essentials and tell them exactly what action they need to take. Formal pathways may need to be followed when communicating with policy-makers. You should also use all the informal networks you have, as getting through the front door can be difficult. Politicians and policy-makers, more than any other group, require the right messenger. Very senior policy-makers tend to have a rather small circle of senior advisers. These people may be easier to approach than the key policy-makers themselves, and they usually make very good messengers. Other channels that can be used include senior officials from international organizations or senior diplomats from donor countries.
Unit 6 Answers

Warm-up questions

1. Match each ethical principle with its definition.

   __b__  respect for persons  a. Refers to minimizing risk to individuals, not only physical risk but also risk of psychological harm and stigmatization

   __a__  beneficence  b. Requires investigators to see study subjects not as passive sources of data, but as persons whose rights and welfare must be protected

   __c__  justice  c. Risks and benefits from studies should be distributed fairly and evenly in populations

2. It is important that everyone the surveillance system encounters is treated with respect, from community leaders and local officials, to those surveyed.

3. What is informed consent? Informed consent means that you tell the person enough about the nature of the surveillance for them to make a proper (informed) decision about whether or not to take part.

4. Name two pieces of information that should be provided before a person can make an informed decision to take part in a survey?

   • the nature of the survey (for example, who is conducting the survey, purpose of the survey, length of interview, type of question, etc.)
   • the potential risks and benefits
   • how the information will be used
   • how their privacy will be protected (names or addresses are not written)
   • that participation is voluntary
   • participants have the right to refuse to answer any questions or stop the interview at any time, especially as they may find some of the questions sensitive

5. True or false? In surveillance, written consent forms are the most appropriate way to document that the process of informed consent has occurred. False. In order to ensure total confidentiality, it is usually best to obtain verbal consent, as this means that the name of the respondent does not need to be recorded.

6. What are two ways to ensure a participant’s confidentiality?

   • Ensure names or other means of identification are not recorded on surveys.
   • Store data safely and appropriately.
   • Train fieldworkers on the importance of confidentiality.
   • Have clear disciplinary procedures for staff who breach confidentiality.
   • Identify problems and possible solutions related to confidentiality.
7. Match each of the following ethical issues with a potential solution.

__b__  loss of earnings      a. ensure fully informed consent.
__a__  increases discrimination of the group
__c__  participants get no direct benefit from surveillance

Case study
1. Below is an example of a consent form that could be used with FSW:

Introduction: "My name is____________. I am working for____________. We are interviewing people here in [name of city, region or site] in order to find out about [describe purpose of study]. Have you been interviewed in the past few weeks [or other appropriate time period] for this study? If the respondent has been interviewed previously during this round of BSS, do not interview the person again. Tell them you cannot interview them a second time, thank them, and end the interview. If they have not been interviewed before, continue:

Confidentiality and consent: "I am going to ask you some very personal questions that some people find difficult to answer. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time. However, your honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. We would greatly appreciate your help in responding to this survey. The survey will take about XX minutes to ask the questions. Would you be willing to participate?"

_______________________________________________________________
(Signature of interviewer certifying that informed consent has been given verbally by respondent)
Unit 7 Answers

Warm-up questions

1. Which of the following is an example of a question you should answer in order to select appropriate geographical areas during the pre-surveillance assessment?
   a. What are the regional differences in terms of HIV transmission and risk behaviour?
   b. Where are the interventions located?
   c. How much money and staff are available for surveillance?
   d. All of the above

2. Match each pre-surveillance assessment method with its description.

   a. Assess what is currently known about the national epidemic or sub-epidemic.  
      a. This step involves reviewing existing surveillance data, published and unpublished literature, and talking to people who are knowledgeable about the epidemic.

   c. Conduct pre-surveillance assessment using qualitative assessment methods and mapping.  
      b. You can perform this step using existing information from general population surveys or collecting the information if none exists.

   b. Gather information on risk behaviours and HIV levels in the general populations.  
      c. This step involves fieldwork to further identify and verify hotspots, as well gathering information to clearly define populations to be included in surveillance and to guide surveillance fieldwork.

3. Methods used in quantitative research include large sample size, random samples and shorter interviews. Methods used in qualitative research include unstructured questionnaires, lengthy interviews and fewer well-trained fieldworkers.

4. Suppose you want to determine in which areas of a city street-based sex occurs. Which of the following is not an appropriate method to use during a pre-surveillance assessment?
   a. literature/data review
   b. in-depth qualitative interviews
   c. general population survey
   d. all are appropriate
Case study

Below are examples of some of the activities that must be done prior to data collection:

- Carry out initial consensus building meeting with surveillance committee.
- Identify data needs and key indicators.
- Identify and select populations to be included in surveillance and define eligibility criteria.
- Select the regions/cities/areas that will be included in the surveillance.
- Determine the sampling options, sampling frame and sample size requirements.
- Define eligibility criteria.
- Create alliances with the survey populations and gatekeepers.
- Prepare logistics and supplies.
- Design, revise, translate and pre-test the questionnaires.
- Identify potential fieldwork problems and solutions.
- Produce field plan including how quality will be ensured.
- Define the timeline, budget and available resources.
- Get ethical clearance.
- Recruit statistician and data managers.
- Produce a data analysis plan and develop database.
- Produce a data use plan.
- Recruit and train supervisors, interviewers and data entry clerks.
This module introduces behavioural surveillance with an emphasis on pre-surveillance activities, measures and indicators, survey methods, sampling approaches, data use and ethical considerations. After completing this course, participants should:

- identify the uses of behavioural surveillance
- understand the methodological difficulties with indicators for behavioural surveillance and select indicators most suited to particular situations
- understand sampling issues and options for behavioural surveillance and understand the criteria for choosing a sampling approach
- describe the types of data analysis commonly used in behavioural surveillance and understand the steps in ensuring appropriate data analysis and use
- be able to discuss the ethical consideration unique to behavioural surveillance.

This course is meant primarily for state/national-level surveillance officers, planners and decision makers. This module can also be used for self-study.
Module 6

Surveillance of Populations at High Risk for HIV Transmission
Module 6

Surveillance of Populations at High Risk for HIV Transmission

Participant Manual

2007

World Health Organization
Regional Office for South-East Asia
Other HIV surveillance training modules of this series

Module 1 - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual
Module 2 - HIV clinical staging and case reporting: participant manual
Module 3 - HIV serosurveillance: participant manual
Module 4 - Surveillance for sexually transmitted infections: participant manual
Module 5 - Surveillance of HIV risk behaviours: participant manual
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**Module 6**

**Summary**

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Introduction

How to Study this Module

What you should know before the course

This course builds upon the information provided in Module 5: Surveillance of High risk Behaviours. This course is meant primarily for those involved in the planning and implementation of HIV surveillance in high risk populations. As a participant, you should understand the basic epidemiology of HIV/AIDS and public health surveillance.

Module structure

The module is divided into units. The units are convenient blocks of material for a single study session.

This module can also be used for self-study.

Because you already know quite a bit about HIV/AIDS, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answer may just be a guess. Answer the questions as best you can.

You will keep to yourself the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions. You can then again check your work.

As you study this module, you may come across italicised terms that are unfamiliar. In Appendix B, you will find a glossary that defines these words. The glossary also contains acronyms that you may not recognize.

Module summary

This module provides an introduction to surveillance in populations at high risk for HIV transmission, with a focus on South-East Asia.

Appendices

More information is provided in:

Appendix A, References and Further Reading Material
Appendix B, Glossary and Acronyms
Appendix C, Useful Links
Appendix D, Answers to Warm-Up Questions and Case Studies
Additions, Corrections, Suggestions
Do you have changes to suggest for this module? Is there other information you’d like to see? Please email us. We will collect your letters and email and consider your comments in the next update to this module.

Email address:

HIV/AIDS Unit
Department of Communicable Diseases
World Health Organization
Regional Office for South-East Asia
World Health House
Indraprastha Estate
Mahatama Gandhi Marg
New Delhi 110 002, India.
Email: hiv@searo.who.int
Fax: 91 11 23370197
Overview

What this unit is about

This unit introduces the surveillance of populations at high risk for HIV transmission (or most-at-risk populations). This unit discusses the special ethical considerations of conducting behavioural and sero-surveillance in high risk groups, as well the sampling approaches best suited for high risk populations.

Warm-up questions

1. A high risk group is at increased risk of HIV infection because of higher risk behaviours.
   
   True  False

2. Which of the following groups are at high risk for HIV infection in the South-East Asia region?
   a. sex workers  
   b. injection drug users  
   c. men who have sex with men  
   d. all of the above

3. In low-level epidemics, surveillance of most-at-risk populations can serve as an early indicator of the presence of HIV in a country.
   
   True  False

4. List the two sampling methods that are commonly used in HIV surveillance of populations at high risk for HIV transmission.
   a.  
   b.  

5. An example of a potential legal harm to members of high risk groups because of HIV surveillance activities is _________________.

Introduction

What you will learn

By the end of this unit you should be able to:

- discuss the importance of surveillance in populations at high risk for HIV transmission in different epidemic settings;
- identify high risk populations in the South-East Asia region;
- discuss the advantages and disadvantages of different sampling approaches, especially in the context of surveillance among populations at high risk for HIV transmission;
• understand the special ethical issues of surveillance of populations at high risk for HIV transmission.

**Background**

Public health surveillance for HIV is the systematic and regular collection of information on the occurrence, distribution of and trends in HIV infection. Surveillance data should be as accurate and complete as possible, so that these may be analysed for effective prevention and control of the HIV epidemic.

**Second-generation surveillance**

*Second-generation surveillance* refers to activities outside of those that are generally considered to be a part of routine case surveillance, such as case reporting and sentinel sero-surveys. Second-generation surveillance uses additional sources of data to gain a more comprehensive understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spread them.

An integral part of second-generation surveillance systems is determining HIV prevalence in groups that are at high risk of infection. These groups of people are most at risk for being involved in transmitting HIV or contracting HIV. The group may be identified by the following:

• the presence or absence of HIV infection
• the presence of risky behaviours that create transmission events
• an occupation or other socioeconomic status that can be associated with risky behaviours.

**Populations at high risk for HIV transmission**

Sometimes referred to as 'at-risk groups' or 'most-at-risk populations,' members of high risk groups are at increased risk of passing HIV on to others, or of contracting HIV from others. They are often important in establishing, accelerating or sustaining the HIV epidemic. Therefore, it is important to understand the impact that HIV has had within these groups. Throughout this training document we will refer to these groups as 'populations at increased risk.' In Asia, populations at increased risk include:

• sex workers and their clients
• injection drug users (IDUs)
• men who have sex with men (MSM)
• mobile populations and migrants
• out-of-school youth
• prisoners
• uniformed personnel

In this module we describe methodological aspects of working with sex workers, including female, male and transgender sex workers.

Populations at increased risk are most likely to get HIV infection first in a new epidemic. They are infected at higher prevalence than the general population. In other words, a
population at increased risk will become infected at a faster rate than people who are not members of a population at increased risk.

For information on the issues unique to a specific at-risk group, refer to the unit corresponding to the populations at increased risk that interest you.

Table 1.1

**Populations at increased risk discussed in Units 2-8**

<table>
<thead>
<tr>
<th>Group</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex workers (SWs)</td>
<td>2</td>
</tr>
<tr>
<td>Injection drug users (IDUs)</td>
<td>3</td>
</tr>
<tr>
<td>Men who have sex with men (MSM)</td>
<td>4</td>
</tr>
<tr>
<td>Mobile populations and migrants</td>
<td>5</td>
</tr>
<tr>
<td>Out-of-school youth</td>
<td>6</td>
</tr>
<tr>
<td>Prisoners</td>
<td>7</td>
</tr>
<tr>
<td>Uniformed personnel</td>
<td>8</td>
</tr>
</tbody>
</table>

**A central role**

Populations at increased risk play a central role in the spread of HIV infection. At the beginning of an HIV epidemic, the first infections appear in these groups, because they have higher risk behaviours. These behaviours, for instance, include:

- having sex without using a condom (*unprotected sex*) with multiple partners and/or having a high number of new partners
- injecting drugs with shared needles.

HIV is then transmitted quickly to other members of these groups through their networks of sexual and injecting drug partners. For example, if an HIV-infected person shares a needle with a group of drug users, the entire group or network may be exposed to HIV through this needle.

**Bridges**

Populations at increased risk also serve as *bridges* to other groups and the general population, since they can introduce HIV into these groups. For example, a client of an HIV-infected sex worker may get HIV infection. He may then have unprotected sex with his wife, infecting her. In this scenario, he has acted as a bridge, from which HIV infection has passed from the sex worker to his wife.

**Epidemic states**

Although it is important at all states, HIV surveillance in populations at increased risk is used differently at different *states* of the epidemic. This is illustrated in Table 1.2.
Table 1.2  
**Uses of HIV surveillance data in populations at increased risk at different states of the epidemic**

<table>
<thead>
<tr>
<th>Epidemic state</th>
<th>Situation</th>
<th>Uses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low-level</strong></td>
<td>• HIV has not reached significant levels in high risk groups.</td>
<td>• Early warning of a possible epidemic.</td>
</tr>
<tr>
<td></td>
<td>• HIV is largely confined to people within high risk groups who exhibit higher risk behaviours.</td>
<td>• Triggers interventions to prevent HIV in populations at increased risk.</td>
</tr>
<tr>
<td><strong>Concentrated</strong></td>
<td>• HIV has spread rapidly in one or more high risk groups.</td>
<td>• Monitor infection in populations at increased risk.</td>
</tr>
<tr>
<td></td>
<td>• Epidemic is not well-established in the general population.</td>
<td>• Monitor effects of intervention programmes on HIV prevalence and behaviours.</td>
</tr>
<tr>
<td><strong>Generalised</strong></td>
<td>• Epidemic has matured to a level where transmission occurs in the general population (not dependent on populations at increased risk).</td>
<td>• Monitor for initial decreases in HIV prevalence in populations at increased risk.</td>
</tr>
<tr>
<td></td>
<td>• Without effective prevention, HIV transmission continues at high rates in populations at increased risk.</td>
<td>• Monitor effects of intervention programmes on HIV prevalence and behaviours.</td>
</tr>
<tr>
<td></td>
<td>• With effective prevention, in general, prevalence will drop in populations at increased risk before they drop in the general population. For example, following a prevention campaign targeted at sex workers, surveillance should first find a decrease in STIs in the sex workers, then in male sentinel populations, and then in antenatal clinics.</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1.1 shows the state of the HIV epidemic in South-East Asian countries (next page).
HIV prevalence among various high risk groups

Surveillance in populations at increased risk has varied from country to country in the South-East Asia region. Most countries have been relatively successful in gathering HIV surveillance data from female sex workers and STI clinic patients. Several have been able to conduct surveys among MSM, IDUs, prisoners, migrant populations and uniformed personnel. Examples are shown below.

- In India, national sentinel surveillance conducted in 2005 found that 8.4% of FSWs were infected with HIV.¹
- In 2005, data from sentinel surveillance revealed an HIV prevalence of 2% among FSWs in Kathmandu, Nepal.²
- In 2005, sentinel surveillance in Dhaka, Bangladesh found the prevalence of HIV among IDUs to be 4.9%.³
- In 2005, sentinel surveillance in Dhaka, Bangladesh found the prevalence of HIV among MSM to be 0.4%.⁴
- In 2005, sentinel surveillance found the prevalence of HIV among MSM in Kathmandu, Nepal to be 3.9%.⁵
- In Bangkok, Thailand, the overall HIV prevalence among MSM increased from 17.3% in 2003 to 28.3% in 2005.⁶

Pre-surveillance Activities

Conducting pre-surveillance activities is the first step in conducting behavioural and biological surveillance. Pre-surveillance activities include:
1. Identifying a co-ordinating body
2. Agreeing on the purpose of surveillance
3. Establishing criteria for selecting populations and geographic coverage areas
4. Gathering information to help with the decision about populations and geographic locations and to guide survey implementation
5. Finalising the selection of sub-populations and geographic locations for surveillance

Before conducting biological and behavioural surveillance in high risk populations, you should conduct formative research to gain an understanding of the populations, places and risk behaviours in which you are interested.

A pre-surveillance assessment is conducted to:

- identify key indicators to measure
- characterise the diversity of sub-populations
- determine the geographic areas and venues where at-risk populations may be found in high numbers.

The following three methods should be used for the pre-surveillance assessment:

1. Assess what is currently known about the national epidemic or sub-epidemic to identify potential hotspots and at-risk or vulnerable populations.
2. Conduct pre-surveillance assessment using qualitative assessment methods and mapping to further identify and verify hot spots. You should also gather information to clearly define the populations to be included in surveillance and to guide surveillance fieldwork.
3. Gather information on risk behaviours and HIV levels in the general populations to help validate whether the so called high risk populations are really at higher risk than the population at large.

Reviewing existing literature is central to conducting a pre-surveillance assessment. There are several sources of information that need to be reviewed, including the following: peer-reviewed scientific literature, abstracts from regional and international AIDS conferences, grey literature (literature that is not published in easily accessible journals or databases; for example, programme evaluations and governmental reports) and basic surveillance data.

Further information on how to conduct a pre-surveillance assessment is presented in Module 5: Surveillance of High Risk Behaviours.


## Sampling Methods

### Definitions

We sample when we desire to measure characteristics of a specified target population, but we lack the time and resources to obtain information from every member of the target population. For example, if we want to measure condom use among commercial sex workers in a capital city, but it is not feasible to question every sex worker about their behaviours, we select a sample to question. Table 1.3, on the next page, summarises the conventional sampling techniques.

Table 1.3

**Summary of conventional sampling techniques**

<table>
<thead>
<tr>
<th>Sampling Method</th>
<th>Sampling Steps</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| **Simple random** | 1. Construct sample frame for survey population.  
2. Select people randomly from sample frame using random number table or lottery draw. | 1. Concept is easy to understand and analyse. | 1. Requires sample frame of entire target population.  
2. Logistically difficult if sample geographically dispersed.  
3. Using random number/lottery time-consuming. |
| **Systematic** | 1. Construct sample frame for survey population.  
2. Calculate sampling interval (SI).  
3. Select random start between 1 and SI and select that person.  
4. Add SI to random start and select person, etc. | 1. Random numbers or lottery not required.  
2. Easy to analyse. | 1. Requires sample frame of entire target population.  
2. Logistically difficult if sample geographically dispersed. |
| **Stratified** | 1. Define the strata and construct sample frame for each strata.  
2. Take a simple/systematic sample from each strata.  
3. Calculate indicator estimates for each strata and for population. | 1. Produces unbiased estimates of indicators for the strata.  
2. Can increase precision of indicator estimates. | 1. Requires sample frame of entire survey population.  
2. Logistically difficult if sample geographically dispersed.  
3. Requires sample large enough to make precise estimates for each strata.  
Table 1.3
Summary of conventional sampling techniques, continued

<table>
<thead>
<tr>
<th>Sampling</th>
<th>Steps</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cluster: Probability proportional to size (PPS) or equal probability sampling</td>
<td>1. Construct sample frame of clusters.</td>
<td>1. Only need sample frame of clusters and individuals in selected clusters.</td>
<td>1. Decreases precision of estimates; thus, requires larger sample size.</td>
</tr>
<tr>
<td></td>
<td>2. Calculate SI, select random start between 1 &amp; SI.</td>
<td>2. Sample concentrated in geographical areas.</td>
<td>2. Size of clusters required prior to sampling.</td>
</tr>
<tr>
<td></td>
<td>3. Select cluster whose cumulative size contains the random start.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Add SI to random start &amp; select cluster.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Sample equal numbers of people from selected clusters.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Only need sample frame of clusters and individuals in selected clusters.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Sample concentrated in geographical areas.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Don’t need cluster sizes prior to sampling.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Cluster: Equal probability, fixed cluster size | 1. Construct sample frame of clusters.                                | 1. Only need sample frame of clusters and individuals in selected clusters. | 1. Decreases precision of estimates; thus, requires larger sample size.       |
|                                               | 2. Select clusters using simple/systematic sampling.                  | 2. Sample concentrated in geographical areas.                              | 2. Weighted analysis required for unbiased estimates.                        |
|                                               | 3. Sample equal numbers of people from selected clusters.             | 3. Don’t need cluster sizes prior to sampling.                            | 3. Size of clusters required for weighted analysis.                          |

| Cluster: Equal probability, proportional cluster size | 1. Construct sample frame of clusters.                                | 1. Only need sample frame of clusters and individuals in selected clusters. | 1. Decreases precision of estimates; thus, requires larger sample size.       |
|                                                     | 2. Select cluster using simple/systematic sampling.                   | 2. Sample concentrated in geographical areas.                              | 2. Size of clusters required for proportional sampling.                      |
|                                                     | 3. Sample equal proportions of people per cluster.                   | 3. Sample size; thus, precision of estimates unpredictable.                |                                                                              |
Newer Sampling Methods

Two new sampling methods combine the methods of probability and non-probability sampling to identify with relative ease samples that are representative and from which results can be generalised. These are:

- respondent-driven sampling (RDS)
- time-location sampling (TLS).

RDS and TLS are ideally suited for surveys of high risk groups, especially those that are harder to find.

Respondent-driven sampling

In snowball sampling, investigators seek out potential participants referred to them by current participants. RDS combines the methods of snowball sampling with a mathematical model in a way that weighs the sample to compensate for the non-random way it was collected. It is an experimental sampling method that does not require a sampling frame. It is especially good for finding hard-to-reach groups, which are small compared to the general population.

Most studies will survey only the accessible or visible part of a group and miss those that are more hidden. For instance, a survey of sex workers working in bars and on the street in the red light district of a city will miss those sex workers who work at home, in other areas of the city and in brothels. Even snowball samples where sex workers refer their peers for up to six rounds (that is, one person will refer other people who will refer other people, up to six rounds of referrals) will not result in the entire population of sex workers being sampled, because not everyone will necessarily know each other. In other words, not all sex workers will be part of the same network. This type of network-based sample can lead to biased samples.

RDS overcomes this problem by combining how well network-based samples recruit people in the network with standard probability sampling methods. This makes it possible to draw statistically valid samples of previously hard-to-reach groups. In essence, respondents recruit their peers, as in network-based samples, and researchers keep track of who recruited whom and their numbers of social contacts. A mathematical model of the recruitment process then weights the sample to compensate for recruitment patterns. A greater description of the methods and statistical tests used in respondent-driven sampling can be found at www.respondentdrivensampling.org.

In the sex worker example mentioned above, a respondent-driven sample would choose one sex worker to start with. She would refer three—and only three—of her co-workers, and receive a small incentive for each referral. Each of her co-workers would, in turn, refer three of their co-workers, and so on for six or more rounds. Survey staff would ask each person in the survey how many people they know who work in sex work, while drawing blood or asking behavioural questions. Based on the knowledge of how many people each person knows, a picture of the entire network can be assembled based on random recruitment within the network. Using the respondent-driven sampling method, an overall estimate of, for instance, HIV prevalence, can be made with a minimum of sampling bias.
**Time-location sampling**

TLS, which is also called time-venue, time-space or venue-day-time sampling, combines the methods of targeted sampling and cluster sampling in a way that produces a probability sample. Time-location sampling is like conventional cluster sampling, but addresses the problem of everyone in the target population not being in the same place at the same time, because clusters are defined by both location and time. This strategy requires extensive ethnographic mapping to prepare a sampling frame that captures the variability in the time and location of behaviours and the number of group members.

Preparing the sampling frame involves first creating a list of all places (or venues) where the members of the target population congregate (for instance, in brothels). The second part of preparing the sampling frame is figuring out at what times the target population congregates at these locations. As an example, if brothels were open seven evenings per week from 8PM to 4AM, and if there were 20 brothels in a city, there would be 7 x 20—or 140—time-location sampling units. If the sex workers who worked from 8PM to midnight were different from the sex workers who worked from midnight to 4AM, we could also divide the time frame into two halves, from 8PM to midnight and from midnight to 4AM. We would then have 7 x 20 x 2—or 280—time-location sampling units. These units are essentially clusters.

Once the time-location clusters are defined, some numbers are selected randomly. The number needed will depend on the number of persons in the target population in each time-location cluster and how large the sample size needs to be. For instance, we could choose 30 time-location clusters. Once the sample of clusters is chosen, people in the clusters can be chosen for interview by various means. Some examples are:

- ‘take-all’ approach, in which all persons in the cluster are asked to participate
- random sample of persons in the cluster.

If clusters are of different sizes or if the target population has been enumerated, probability proportional to size methods may need to be used to ensure that larger clusters contribute more people to the sample (see Appendix 1.1). Time-location sampling can be further refined by using different strata. For instance, you could include one sample of casual sex workers and one sample of direct sex workers.

**Comparing RDS and TLS**

The sampling steps and the advantages and disadvantages of time-location and respondent-driven sampling are summarised in Table 1.4.
Table 1.4
The advantages and disadvantages of time-location and respondent-driven sampling

<table>
<thead>
<tr>
<th>Sampling</th>
<th>Steps</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| TLS      | 1. Calculate the required sample size.  
  2. Identify clusters through ethnographic mapping.  
  3. Construct a sample frame of clusters, defining clusters by both location and time if the population is floating.  
  4. Select clusters and individuals in clusters using PPS or equal probability sampling. | 1. Allows us to do a probability sample of populations that are hidden or floating.  
  2. Only need sample frame of clusters and individuals in selected clusters.  
  3. Sample concentrated in geographical areas. | 1. Mapping and ethnographic work can be time-consuming and clusters/sites can close rapidly.  
  2. Only reaches subsets of population that come into contact with the locations where sampling occurs.  
  3. Difficult to identify and access respondents.  
  4. Difficult to maintain randomness while selecting respondents within clusters.  
  5. PPS not often done due to difficulties estimating cluster size; samples often require weighting.  
  6. This is not always done, which results in biased estimates. |
| RDS      | 1. Start with initial contacts or ‘seeds’ who are surveyed and then become recruiters.  
  2. Each recruiter invites up to three people they know in the high risk group to be interviewed.  
  3. The new recruits become the recruiters.  
  4. Five to six recruitment waves occur. | 1. Ease of field operations.  
  2. No need for ethnographic mapping or sampling frame.  
  3. Target population recruits for you; good when the group does not trust surveillance workers.  
  4. Less visible members of the population reached.  
  5. Lower cost. | 1. Population must be a network.  
  2. Need to keep track of links between recruiters and recruits.  
  3. Ethical issues involved in using incentives.  
  4. Requires strong assumptions.  
  5. Still in experimental stage.  
  6. Special analyses. |
**Sampling approach criteria**

You should assess sampling options for each high risk group of interest. Answering the following questions can help guide the selection of sampling strategies.

1. Is the population of interest the general population or youth? If **yes**, conventional cluster sampling is recommended.
2. Do group members congregate in accessible locations/sites in high proportions? If **no**, RDS is recommended.
3. Is it possible to construct a list of all group members associated with each site? If **no**, TLS or RDS is recommended.
4. Are all group members on the list (not just those who happen to be present at a site) readily accessible during data collection? If **no**, TLS or RDS is recommended.

Conventional household or institutional survey methods are feasible only when answers to questions 2-4 are “yes,” (and also feasible for the general population and youth). These questions are represented diagrammatically in Figure 1.2.

Detailed information on the sampling and survey methods available for conducting surveillance among high risk groups is provided in Module 5: Surveillance of High risk Behaviours. Detailed information on the survey methods applicable to behavioural and biological surveillance of high risk groups is presented later in this module.

The CDC Global AIDS Program (GAP) surveillance team is developing an interactive sampling selection tool for use in surveillance study sampling design. Proper sampling design is critical to the success of your study. The tool is scheduled to become available in 2007. The date of release and the URL will be announced by various means by the CDC-GAP and WHO regional offices. The sampling selection tool will provide:

- An interactive, branching decision tree that includes detail on sampling design
- Supporting resources that may not be readily available, such as:
  - a bibliography with downloads or links to studies that have used various sampling designs
  - comprehensive information on populations at increased risk for HIV transmission
  - details of sampling designs.

**Sample size calculation**

Annex 1.1: Formula for Sample Size Calculation provides pre-calculated sample-size estimates for a range of possible scenarios in behavioural and sero-surveillance.

**Measures and Indicators**

Behavioural surveillance indicators should measure behaviours that are key to the spread of HIV and that are targeted by HIV prevention programmes. These are:

- behaviours that increase the chance that an uninfected person will come into contact with an infected person (for example, number and types of sexual partners)
- behaviours that increase the chance that HIV will be transmitted if contact with an HIV-infected person occurs (for example, condom use or sharing needles).
The selection of indicators for surveying high risk groups should be determined by the country’s data needs. Essential indicators for the sex workers, injection drug users and the general population are shown in Table 1.5.

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Module 5: Surveillance of High risk Behaviours and at the following websites:

- United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
- Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among FSWs. These guidelines are available online at: http://www.fhi.org.
- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviours relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Indicators for the general population can also be used with minor modifications for some high risk groups, such as migrants, uniformed personnel and prisoners. It is also usual for data to be collected on factors that promote high risk behaviours (for example, alcohol or drug use) and on background information. In this way, indicators can be compared across different socio-demographic groups.

Table 1.5

<table>
<thead>
<tr>
<th>Essential indicators for behavioural surveillance in injection drug users, female sex workers and men who have sex with men</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Injection drug users</strong></td>
</tr>
<tr>
<td>Proportion who shared needles last time.</td>
</tr>
<tr>
<td>Proportion who did not use clean needles consistently in past week (or other time reference period).</td>
</tr>
<tr>
<td>Proportion who shared drugs.</td>
</tr>
<tr>
<td>Proportion who used condoms.</td>
</tr>
</tbody>
</table>
Further information on the behavioural measures used in surveillance of high risk groups is provided later in this module and in Module 5: Surveillance of High risk Behaviours.

**Biological measures**

There are a number of choices to make about which biological measures to use in surveys of high risk groups. First and foremost is the choice as to which infections to study. Choices include HIV, which is almost always included, and other infections that are markers of behaviours associated with HIV transmission. The following table summarises this information:

<table>
<thead>
<tr>
<th>Type of transmission</th>
<th>Infections to test for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual</td>
<td>• syphilis</td>
</tr>
<tr>
<td></td>
<td>• gonorrhoea</td>
</tr>
<tr>
<td></td>
<td>• chlamydia</td>
</tr>
<tr>
<td></td>
<td>• hepatitis A</td>
</tr>
<tr>
<td></td>
<td>• herpes simplex virus type 2</td>
</tr>
<tr>
<td></td>
<td>• trichomoniasis</td>
</tr>
<tr>
<td></td>
<td>• <em>H. ducreyi</em> (chancroid)</td>
</tr>
<tr>
<td></td>
<td>• <em>T. pallidum</em></td>
</tr>
<tr>
<td>Parenteral (blood-borne)</td>
<td>• hepatitis C</td>
</tr>
<tr>
<td></td>
<td>• human T-lymphotropic virus type 1 (HTLV-I)</td>
</tr>
<tr>
<td></td>
<td>• syphilis</td>
</tr>
</tbody>
</table>

The setting in which the survey will be conducted is important. If there is the possibility of only a single visit, rapid testing for HIV is important. If there are problems with drawing blood, you can test saliva for HIV. This is useful if populations have difficult venous access (as with injection drug users) or if patients fear needles.

Later in this unit, we review the different biological measures and their advantages and disadvantages in high risk and hard-to-reach groups.

**Sexually transmitted infections**

When high risk groups are at risk because of sexual transmission of HIV, rates of acute STIs are often used as a proxy for the presence of behaviours that could result in the transmission of HIV. Persons whose sexual risk is high enough to acquire an STI may also acquire HIV if they are exposed to it. Moreover, STIs are often more common than HIV, making studies more convenient than HIV prevalence surveys. They can serve as an early warning sign, because STIs are often present in a population before HIV enters it. In practise, because HIV cohort studies are expensive and logistically complicated and because HIV incidence measures are not widely available, monitoring and evaluation of the success of HIV prevention programmes often relies on STI incidence and prevalence.

Examples of populations in which STIs serve as a good proxy for behavioural risk of HIV infection are:
- sex workers
- STI clinic patients
- men who have sex with men
- mobile populations and migrants
- prisoners
- uniformed personnel.

Rates of STIs can also be used to evaluate HIV prevention programmes. Both ulcerative STIs (syphilis, chancroid, herpes simplex virus type 2) and inflammatory STIs (gonorrhoea, chlamydia) can increase the risk of acquiring and transmitting HIV infection. Therefore, controlling STIs in high risk groups and groups with high HIV incidence is an important HIV prevention strategy. Evaluating the success of these STI control programmes is done primarily by examining incidence and prevalence of STIs.

**Testing for STIs**

STIs that are most frequently measured are:

- syphilis
- gonorrhoea
- chlamydia
- herpes simplex virus type 2
- hepatitis A
- trichomoniasis.

In Asia, hepatitis B virus (HBV) is often acquired in childhood, and is thus a less reliable marker for injection drug use than it is in other regions.

Depending on the organism, a positive test can mean either recent infection (indicating recent high risk sex) or past infection (indicating past high risk sex). Because some STIs are frequently asymptomatic, their true prevalence cannot be determined by the presence of symptoms alone. For chlamydia and gonorrhoea, especially in women, testing is necessary.

Recent high risk sex can be determined by a positive test for:

- gonorrhoea
- chlamydia
- syphilis (high-titre syphilis means new infection, low titres mean past infection)
- trichomoniasis.

Past high risk sex is usually determined by a positive test for:

- syphilis (low titre)
- herpes simplex virus type 2
- hepatitis A (IgG).

Serological tests for syphilis, herpes simplex virus type 2 and hepatitis A require blood samples. While antibody tests for chancroid can be done, they are not widely available.
Gonorrhoea and chlamydia can be detected in either urine or genital swabs (urethral swabs in men, which are rarely done, and endocervical or vaginal swabs in women). Often, because of the ease of collection of urine for detection of gonorrhoea and chlamydia, these infections are measured in hard-to-reach groups.

Syphilis is diagnosed serologically, and high-titre syphilis (for example, a positive specimen with a titre of 1:8 or higher) is an especially good marker of recent sexual risk-taking. If any of the bacterial infections (syphilis, gonorrhoea or chlamydia) are detected, there is an ethical obligation to treat the infection. Therefore, studies in which treatable bacterial STIs are being measured must be able to bring in participants back for treatment and for management of their sexual contacts.

Parenterally transmitted infections
Groups at high risk for parenterally acquiring HIV, such as injection drug users, have increased risk of other blood-borne infections. Hepatitis C virus is the blood-borne infection most typically measured.

Hepatitis C can be measured using a variety of laboratory tests, but is most often measured using a simple EIA. As with HIV, antibodies will be present for long periods of time—often decades—for most patients with hepatitis C. Although EIAs can detect more than 95% of chronically infected patients, they can detect only 50% to 70% of acute infections. For this reason, a recombinant immunoblot assay (RIBA) is often used as an extra test for hepatitis C.

In addition to these antibody and antigen tests that detect specific infections, it is possible to screen for liver damage—an indirect marker of current or past hepatitis—using liver function tests, most commonly alanine-leucine transferase (ALT) and less commonly asparate aminotransferase (AST). Note that ALT can be elevated in persons with alcoholic damage to the liver, though it is more prominent with AST.

The full range of available tests is shown in Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups.

It should be noted that, in some countries, the re-use of needles in medical settings and piercing and scarification practises contribute to parenteral transmission of hepatitis C.

Ethical Considerations
High risk groups are often not included in regular surveillance activities because they can be difficult to reach. Because they are not included, there can be large gaps in our knowledge of the HIV situation in a country or district. To have the most accurate picture of the HIV epidemic, it is essential to understand the spread of HIV in high risk groups. Additionally, surveillance data can contribute to advocacy for improved care and treatment for these vulnerable populations.

Potential harms
Many high risk groups are marginalised, and sometimes their behaviour is illegal. High risk groups who have a legitimate basis to fear reactions of the larger society include the following:
Module 6: Surveillance of Populations at High Risk for HIV Transmission

- sex workers
- injection drug users
- men who have sex with men
- prisoners.

However, some level of risk probably exists for all high risk groups. A list of potential harms is listed in Table 1.7

Table 1.7
Potential harms caused by HIV and behavioural surveillance in high risk populations

<table>
<thead>
<tr>
<th>Type of harm</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Public attack, abuse, loss of healthcare services.</td>
</tr>
<tr>
<td>Psychological</td>
<td>Depression, suicide.</td>
</tr>
<tr>
<td>Legal</td>
<td>Arrest, prosecution.</td>
</tr>
<tr>
<td>Social</td>
<td>Disclosure to family, workplace discrimination, loss of employment, isolation.</td>
</tr>
</tbody>
</table>

WHO ethical guidelines
In 2003, WHO published a set of guidelines specifically directed at the ethical considerations involved in second-generation surveillance (available at www.who.int/hiv/pub/epidemiology/sgs_ethical). These guidelines provide an overview of medical ethics, the ethics of epidemiological research and the ethics of surveillance. Other issues addressed are:

- data collection in behavioural surveillance and sero-surveillance
- consent
- data use and dissemination
- right to access test results.

Confidentiality
Confidentiality protects subjects from adverse consequences that may arise from participating in a study or survey. If a person’s HIV infection becomes known, he or she may suffer discrimination, stigma or even be subject to criminal charges in some situations. Be aware of any particular provisions in your country’s laws that may complicate participation. These may include:

- laws around age of legal adulthood, including when adolescents can consent to participate in studies
- laws prohibiting sex work or sex work under a certain age
- laws prohibiting men to have sex with men
- laws prohibiting injection drug use
- laws requiring reporting of individuals with HIV infection
- laws that protect study results from legal proceedings.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will
take to minimise them. Explaining these issues to them is part of the informed consent process.

**Informed consent**

Surveys and studies in high risk groups usually require the formal informed consent of people participating. This entails disclosing information that will be relevant to a person’s taking the decision whether to participate.

Whenever informed consent is obtained, participation bias is an important issue. It may be useful to add a check box on consent forms to indicate those who choose not to participate in order to assist evaluation of participation bias. If this is not possible, other means of collecting information on non-participants can be incorporated in the data collection process.

**Written consent forms and surrogate consent**

Written consent forms are generally required to document that the process of informed consent has occurred. The appropriate reading level of consent forms is eighth grade level or lower. When literacy is low, consent can be obtained verbally. In that case, verbal consent needs to be documented. Examples of written and a verbal consent forms are included in Annex 1.2. For suggested wording and language for the specific elements that are required in consent forms, please refer to the CDC website: www.cdc.gov/od/ads/docs/consent.pdf.

When subjects are not capable of giving informed consent, either in writing or verbally, surrogate consent can be obtained. Examples of this are when a parent gives consent for a child or a guardian gives consent for an adult with severe illness. Countries may also have laws and standards about the age at which an adolescent can participate in research without their parents’ consent. You should familiarise yourself with these laws in your country before you start the survey.

Although potential participants in surveillance and research activities are informed that participation in these activities is entirely voluntary, some groups may feel coerced into participation. Prisoners and potentially lower ranking members of uniformed services are especially vulnerable to the belief that if they don’t participate they will be punished. In these situations, measures must be taken to ensure that effective communication and understanding is involved in the informed consent process.

Further information on the ethical issues related to surveillance of high risk groups is provided in Units 2 through 8.

**Summary**

A key component of behavioural study and sero-surveillance is determining HIV prevalence in groups that are at high risk of acquiring and transmitting HIV. Surveillance of these groups is particularly important at the beginning of an HIV epidemic, as the first infections often appear in these groups. Surveillance data must be disseminated to the populations and agencies that can use these data.
In South-East Asia, populations at increased risk include female sex workers, injection drug users, men who have sex with men, mobile populations, out-of-school youth, prisoners and uniformed personnel. Many populations at increased risk are vulnerable to a variety of social factors, and as a result, surveillance and special studies in these groups raise several ethical issues. There are several conventional probability sampling methods that can be used for sampling populations. As many populations at increased risk are hard-to-reach sections of population, respondent-driven sampling and time-location sampling are ideally suited for surveys of high risk groups.

Exercises

Warm-up review
Take a few minutes now to look back on your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion
Get into small groups to discuss the following questions.

1. In your country, what populations are most at risk of acquiring HIV?
2. Does your country conduct HIV surveillance among these populations? If yes, how frequently?
Annex 1.1. Formula for Sample Size Calculation

The sample size needed to conduct behavioural and biological surveys can be based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. For example, you would like enough sex workers in your survey rounds to show that condom use at last paid sex increased from 20% in the year 2006 to 30% in 2007.

The general formula for the needed sample size (n) is:

\[
\frac{\left( Z_{1-\alpha} \sqrt{2P(1-P)} + Z_{1-\beta} \sqrt{P_1(1-P_1) + P_2(1-P_2)} \right)^2}{(P_2 - P_1)^2}
\]

Where:

- \( n = \text{Sample size required per survey round (year).} \)
- \( D = \text{Design effect (see below)} \)
- \( Z_{1-\alpha} = \text{The z score for the desired confidence level, usually 1.96 for 95\%} \)
- \( Z_{1-\beta} = \text{The z score for the desired power, usually 0.83 for 80\%.} \)
- \( P_1 = \text{The proportion of the sample reporting indicator in year 1} \)
- \( P_2 = \text{The proportion of the sample reporting indicator in year 2} \)
- \( P = \frac{(P_1 + P_2)}{2} \)

Choosing the values of these numbers is based on the following considerations:

**D design effect**: The design effect can be considered a correction factor for how much a cluster sample differs from a simple random sample. Effectively, the design effect multiplies the sample size by the factor of D. The design effect accounts for the similarities people have when they are sampled within the same cluster. For example, female sex workers within a particular brothel may be similar with respect to condom use because of the social norms, condom availability or intervention programmes of the particular brothel. Choosing a design effect is difficult without prior survey data. Design effects from 1 (that is, none) to 2 (moderate) cover a typical range. For RDS surveys, a small design effect of 1.25 is recommended. For cluster sampling and TLS, a moderate design effect of 2.0 is recommended. The bigger the \( D \), the larger the sample size needed.

**P_1 and P_2**: \( P_1 \) and \( P_2 \) are the measures of interest for which you wish to see a change between survey rounds. For example, you wish to show that condom use at last paid sex for sex workers increased from 20\% in 2006 (\( P_1 \)) to 30\% or greater in 2007 (\( P_2 \)). \( P_1 \) is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be. \( P_2 \) is ideally set at the goal you would like to achieve (for example, a 10\% or greater increase in condom use). In practise, it is usually set at
the smallest change you think is meaningful. For example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. The smaller the change you wish to detect, the larger the sample size you will need. Also, the closer \( P_1 \) and \( P_2 \) are to 50%, the larger the sample size you will need.

\( Z_{1-\alpha} \): The \( Z_{1-\alpha} \) score is a statistic that corresponds to the level of significance desired. Usually, a significant level of 0.05 (or equivalently a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a “two-tailed” statistic). The smaller the significant level (that is, higher confidence level), the larger the sample size you will need.

\( Z_{1-\beta} \): The \( Z_{1-\beta} \) score is a statistic that corresponds to the power desired. Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a “two-tailed” statistic). The higher the power, the larger the sample size you will need.

The table below provides pre-calculated sample size estimates for a range of possible scenarios in behavioural and sero-surveillance.

**Sample size needed per survey wave to detect a change in the proportion of an indicator between survey waves, using a 95% confidence level, 80% power and a design effect of 1.25 and 2.0.**

<table>
<thead>
<tr>
<th>Indicator level in wave 1 ( (P_1) )</th>
<th>Indicator level in wave 2 ( (P_2) )</th>
<th>Sample size needed each wave with a design effect of 1.25</th>
<th>Sample size needed each wave with a design effect of 2.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.10</td>
<td>0.20</td>
<td>247</td>
<td>395</td>
</tr>
<tr>
<td>0.10</td>
<td>0.25</td>
<td>123</td>
<td>197</td>
</tr>
<tr>
<td>0.20</td>
<td>0.30</td>
<td>363</td>
<td>581</td>
</tr>
<tr>
<td>0.20</td>
<td>0.35</td>
<td>171</td>
<td>274</td>
</tr>
<tr>
<td>0.30</td>
<td>0.40</td>
<td>441</td>
<td>706</td>
</tr>
<tr>
<td>0.30</td>
<td>0.45</td>
<td>201</td>
<td>322</td>
</tr>
<tr>
<td>0.40</td>
<td>0.50</td>
<td>480</td>
<td>768</td>
</tr>
<tr>
<td>0.40</td>
<td>0.55</td>
<td>214</td>
<td>343</td>
</tr>
<tr>
<td>0.50</td>
<td>0.60</td>
<td>480</td>
<td>768</td>
</tr>
<tr>
<td>0.50</td>
<td>0.65</td>
<td>210</td>
<td>336</td>
</tr>
<tr>
<td>0.60</td>
<td>0.70</td>
<td>441</td>
<td>706</td>
</tr>
<tr>
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<td>0.75</td>
<td>188</td>
<td>301</td>
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<tr>
<td>0.70</td>
<td>0.80</td>
<td>363</td>
<td>581</td>
</tr>
<tr>
<td>0.70</td>
<td>0.85</td>
<td>149</td>
<td>239</td>
</tr>
<tr>
<td>0.80</td>
<td>0.90</td>
<td>247</td>
<td>395</td>
</tr>
<tr>
<td>0.80</td>
<td>0.95</td>
<td>93</td>
<td>149</td>
</tr>
</tbody>
</table>
Annex 1.2 Examples of Verbal and Written Consent to Participate in a Survey

Example 1a: Verbal consent form (not requiring a written signature)

University of Serosia

Information sheet for research participants

Purpose and background: The University of Serosia is conducting a survey of injection drug users. Participants will undergo a behavioural interview, receive monetary compensation for cost associated with their participation and obtain referrals for HIV prevention counselling and testing. The interview will assess sexual behaviours, drug use, condom use, experiences of discrimination and HIV/STI testing and other HIV and STI related behaviours with both standard and site-specific measures. This study will be based on data from 320 IDUs recruited from social and sexual networks in Indam, Serosia. You have been asked to participate because you were referred to the study by a person in your social or sexual network.

Procedures: If you agree to participate, the following will occur:

- You will be interviewed for approximately 45 minutes.
- You will be asked about:
  - your use of alcohol or other drugs
  - sexual activities
  - experiences of discrimination
  - condom use
  - knowledge of STIs and HIV
  - utilisation of local prevention programmes
  - demographic information.

Risks/Discomforts: This survey is totally anonymous, and no information identifying you will be collected. All the information we will ask of you has to do with your behaviour. You can refuse to answer any question. The information collected will be pooled with information provided by other people. Some of the questions might be considered intrusive or rude in a normal conversation, but are standard questions about infectious diseases and behaviours that transmit these infections. As such, some of the questions may make you uncomfortable for a short time. All data will be kept in locked files accessible only to the study personnel.

Benefits: There are no personal benefits to participating in this study. However, your knowledge and perceptions will be important to developing a better understanding of IDUs and the IDU community in Indam. This information maybe helpful in creating HIV prevention programmes for FSW in your community.
Reimbursement: At the end of the interview, you will be reimbursed 100 Serosian rupees (US$2) in cash for costs associated with participating in this study. You will also be offered the opportunity to refer three more people to the study. If these people participate in the study, you will receive 50 Serosian rupees (US$1) per person who participates. If you are one of the people recruited in the last wave of recruitment, you will receive 150 Serosian rupees (US$3).

Questions: The interviewer has talked to you about this study and answered all your questions. If you have additional questions, you may contact the principal investigators at the University of Serosia.

If you have any comments or concerns about participation in this study, you should first talk with the investigators. If for some reason you do not wish to speak directly to them, you may contact Dr XXXXXX, Senior Lecturer, Department of Medicine, Indam Hospital 4th Floor, University of Serosia. His phone contact is XXXXXX.

Consent: Participation in research is voluntary. You are free to decline to be in this study, or to withdraw from it at any time. Your decision as to whether or not to participate in this study will have no affect on you. Similarly, you may refuse to answer any question or withdraw from the study at any time without any consequence to you.

You will be given a copy of this information sheet to keep.

Example 1b: Written consent form (requiring a written signature)

University of Serosia

Consent to be a research subject

A randomised trial of HIV prevention among injection drug users in Indam, Serosia

A. Purpose and background
Dr. XXX of the University of Serosia is conducting a research study to learn about ways to reduce transmission of human immunodeficiency virus (HIV) among injection drug users in Indam, Serosia. The purpose of this study is to compare two ways to do HIV-prevention health education for drug users at the venues where they receive medical and substance abuse assistance. You are being asked to participate in a group discussion as part of this study because you are a client, manager, doctor or staff member of an agency that provides services to drug users and receives funding from the National HIV Prevention Programme. The purpose of this group discussion is to gather your opinions about the programme, its implementation, its acceptability, and ways to improve the programme.

B. Procedures
If you agree to be in this study, the following procedures will happen.

1. We will ask you to come to a private place for a group discussion with 7-9 other participants. The discussion will be tape recorded and written down at a later time (transcribed).
2. You will be asked to respond to questions about your experiences with the National HIV Prevention Programme, your opinions about it and how, if at all, it has influenced you personally.

The discussion will take approximately two hours.

C. Risks and Discomforts
During this group discussion, other participants will hear what you have to say. We will ask you some personal questions that may cause you to feel embarrassed or awkward. You are free to refuse to answer any questions you do not wish to answer and you may leave the discussion at any time.

Confidentiality: Participation in this discussion will involve a loss of privacy, but information about you will be handled as confidentially as possible. We will not reveal your full name to other participants and at no time during the group discussion will your name be written down in connection with the information you have provided. We will ask you to use only your first name or to choose a fake name. We will also ask you and the other participants not to tell anyone outside of the group what any person said during the discussion. However, we cannot guarantee that everyone will keep the discussions private. Study records will be kept as confidential as possible. All tapes and transcripts of the discussion will be kept in locked filing cabinets and only members of the study team will have access to them. Your name or any other data that might identify you will not be used in any reports or publications resulting from this study.

D. Benefits
There will be no direct benefit to you from participating in this study. However, by taking part in this study, you will be helping the investigators learn about the best ways to promote HIV prevention among drug users who receive services from de-addiction and methadone maintenance programmes in Indam, Serosia.

E. Costs
There will be no cost to you as a result of taking part in this study.

F. Payment
You will not be paid to participate in this study. However, after you complete the focus group discussion you will be offered a small gift as a token of appreciation for your time. You will also be reimbursed for your transport costs to the place where the group discussion takes place.

G. Questions
This study has been explained to you by Dr XXX, Dr XXX or the person who signed below and your questions were answered. If you have any other questions about the research, your rights as a research subject, and/or research-related injuries, you may contact Dr XXX at 123 College Road., Indam, Serosia, (telephone XXX).
If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact Professor XXXX at the Biomedical Research and Training Institute, which is concerned with the protection of volunteers in research projects. You may reach Professor XXXX at XXX. The address is 123 College Road, University of Serosia, Indam.

H. Consent
   You will be given a copy of this consent form to keep.

   YOUR PARTICIPATION IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will not jeopardise your eligibility for future studies.

If you agree to participate, you should sign below.

_________________________   ________________________________
Date                     Signature of study participant

_________________________   ________________________________
Date                     Signature of person obtaining consent
Overview

What this unit is about
This unit describes the background and special considerations for conducting behavioural surveillance and HIV sero-surveillance among sex workers (SWs). The unit ends with an extensive case study concerning female sex workers (FSWs) and specific study issues.

Warm-up questions
1. True or false? SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners.
   True  False

2. List two places where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found.
   a. 
   b. 

3. ___________ SWs do not engage in sex work full time, and may have another source of income. They are also called casual SWs or clandestine sex workers.

4. True or false? Surveillance co-ordinators should meet with SWs to use their expertise in designing the behavioural surveillance approach and questionnaires.
   True  False

5. SWs and their clients are often ___________ to other high risk populations. For example, male clients of FSWs may transmit HIV to their wives and non-commercial sex partners.

6. Name a sampling method that could be used among highly mobile sex workers, such as those who do not work in fixed brothels.

Introduction

What you will learn
By the end of this unit, you should be able to:

- understand the diversity of sex work
- understand the role of SWs in the HIV epidemic
- describe options for sampling SWs
- describe the special ethical considerations associated with conducting HIV surveillance activities in SWs.
Background

This unit focuses on the special issues in conducting behavioural surveillance and HIV sero-surveillance in sex workers (SWs).

Sex work, or the exchange of sex for money, occurs everywhere in the world. Sex work includes many practises and occurs in a wide range of settings. Two broad categories are often used to describe sex workers: “direct” and “indirect.” The typical features of direct and indirect sex workers are shown in Table 2.1.

Table 2.1
Comparing direct and indirect FSWs

<table>
<thead>
<tr>
<th>Direct sex workers</th>
<th>Indirect sex workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• have little or no source of income outside sex work</td>
<td>• are those who may have another source of income or do not engage in sex work full time</td>
</tr>
<tr>
<td>• are also called formal sex workers</td>
<td>• are also called casual sex workers, clandestine sex workers or informal sex workers</td>
</tr>
<tr>
<td>• can be found in brothels</td>
<td>• may provide sex services in places or specific locations where they are employed, such as bars, hotels or massage parlours that are not necessarily or exclusively associated with sex work</td>
</tr>
<tr>
<td>• can be found in high concentration in streets, hotels, bars and massage parlours</td>
<td>• may work by special arrangement via phone or internet</td>
</tr>
<tr>
<td>• may work by special arrangement via phone or internet</td>
<td>• are unlikely to be included in registries or lists of SWs routinely screened at STI clinics</td>
</tr>
<tr>
<td>• may be trafficked (that is, bought and sold) with little freedom of mobility and difficult access to persons other than their handlers or clients</td>
<td>• may not identify themselves as SWs.</td>
</tr>
<tr>
<td>• may be registered in areas where sex work is legal or tolerated; registries of direct SWs may be maintained through STI clinics to monitor routine STI screening and treatment</td>
<td></td>
</tr>
<tr>
<td>• may identify themselves as a SWs.</td>
<td></td>
</tr>
</tbody>
</table>

SWs may cross between direct and indirect sex work or may enter and exit sex work over time.

Some aspects of sex work may not follow these categories. For example, sex may be bartered for material needs, school fees or illicit drugs. This behaviour is called transactional sex. In some areas, persons who engage in transactional sex are not considered sex workers.

Throughout the world, men also buy sex from male sex workers and transgendered (that is, biologically male persons who present as females) sex workers. These populations are often severely affected by HIV. Many of the methods used in conducting surveillance in male sex workers (MSWs) are similar to those used with female sex workers (FSWs). However, in other ways, surveillance among MSWs is very different from surveillance among FSWs. For example, the formative research phases should identify issues with accessing men who have sex with men (MSM) and tracking behaviours specific to male-male sexual practices. Surveillance measures and approaches to sampling male sex workers are also discussed in the unit related to men who have sex with men (MSM). You should keep in mind that MSM and MSWs are different; a male sex worker may not identify himself as homosexual.
**Role of SWs in the HIV epidemic**

SWs are at a high risk both for getting HIV and STIs from their clients and for transmitting them to their clients and their non-paying partners. Factors that may increase HIV risk among SWs include:

- high number of daily clients, increasing the probability of exposure to HIV and STIs
- high *partner concurrency* (that is, having extensive sexual network connections to many persons at the same time increases the spread of HIV and STIs)
- high frequency of use of commercial sex by men in the population
- high levels of other STIs that enhance HIV transmission
- high levels of injecting drug use
- high frequency of sex under the influence of alcohol or drugs (often affecting the ability to negotiate condom use)
- high number of clients under the influence of alcohol or drugs
- loss of control over condom use due to financial and physical coercion or violence
- having non-client partners, steady and non-steady, with whom they do not use condoms
- high levels of mobility and travel (for example, to areas of higher or lower HIV prevalence)
- difficult access to HIV and STI prevention programmes due to the illegal and stigmatised nature of sex work.

**Prevalence of HIV among SWs**

In South-East Asia, the *prevalence* of HIV among SWs varies by country and region, as illustrated in the following data:

- In India, national HIV sentinel surveillance conducted in 2005 found that 8.4% of FSWs were infected with HIV.\(^7\)
- In 2004, the HIV prevalence among FSWs in Bangkok was 4.3%, down from 8.5% in 2000.
- HIV prevalence among FSW in Yangon and Mandalay, Myanmar was 33% and 53.6%, respectively, in 2003.
- In 2005, data from sentinel surveillance found an HIV prevalence of 2% among female sex workers in Kathmandu, Nepal.\(^8\)
- In 2004, a cross sectional survey conducted in Jakarta, Indonesia found that the HIV prevalence among transgendered sex workers was 22%, and was 3.6% among male sex workers.\(^9\)
- In 2004, among 519 male sex workers tested from among four provinces in Thailand, 9.6% were found to be infected with HIV.\(^10\)

**Role of SWs in surveillance**

SWs can play a critical role in HIV surveillance at all states of the epidemic.

- In countries with *low-level epidemics*, where the HIV prevalence has not consistently exceeded 5% in any defined sub-population, FSWs may be the first to be detected with HIV infection.
- FSWs are often one of the first populations to reach HIV prevalence levels above 5%, leading to a country’s epidemic classification as *concentrated*. 
• In generalised epidemics, where transmission is widespread in the general population, behavioural changes in response to prevention programmes may be detected first among FSWs. For example, the results of consistent condom use may be detected first among FSWs.

SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners and other factors listed above. Therefore, behavioural and HIV sero-surveillance among SWs plays a central role in determining the magnitude and direction of the HIV epidemic in all epidemic states.

Bridges and overlap with other populations
SWs and their clients are often bridges to other high risk populations. For example, male clients of FSWs or MSWs may transmit HIV to their wives and non-commercial (steady and non-steady) sex partners.

Some groups of men become the clients of SWs more frequently than the general population. These include:

• truck drivers or persons in other occupations that require travel
• military personnel
• police officers
• STI clinic patients.

SWs also overlap with many other high risk populations covered in this module. SWs are found among IDUs, out-of-school youth and prisoners.

Additionally, many SWs are mobile. Some are trafficked from rural areas or across international borders, while others voluntarily migrate to urban centres or other areas where men congregate, such as truck stops. The often desperate conditions of being a refugee or involuntary migrant may force women to sell sex to survive. Therefore, SWs may include both migrants who later become sex workers and women and children who are trafficked for the purpose of sex work.

Conducting Formative Research

Pre-surveillance assessment
The first step in planning HIV surveillance in SWs is to gain an understanding of the population in your area through formative research. Pre-surveillance assessment activities are conducted to identify key indicators to measure, the diversity of the sub-populations of SWs and the geographic areas and venues where SWs may be found in high numbers. The aims of the pre-surveillance process include:

• agreeing on the purpose and uses of surveillance data for SW programmes
• defining who is an SW for surveillance purposes
• identifying a co-ordinating or decision-making body
• selecting sub-populations to include
• delineating the geographic coverage areas
• selecting which indicator variables to collect.
Consider where to find SWs

Surveillance requires gaining access to the full range of SWs sub-populations and areas. However, locating all areas where SWs can be found and gaining access to SWs within these areas can be challenging.

You can locate and gain access to SWs by:

- visiting the venues where they congregate
- interviewing and working with the persons who facilitate or regulate contact
- collaborating with organisations that provide services to SWs.

Because SWs are often socially marginalised or rigidly controlled or trafficked by their handlers, forming key alliances may be necessary to obtain surveillance data. Examples of key alliances for gaining access to SWs include:

- influential current and former SWs
- police
- handlers or other gatekeepers, such as pimps, madams and brothel managers or owners
- governmental and non-governmental organisations conducting SW HIV prevention and care programmes
- national and international sex worker advocacy groups
- national and international organisations that broadly advocate for women’s interests
- rickshaw and taxi drivers.

These people and organisations can also later assist with implementing surveillance activities. For example, former FSWs can be hired and trained as recruiters or interviewers.

Conducting ethnographic mapping

*Ethnographic mapping* entails the creation of a comprehensive description of the population with regard to:

- the places where SWs can be found
- the time periods of high and low volume of business
- types of sex work and sub-populations of SWs in your area.

This comprehensive description is used broadly to guide where and when SWs can be found to be recruited for surveillance activities, and what sub-populations can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a *sampling frame*, or comprehensive roster, representing the SW population in your area. This sampling frame provides the basis for some *probability-based sampling* methods (for example, *time-location sampling* and *multi-stage cluster sampling*).

The places where SWs congregate in large numbers include:

- brothels, hotels, bars, discos and massage parlours where direct sex work is known to take place
• hotels, bars, discos and massage parlours where indirect sex work may take place
• streets, parks, beaches, truck stops and other outdoor areas where sex workers congregate.

You can make a count or estimate of the number of SWs associated with each of these places. For example:

• for each brothel, make a census for the number of SWs
• for a particular street, count the number of SWs found during four-hour time periods on different times of the day and during different days of the week or month
• for each bar, count the number of SWs in four-hour time periods on different times of the day and during different days of the week or month.

With each venue and time period, the types of SWs should be recorded, if possible. For example, how many SWs are part-time compared to how many are full-time? How many are direct sex workers and how many indirect sex workers?

Some SWs do not congregate in a particular location. They are accessed by clients through other channels, such as newspaper ads., internet ads., the telephone or word of mouth. Such SWs may not have agents who arrange meetings. At present, the role these types of sex workers play in the HIV epidemic is thought to be relatively small. The ways in which they can be included in future surveillance activities is under research.

An additional component of formative research entails an assessment of how networked, or interconnected, sex workers are with each other in terms of the venues where they work and the types of sex work in which they are involved. For example, do brothel-based SWs interact with street-based or indirect SWs? Do female sex workers interact with male or transgendered sex workers?

Is there an SW registration system?
In some countries of South-East Asia, there are formal registration systems for SWs. The registration process is usually part of an ongoing programme for STI screening and treatment. Registries can be used as a sampling frame for SWs or incorporated into a more comprehensive sampling frame produced by ethnographic mapping.

Bear in mind that not all SWs are likely to be registered. Registries may not include the full range of SWs (direct and indirect) in an area. Examples of non-registered sex workers may include indirect sex workers or those who are very young, new to the trade, foreign to local conditions, working outside establishments or practicing sex work part-time. Furthermore, in some areas, HIV-infected sex workers are excluded from the registration system under the potentially false presumption that they would no longer engage in sex work.

Examine STI clinics
You may also identify SWs in large numbers at STI clinics.

• Some STI clinics are located in red light districts, or areas of concentrated sex work, and cater specifically to SWs.
Other STI clinics do not specifically cater to SWs, but do include a high number of them among their patients.

If the clients of STI clinics are to be considered for SW surveillance, information on whether the female clients engage in sex work or not must be systematically and routinely recorded.

**Selecting a Sampling Method**

In the past, finding samples of SWs and other hard-to-reach populations were matters of convenience; and as such known as convenience or non-probability samples (for example, surveys of FSWs attending STI clinics, or interviews of the most visible FSWs found in certain areas). While non-probability samples can provide some information, these data can be biased for a number of reasons. For example, HIV prevalence and risk behaviours may be different in the most visible sub-populations of SWs, compared to those that are more hidden. There are probability and quasi-probability sampling methods now available that can be successfully used to obtain more representative samples of SWs.

Depending on how SWs are organised and how easily they can be accessed, different sampling methods may be more or less feasible. Several basic strategies for sampling hard-to-reach SW populations are:

- simple *random sample* from a registry (such as a registry of FSWs in a particular area)
- *consecutive sampling* via *unlinked anonymous testing* or UAT (for example, of MSW, STI clinic patients)
- multi-stage cluster sampling
- time-location sampling (TLS)
- respondent-driven sampling (RDS) (for example, to obtain a sample of transgendered sex workers).

Figure 2.2 on the next page will help you select an appropriate sampling method for SWs in your area.
Figure 2.2

**Selecting sampling methods for SWs**

1. Is there a registry of SWs (for example, a list of SWs routinely screened for STI)?
   - Yes → *Simple random sample*
   - No →

2. Is there an STI clinic that serves SWs in the area?
   - Yes → Unlinked anonymous testing (UAT)
   - No →

3. Do SWs congregate in identifiable and accessible locations in high numbers?
   - Yes → RDS (for example, SWs reached via newspaper, internet ads. or agents)
   - No →

4. Is creating a list of SWs associated with each site feasible (for example, the number of SWs in each brothel, massage parlour, etc.)?
   - Yes → TLS or RDS
   - No →

5. Will a high proportion of SWs associated with the site be present on a chosen day/time?
   - Yes → Multi-stage cluster sample
   - No → TLS or RDS

*Note that a simple random sample of SWs registered at an STI clinic may miss populations at high risk (for example, unregistered, indirect or highly mobile SWs). In addition, HIV-infected sex workers may be selectively excluded from such a registry.

**Measures**

**Biological measures**

Measuring HIV sero-prevalence among SWs is an integral component of surveillance. The high sexual risk among SWs also makes STI testing a useful and feasible indicator for surveillance (For a description of the available STI tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups).
• **Syphilis testing** is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.

• **Accurate tests for gonorrhoea and chlamydia** are expensive and usually require a urine specimen.

• **Herpes simplex virus type-2** (HSV-2) testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.

In areas where there may be suspected overlap between SWs and IDUs, biological markers may include **hepatitis C virus** (HCV). Tests for HCV may be expensive.

In some parts of Asia, **hepatitis B virus** (HBV) is often acquired perinatally or from child to child contact in household settings, and may therefore be less of a marker for injection drug use than in other regions.

**Behavioural measures**

Measuring changes in sexual behaviour among sex workers helps explain trends in HIV and STI prevalence data. Among sex workers, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Several international organizations have sought to standardize a set of “core” or basic indicators of HIV risk among SWs. These include:

• percent of SWs who received HIV testing in the last 12 months and who know the results (UNGASS)
• percent of SWs who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV (UNGASS)
• percent of SWs reporting the use of a condom with their most recent clients (UNGASS)
• in response to prompting, correct identification of the use of condoms as means of protection against HIV infection (MEASURE)
• condom use during every episode of vaginal intercourse during the preceding three months (MEASURE)
• age of sexual debut (MEASURE)
• having been forced to have sex in the last 12 months (MEASURE)
• sex while intoxicated during the last 12 months (MEASURE).

These basic indicators may be supplemented with local measures of particular importance in your area (as determined by your formative research phase). These additional indicators may include:

• sex work venues
• number of clients
• number of non-client sex partners, types
• condom use with non-client partners
• injection drug use
• migration, mobility
• STI treatment-seeking
• history of imprisonment
• marital status
• basic demographic characteristics.

Reference to indicators
Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

• United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
• Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among SWs. These guidelines are available online at: http://www.fhi.org.
• The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviours relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practices). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Special Ethical Considerations
Because sex work is stigmatized and often illegal, SWs are a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

• loss of confidentiality, inadvertent identification as an SW
• inadvertent disclosure of HIV status
• negative reaction and backlash in response to publicized results
• physical abuse by their pimp or brothel manager
• loss of income.

Consider your ability to obtain true informed consent when SWs may be coerced to participate or not participate by their brothel managers, pimps, agents or other handlers.

Assuring confidentiality
Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country’s laws that may complicate participation. These may include:
• laws prohibiting sex work or sex work under a certain age
• laws prohibiting injection drug use
• laws prohibiting male-male sex
• laws requiring reporting of individuals with HIV infection.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise them. Explaining these issues to them is part of the informed consent process.

Step you can take to minimize threats to confidentiality may include:

• conducting interviews with SWs in private settings
• keeping the names of the SWs separate from the data collected about them
• limiting access to any identifying information to authorized study personnel only
• keeping study documents in a locked, limited-access room
• having all staff sign confidentiality forms and undergo training in research ethics.

Of note: the unlinked anonymous testing (UAT) methods preclude the disclosure of participants’ names or other identifying information by design. Module 3: HIV Sero-Surveillance covers the methods of UAT in detail. In settings where confidentiality cannot be guaranteed and the potential harm of being identified as a SW or HIV infected person is severe, the UAT sampling method may be desired.

Summary

Sex work occurs in a wide range of settings and in a diverse group of sub-populations. SWs are at high risk for getting HIV and STIs from their clients and transmitting them to other clients and their non-paying sex partners. Behavioural and HIV sero-surveillance among SWs plays a central role in all epidemic states. Depending on how SWs are organized and how easily they are accessed, different sampling methods may be more or less feasible. As sex work is stigmatised and often illegal, special ethical issues must be considered when conducting surveillance among SWs.

Exercises

Warm-up review
Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion
Get into small groups to discuss the following questions.

1. Does your country conduct behavioural and/or sero-surveillance of sex workers?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods are used to sample sex workers?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of sex workers?

5. In the past five years, has the prevalence of HIV among sex workers increased, decreased or remained about the same?

Apply what you have learned/case study
Try this case study individually or in a group. We'll discuss the answers in class.

Behavioural Surveillance Among Brothel-Based Sex Workers In Tapang, Serosia

Part 1: Collecting information to plan surveillance activities
Tapang is a port city in Serosia with a total population of ten million. A large number of male workers from adjacent cities and provinces migrate to Tapang for employment. It is also a transit point for sea-farers and truck drivers. In response to a high demand, there is a sizeable commercial sex industry operating in the city. In 2003, there were an estimated 20,000-30,000 sex workers in Tapang. It is believed that most of the sex trade in Tapang is brothel-based.

The annual HIV sero-surveillance data, published by the National AIDS Programme, Ministry of Health, Serosia, indicates that the HIV prevalence among sex workers has remained high in the past five years. Recently, the Kate Foundation, a philanthropic international agency, awarded a five-year grant of US$ 2 million to Tapang Municipal Corporation for implementing prevention interventions among sex workers. Annual instalments of the grant will be released after the performance of the prevention programme has been reviewed. The Kate Foundation has allocated 15% of the total grant for surveillance and monitoring and evaluation activities.

The Commissioner of Public Health, Tapang City, directs the HIV programme manager to develop a package of evidence-based interventions to reduce HIV transmission among sex workers.

The HIV programme manager decides to undertake a behavioural survey among brothel-based sex workers in Tapang. He holds a meeting with his team of epidemiologists and social workers to plan for the survey, particularly the following:

1. What information is required for planning the survey?

2. How will the Tapang HIV team obtain this information?

Part 2: Building key alliances with community networks involved with sex workers
To obtain background information for designing a behavioural survey, the HIV team reviews several documents, including published literature, grey literature, reports of NGOs, clinic records of the public and private clinics and reports from the police department. Grey literature is material that is not published in easily accessible journals or databases. Examples of grey literature include the following:
Interviews of key informants are also conducted using open-ended questions. Several key informants are contacted, including pimps, bar owners, pan shops, auto rickshaw drivers, police and NGO managers and outreach health workers. The HIV team collects information on how the brothel-based sex trade is operated, the location and number of brothels, the number of sex workers in each brothel, the business hours of sex workers, health services available in the area and NGOs operating in the area.

Using information from formative research, the HIV team maps the brothels in Tapang. It is noted that 80% of the brothel areas are concentrated in the southern part of the city named Redpura. There are approximately 80 brothels in Redpura. On average, there are 30 sex workers in each brothel. As commercial sex work in Serosia is illegal, the brothel owners allow limited visibility and mobility of sex workers. Although there are several public health clinics in the area, these remain largely underutilised due to the lack of availability of drugs. Sex workers frequently visit private practitioners for treatment of STIs and other ailments.

Since the majority of the brothels are concentrated in Redpura, the HIV programme manager decides to first undertake a behavioural survey among sex workers in Redpura. The HIV team realises that in order to access sex workers, it is necessary to enlist support of stakeholders.

3. Who are the key stakeholders and community groups with whom it is necessary to build alliances?

4. How will the HIV team engage the different stakeholders?

Part 3: Choosing approaches to behavioural survey

The HIV team meets with NGO managers, brothel owners, agents, pimps, madams, auto drivers, hotel managers, bar owners and the police in the area.

A briefing meeting is organized at which the HIV programme manager informs the stakeholders about the need for and purpose of the behavioural survey. The expected outcome of the survey is explained to the audience.

With verbal assurance of the cooperation of the stakeholders, the HIV team is now ready to move to the next step.

5. What are the possible approaches to conducting a behavioural survey among sex workers in Redpura?

6. What are the advantages and disadvantages of each approach?
Part 4: Choosing a sampling approach

The Tapang HIV team has two options: 1) to undertake a community-based survey at the workplace of sex workers (for example, brothels); or, 2) to undertake an institutional survey at the public health clinic where sex workers access treatment of sexually transmitted infections (STIs).

The team weighs the pros and cons of each approach. It is less expensive and logistically easier and quicker to use an institutional approach. However, the team feels that the reach of the public clinics is limited, as nearly three-fourths of the sex workers are utilising services from private practitioners in the area. It is more expensive to undertake a community-based survey. However, the findings of the survey will be more representative of all sex workers in the brothels.

Given the availability of adequate resources, the cooperation assured by the stakeholders and the strengths of a community-based survey, the team decides to undertake a community-based cross-sectional survey of risk behaviours among brothel-based sex workers in Redpura.

7. What sampling design can be used to select representative respondents for the interview?

8. What would be an adequate sample size to detect an increase in consistent condom use (defined as use of condoms during every episode of vaginal intercourse during the preceding three months) with clients among FSWs from 20% in the current year to 35% if the survey is repeated in two years? (Refer to table with the sample size options).

Part 5: Collecting behavioural data

The most conservative sample size to detect an increase of 15 % points (20%-35%) in the proportion of sex workers who reported consistent condom use (with 80% power of detecting a change of this magnitude at the 95% confidence level significance), is 274 FSWs per survey year. The sample is increased by 10% to account for non-response, refusal, etc. Thus, the final sample size is rounded to 300 per survey year.

The surveillance team is able to obtain a reasonably complete listing of brothels in Redpura with the approximate number of FSWs in each brothel. This helps in constructing a sampling frame. A two-stage cluster sampling design is used. In stage I, 20 brothels are randomly selected using a list of random numbers. In stage II, a fixed number of 15 sex workers are selected in each brothel by random sampling.

9. What behavioural variables should be collected?

10. What special ethical considerations need to be considered for this surveillance activity?

Part 6: Analysing and disseminating data

Note: While analysis and dissemination of data are not covered in this module, it is expected that participants have a basic understanding of these activities.
Trained interviewers contact sex workers at the selected brothels during non-business hours. They explain the purpose of the study to sex workers and obtain verbal consent. Confidentiality is assured. The interviews are conducted in privacy and in a non-coercive manner. Personal identifiers are not collected.

The interviewers administer a pre-tested, semi-structured questionnaire to the selected sex workers to assess their sexual risk behaviours and practises. Variables collected are: socio-demographic variables, including age and formal schooling; duration of engaging in sex work; number of clients entertained per week; risk perception of acquiring HIV; history of a vaginal discharge or ulcer in the past year; STI treatment-seeking; STIs correctly treated; consistent condom use; onsite availability of condoms; reasons for non-use of condoms and condom negotiation practises.

Data are entered in a database, cleaned and analysed using STATA. A summary of the results is presented to the Tapang City Public Health Commissioner.

- A total of 289 sex workers were interviewed. The mean age of respondents was 30.9 years; 20% were non-literate and 44% had a primary education. On average, each sex worker had entertained 13 clients in the previous week.
- Nearly all respondents had heard about HIV/AIDS and 92% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
- Among the respondents, 22% reported having had a vaginal discharge or genital ulcer in the past year; of these, 63% sought care from a private practitioner, 5% sought care from public clinics and the remainder ignored their symptoms.
- Among the respondents, 64% had used a condom with their most recent client. Refusal by clients was the most common reason for non-use of condom; 86% reported insisting that their clients must use condoms. However, respondents encountered clients who refused sex without a condom, 48% successfully renegotiated condom use, 30% increased fees and had sex without a condom and the remaining 22% refused sex.
- Only 23% of the respondents reported consistent condom use with regular partners.
- Of those who had used a condom with their most recent client, 12% had obtained it from the client, 32% from a peer or an NGO worker and the others from a pharmacy. Only 37% of respondents reported having a condom at the time of the interview.

11. What interventions should be initiated based on these results?

12. How would the HIV programme manager disseminate the results of the survey?

Part 7: Epilogue

Based on the community survey, brothel-based sex workers in Redpura were highly at risk of acquiring and transmitting HIV. Sex workers had a high partner turnover; a large proportion of them had untreated STIs, and condom use was low with clients and even lower with non-paying partners. Inadequate condom negotiation skills and lack of onsite condom availability resulted in low condom use. Urgent targeted interventions were needed to increase safe sex practises among sex workers in Redpura.
Based on these findings, the public health commissioner of Tapang directs the HIV programme manager to initiate the following interventions:

- engage peers and NGO outreach workers to educate sex workers about the need for consistent condom use with clients and regular partners
- conduct workshops to improve condom negotiation skills of sex workers
- distribute condoms to sex workers through peers and NGO workers
- ensure a regular supply of STI antimicrobials at public health clinics and train health workers at public and private health clinics in correct STI management.

The HIV survey team organises a two-hour debriefing of stakeholders, including representatives of the Kate Foundation and other donors, NGO managers and staff, and some brothel owners and sex workers. The HIV manager presents the findings of the survey, as well as the planned interventions. Goals are set to gauge the reach and impact of these interventions in two years’ time. A full report of the survey is posted on the website of the Tapang health department and distributed to a wide audience.
UNIT 3

Injecting Drug Users

Overview

What this unit is about
This unit describes the background and special considerations associated with conducting HIV behavioural and sero-surveillance among injection drug users (IDUs). The unit includes a case study highlighting special issues in conducting surveillance among IDUs.

Warm-up questions
1. List two examples of blood-to-blood (or parenteral) transmission of HIV.
   a. 
   b. 
2. Which of the following sampling methods can be used for surveillance in IDUs?
   a. time-location sampling
   b. multi-stage cluster sampling
   c. convenience sampling
   d. simple random sampling from a drug treatment clinic registry.
3. List two organizations with which you can form alliances as you develop your HIV surveillance system for IDUs.
   a. 
   b. 
4. List two interventions that can help reduce HIV transmission among IDUs.
   a. 
   b. 
5. What are the ethical issues must you consider when conducting surveillance in IDUs?

Introduction

What you will learn
By the end of this case study, you should be able to:

- describe special considerations associated with HIV surveillance in IDUs
- describe options for sampling and surveillance methods among IDUs
- list key biological and behavioural measures used for tracking the HIV epidemic among IDUs
- describe the special ethical considerations associated with conducting HIV surveillance activities among IDUs.
Background

Definitions
This unit focuses on the special issues in conducting behavioural surveillance and HIV sero-surveillance in injection drug users (IDUs).

Drugs injected by IDUs can include:

- opiate derivatives, such as heroin
- cocaine
- methamphetamine
- other sedative and hypnotic drugs
- combinations of these drugs.

Most of these drugs are highly addictive and expensive and obtaining and injecting drugs dominate the lives of these individuals.

Drugs can be injected by different routes, including the following:

- intravenously (into a vein)
- intramuscularly (into a muscle)
- subcutaneously (below the skin)
- intradermally (into the layers of the skin)

The risk of HIV infection is greatest with intravenous injection, but the other types of injection also carry high risks of transmission.

The use of non-injectable drugs, such as smoking marijuana, ingesting sedative-hypnotic drugs, inhaling cocaine, sniffing glue and drinking alcohol, cannot directly lead to HIV transmission. However, they can indirectly contribute to the problem of HIV, since they can be associated with the necessity of sex work in order to acquire funds to buy drugs, or with poor decision-making about sexual risks. This poor decision-making is also called disinhibition.

If the goal of your surveillance system is to track HIV among injecting drug users then efforts must be made to accurately distinguish IDUs from other drug users. Screening for injection may occur at the facility level (for example, de-addiction clinics specifically for IDUs) or by trained interviewers. Methods for identifying true injectors include physical examination for track marks and other signs of injection, or detailed interviews on how drugs are prepared for injection.

Role of IDUs in the HIV epidemic
IDUs are at high risk for HIV infection because of the practise of sharing needles and syringes to inject drugs. Every time a needle or syringe is shared, the person injecting may also inject a small amount of the previous user’s blood that has remained behind in the barrel of the needle or tip of the syringe. This can be a very efficient means of transmitting a number of viruses, including HIV, hepatitis B and hepatitis C. Parenteral transmission is the term that refers to blood-to-blood transmission, such as transmission through:
• transfusion of blood
• transfusion of blood products (for example, anti-haemophiliac factors)
• needlestick injuries (for example, in healthcare personnel)
• re-use of needles in medical settings, for blood donation and other procedures
• organ transplantation
• injection of illegal drugs intravenously, intramuscularly, subcutaneously or intradermally.

Further, IDUs are also at risk for sexual transmission of HIV, through sex work and through their regular partners.

In most regions of the world, injection drug users are a hard-to-reach population because drug use is illegal and stigmatised. The need for money to buy drugs can also lead to crime and sex work, thus further marginalising IDUs. The desire to remain hidden from authorities also makes IDUs hard to reach for prevention programmes and for conducting surveillance activities.

Prevalence of HIV among IDUs
Injection drug use is one of the main modes of HIV transmission in virtually all parts of the world, particularly in industrialized countries and those with middle-level incomes, including many in Asia. In some countries of South-East Asia, injection drug use has emerged as one of the strongest drivers of HIV infection. In many countries with low-level and concentrated epidemics, HIV has spread most rapidly among IDUs.

Historically, regions where heroin trafficking takes place can have explosive epidemics once HIV is introduced. Such has been the case in the Indian states of Nagaland and Manipur and the countries of Myanmar, Thailand, Vietnam and Nepal, which are all located in or near one of the world’s major opium-producing areas.

Parts of Myanmar, Thailand and Vietnam have all recorded very high levels of HIV infection among IDUs. In some places (including Myanmar, Thailand and Manipur), HIV infection rates have 'stabilised' among IDUs at levels between 40% and 60% for nearly a decade.

In South-East Asia, the prevalence of HIV infection among IDUs varies by country and region, including the following examples:

• nearly 50% of IDUs in treatment in Jakarta, Indonesia were living with HIV in 2003.\textsuperscript{11}
• in 2002, the prevalence of HIV among male injectors in Nepal ranged from 22% to 68%.
• in 2005, a national survey in Myanmar found an HIV prevalence of 43% among IDUs.\textsuperscript{12}
• according to India’s National AIDS Control Organisation, about 10% of HIV-infected people in India contracted the virus through injection drug use.\textsuperscript{13,14}
• in 2005, 40% of IDUs in Chennai and 29% in Mumbai, India were infected with HIV.
• in Thailand, HIV prevalence among IDUs varied from 36% in Bangkok to 39% in Songkla Province to 50% in Chon Buri Province in 2005.
Parts of China, Indonesia and Vietnam have seen HIV take off among drug injectors in recent years, as shown in Figure 3.1.

Figure 3.1
HIV prevalence among injecting drug users in selected south-East Asian countries, 1991-2005

Note: Data unavailable for some years is reflected by dotted line
Source: National surveillance reports.

Role of IDUs in surveillance and bridges with other populations
In countries with substantial number of IDUs, HIV may first appear in the population, spread rapidly, and reach the highest prevalence. IDUs may be further connected to other populations at risk for HIV. In particular, a large proportion of both male and female IDUs may engage in sex work to support their addictions. Other IDUs may have sexual partners who are not IDUs themselves. Finally, the mothers of HIV-infected children are often female IDUs or female partners of male IDUs in countries with low-level and concentrated epidemics.

IDUs therefore overlap with many other high risk populations covered in this module. IDUs are found among MSM, prisoners, out-of-school youth and female sex workers. Therefore, HIV surveillance of IDUs can serve to monitor the reach, acceptance and effectiveness of intervention programmes for both IDUs and other populations at high risk.

Conducting Formative Research

Pre-surveillance assessment
The first step in planning HIV surveillance in IDUs is to gain an understanding of the population in your area through formative research. Pre-surveillance assessment activities are conducted to identify key indicators to measure the diversity of the sub-populations of IDUs and the geographic areas and venues where IDUs may be found in high numbers.
The aims of the pre-surveillance process include:

- agreeing on the purpose and uses of surveillance data for IDU programmes
- identifying a co-ordinating or decision-making body
- selecting IDU sub-populations to include?
- delineating the geographic coverage areas
- selecting which indicator variables to collect (behavioural and biological)
  - determining the primary drugs used in the area
  - ascertaining whether there are any unusual drug preparations or use practises in the area (such as homemade drug solutions prepared with blood).

As IDUs tend to form close-knit communities, HIV prevalence may differ considerably in places that are relatively close within a given country, or even within a given city. Identifying points of access and forming alliances with organisations and persons trusted by IDUs will help you to more fully understand the culture and diversity of IDUs in your area.

**Consider where to find IDUs**

Due to the illegal and stigmatised nature of injecting drugs, locating and accessing this population can be difficult. Individual IDUs may be reluctant to participate in surveillance activities if they fear arrest and criminal charges. A useful starting point for gaining access to IDUs is to speak with individuals who deal with IDUs through the healthcare system, through prevention programmes and through the justice system. In addition, working with former and current IDUs can guide you to the places where IDUs can be found and into the social networks of different groups of IDUs. Persons to contact include the following:

- former and current drug users
- staff of needle-exchange programmes
- staff of NGOs working with IDUs
- law enforcement, police and criminal justice staff
- the staff of drug treatment and methadone centres
- social welfare and service organisations
- drug dealers
- staff of healthcare institutions that provide care for IDUs, such as hospital casualty departments who may see, for example, large numbers of overdoses and wound infections.

These same people and organisations can also later assist in implementing surveillance activities. For example, former IDUs can be hired and trained as recruiters or interviewers. Hiring former IDUs gives you the added advantage of using their experience to distinguish true IDUs from non-injecting drug users. Alliances with institutions dealing with IDUs may also assist with referrals to treatment or with minimising police interference during field activities.

In different countries, drug treatment centres may be referred to as de-addiction centres or clinics, detention centres or recovery centres. In this module, when referring to these types of centres, we will use the general term ‘drug treatment centre.’
Conducting ethnographic mapping

*Ethnographic mapping* entails the creation of a comprehensive description of the IDU population with regard to:

- the places where IDUs can be found
- time periods of high and low-volume drug use
- the types of drugs used.

This comprehensive description is used broadly to guide where and when IDUs can be found to be recruited for surveillance activities, and which sub-populations can be found in different areas. More specifically, detailed *ethnographic mapping* can be used to produce a *sampling frame* or comprehensive roster representing the IDU population in your area. This sampling frame provides the basis for some *probability-based sampling* methods (for example, *time-location sampling* and *multi-stage cluster sampling*).

IDUs can be found in relatively large numbers at a variety of facilities. These include:

- drug treatment clinics, including de-addiction and methadone maintenance clinics
- needle-exchange programmes
- jails or prisons
- social service organisations serving IDUs or IDU drop-in centres run by NGOs
- hospitals.

Outside facilities, the places where IDUs can be found in relatively large numbers can be identified through key informants from the above listed institutions, and through police reports of drug-related arrests.

Check at drug treatment centres or methadone maintenance programmes

Surveillance in IDUs has historically been based at drug-treatment centres and other centres of care, such as the accident and casualty departments of hospitals. This is because these facilities are places where IDUs are easily accessed. Often, *sentinel surveillance* using *unlinked anonymous testing* (UAT) of patients is used (see Module 3: HIV Sero-Surveillance). Other countries have relied on IDUs who have been arrested and imprisoned, also using the UAT or *mandatory testing* approach. However, neither of these populations is likely to represent the important group of IDUs who are not arrested or do not seek treatment. Sometimes, *targeted intervention* sites provided by NGOs are used for collection of data using a VCT approach (for example, in India and Myanmar).

The illegal nature of injecting drug means that those most at risk may avoid the official healthcare system altogether. Therefore, they will be under-represented in surveillance based at drug treatment centres and other sites where surveillance is implemented. Thus, basing measurement on IDUs presenting for treatment at rehabilitation clinics or among those arrested for drug-related offences may provide highly biased information. These sites may not give a clear picture of behaviour or infection in the larger population of IDUs. Because of this, community-based sampling approaches for IDUs are preferred.
Selecting a Sampling Method

A number of sampling techniques have been used by researchers to access hidden or hard-to-reach populations, such as IDUs. These have included:

- consecutive sampling at treatment facilities, using unlinked anonymous testing
- consecutive sampling in jails and prisons, using unlinked anonymous testing
- respondent-driven sampling (RDS)
- time-location sampling (TLS)
- targeted sampling and targeted interventions.

All these sampling methods have advantages and limitations. Further details of these methods and their relative advantages and limitations are described in Modules 3: HIV Sero-Surveillance and Module 5: Surveillance of High Risk Behaviours.

Figure 3.2 will help you select an appropriate sampling method for IDUs in your area.

**Figure 3.2**

**Decision tree for selecting sampling methods for IDUs**

1. Is there a service or clinic (or jail/prison) that serves IDUs in the area and routinely collects blood (for example, de-addiction clinic without registries, STI clinics*)?
   - Yes → Consecutive sampling using unlinked anonymous testing
   - No →

2. Do IDUs congregate in identifiable and accessible locations in high numbers?
   - Yes → RDS
   - No → TLS or targeted sampling**

* Not all IDUs may enter these facilities.

** Targeted sampling may be used when, through formative research, you have determined the relative size of the sub-populations of IDUs in the different areas. For example, if you know that 25% of IDUs in your area are youth who congregate near the beach, 30% are MSM in the city centre and 45% are in the red light district, you can target your sampling to locations in the neighbourhoods in these proportions.
Safety factors
Recruiting and/or interviewing IDUs in drug-use areas or other dangerous neighbourhoods may compromise the safety of interviewers. Consider the safety of the data collectors when determining what sampling design is most appropriate for your situation. If during formative research you find that particular locations or times are too dangerous for data collectors, some sampling designs, such as time-location sampling, may not be feasible.

Measures

Biological measures
Measuring HIV sero-prevalence among IDUs is an integral component of surveillance. Biological measures that also serve as markers for risk of parenteral infection include the following.

- Anti-hepatitis B core antigen (anti-HBc) is a non-specific marker of acute, chronic or resolved HBV infection. Anti-HBc is usually found in chronic HBV carriers, as well as those who have cleared the virus, and usually persists for life.
- Hepatitis B surface antigen (HBsAg) is a marker of infectivity. Its presence indicates either acute or chronic HBV infection. In some people (particularly those infected as children or those with weak immune systems, such as those with AIDS), chronic infection with HBV may occur when HBsAg remains positive.
- Hepatitis C (Test may be expensive).

Additionally, in Asia, HBV is often acquired parinatally or from child-to-child contact in household settings, and is thus not as reliable a marker for injecting drug use as it is in other regions.

IDUs are also at risk of HIV through sexual behaviour. Biological markers for STIs may also be considered in surveillance for IDUs (For a description of the available STI tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups).

Behavioural measures
Measuring changes in injection and sexual behaviour among IDUs helps explain trends in HIV and STI sero-prevalence data. The sharing of needles and syringes provides a very efficient means for the parenteral spread of HIV infection. The probability of HIV infection among IDUs is proportional to the frequency of needle and syringe sharing. The more frequent the sharing, the higher the risk. Some drugs may result in more frequent injection than others. For example, cocaine and methamphetamine injection may become more frequent than heroin injection in many cases. Consequently, the type of drug determines the frequency of injection and, hence, the risk of HIV.

In broad strokes, behavioural surveillance of IDUs attempts to measure:

- the frequency of needle and syringe sharing
- the frequency of unprotected sex.
Several international organisations have sought to standardise a set of “core” or basic indicators of HIV risk among IDUs. These include:

- the percent of IDUs who have adopted behaviours that reduce transmission of HIV (that is, who have both avoided non-sterile injecting equipment and used condoms in the last month (UNGASS)
- the percent of injecting drug users active in the last month who report sharing needles, syringes or other injecting equipment the last time they injected drugs (MEASURE)
- the percent of IDUs who received HIV testing in the last 12 months and who know the results (UNGASS)
- the percent of injecting drug users surveyed who report never sharing injecting equipment during the last month (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex, of those who have had sex in the last 12 months (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex with a non-regular partner in the last 12 months (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex with a regular partner in the last 12 months (MEASURE).

These basic indicators may be supplemented with local measures of particular importance in your area (as determined by your formative research phase). These additional indicators may include:

- injecting locations (for example, shooting galleries)
- frequency of injections
- types of drugs injected
- those with whom IDUs share needles and syringes
- size of social network
- condom use
- history of incarceration
- history of sex work
- contact with female sex workers.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

- United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators
- Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among IDUs. These guidelines are available online at: http://www.fhi.org.
The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practices). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

### Special Ethical Considerations

Because drug use is stigmatised and usually illegal, IDUs are a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of confidentiality or inadvertent identification as an IDU
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicised results
- arrest and incarceration.

Another special ethical consideration when conducting surveillance among IDUs is the person’s ability to provide true informed consent when under the influence of drugs or acutely seeking or withdrawing from drugs. In addition, extra concerns arise in studies that provide monetary incentives for participation. Obtaining cash for drugs may place inappropriate motivation on IDUs to participate.

### Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country’s laws that may complicate participation. These may include:

- laws prohibiting injecting drug use, with severe penalties
- more severe penalties for those identified as dealing drugs
- laws requiring reporting of individuals with HIV infection
- paraphernalia laws.

IDUs asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps you will take to minimise them.

### Ensure interviewer safety

Conducting HIV surveillance among IDUs requires face-to-face contact with drug-dependant persons who may have criminal histories, psychiatric conditions and/or violent tendencies. These persons may pose a risk to the interviewer’s safety. Interviewers should be trained on how to assess intoxication and how to ensure their own safety.
Summary

Due to unsafe injecting practices and unsafe sex, IDUs are at high risk for getting and transmitting HIV and other blood-borne illnesses. In many countries with low-level and concentrated epidemics, HIV has spread most rapidly among IDUs.

Due to the illegal nature of intravenous drug use, locating and accessing this population can be difficult. Depending on how IDUs are organised and how easily they are accessed, different sampling approaches may be more or less feasible. As drug use is stigmatised and usually illegal, special ethical issues must be considered when conducting surveillance among IDUs.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss the following questions.

1. Does your country conduct behavioural and/or sero-surveillance of female sex workers?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods are used to sample injection drug users?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of injection drug users?

5. In the past five years, has the prevalence of HIV among injection drug users in your country increased, decreased or remained about the same?

Apply what you have learned/case study

Behavioural surveillance survey among IDUs in Mandu, Serosia

Part 1: Collecting information to plan surveillance activities

You are the HIV surveillance officer for Mandu. Mandu is a medium-sized city in northern Serosia and a major transit point on the drug-trafficking route between Asia and Western Europe. There have been reports of increasing local injection drug use, particularly among youth in your area that have alerted you to a potential for increased HIV transmission among this population.

Your city has asked you to work with the city’s police authorities to undertake a behavioural and HIV sero-survey of drug injectors in the city.
The police chief suggests that you start with prisoners who were convicted of trafficking heroin and test them.

With the help of prison personnel you conduct unlinked anonymous HIV testing using blood left over from syphilis testing that was done when each prisoner was initially incarcerated.

1. What are the advantages and limitations of this approach?

2. Describe the steps you take to conduct this survey. How do you ensure confidentiality?

3. What biological markers do you include?

4. How might HIV prevalence estimated from prisoners differ from IDUs outside of jails?

Part 2: Building key alliances with community networks involved with injection drug users

HIV prevalence among injectors in the jail is 5.5%. Only 20 injectors were under the age of 25 years. None were female, although the police indicated that many of the sex workers arrested are also injection drug users. No information was collected on needle-sharing or sexual behaviours.

5. Whom do you need to reach in order to measure HIV prevalence among IDUs? What questions do you need to ask them?

You determine that information gathered from jails is not sufficient to fully characterize all the injection drug use in the city. Your office decides to conduct formative research to describe both the young injecting network and other networks and sub-populations of IDUs.

6. Who are the key stakeholders and community groups with whom it is necessary to build alliances?

7. How will the HIV team engage the different stakeholders?

Part 3: Choosing approaches to combined behavioural and biological surveillance

The HIV surveillance team meets with key informants, including HIV prevention and care GO and NGO personnel, STI clinic and detoxification centre employees, taxi drivers, bar owners, police in the area and former IDUs found through NarcAnon-Asia.

A brief meeting is organised at which the HIV surveillance manager informs the stakeholders about the need for and purpose of combined behavioural and biological surveillance of IDUs in Mandu.
Using information gathered from stakeholders, the HIV team characterizes a wide range of injecting drug users. Three geographically distinct groups of IDUs are identified: 1) a group of young injectors who use heroin and congregate in the centre of Mandu, 2) a group of older injectors who congregate on the outskirts of town, and 3) a group of injecting brothel-based and street-based female sex workers who mainly congregate in Mandu’s red light district. While the groups are geographically and socially distinct, you find that members of the three groups do mix to some extent.

With verbal assurance of the cooperation of the stakeholders, the HIV team is now ready to begin.

8. What sampling schemes would be appropriate for conducting community-based sampling of IDUs in Mandu?

9. What are the advantages and disadvantages of using TLS vs RDS? Which one do you think will work best in Mandu?

Part 4: Implementing RDS

You decide that respondent-driving sampling (RDS) is the most feasible method for sampling IDUs in Mandu. As you have limited financial and human resources, you must accomplish the survey in three months.

10. Which individuals will you select as seeds? Why?

11. What kind of incentives will you give?

12. What are the ethical considerations of providing incentives?

13. What questions do you want to include in your survey?

You decide to plant a total of six seeds, with two seeds in each IDU network (young injectors, older injectors, injecting sex workers). The individuals you select as seeds appear well-connected in the IDU community. Although you could provide financial incentives, for ethical reasons you decide to give meal and clothing vouchers as recruitment incentives.

After three weeks, you determine that, while the seeds you planted among the younger injectors and the injecting sex workers have grown, the two seeds you planted among older injectors have not grown.

14. What are your options for reaching the older IDUs now?

Although you could replant your previous selected seeds or give your seeds more time to grow, since you have limited time and resources, you decide to re-sow and find two new older IDU seeds. The chains continue to grow and you are between one-third and halfway through the time allotted.
15. How will you know if equilibrium is met? What does this mean?

16. What variables will you follow to determine when equilibrium is reached?

You are nearing the end of the recruitment and you have passed your projected sample size.

17. How do you end recruitment? What problems might you encounter when trying to end recruitment?

Part 5: Analysis

Your team exceeds your required sample size and successfully recruits 680 IDUs. It is now time to prepare a report on your findings.

18. What data analysis software do you use?

19. What variables did you need to have collected in order to analyse the data? Do you recall if you mentioned collecting these when planning the survey?

RDSTAT is the most appropriate analysis software for analysing your data. It is available free of charge online at: http://www.respondentdrivensampling.org/main.htm.

In order to analyse your data, it is imperative that you have data on each respondent’s network size and by whom each respondent was recruited.

Part 6: Epilogue

The RDS-adjusted population estimate for HIV was 17.1%. Half of the IDUs were under the age of 25 years and one-fourth were female. Of the respondents, 58.6% said they had used a needle previously used by someone else and 63.0% said they gave a needle they had used to someone else in the last year. Many IDUs indicate that needles available at the pharmacies are too expensive.

Based on these findings, the public health commissioner of Mandu directs the HIV programme manager to initiate the following interventions:

1. Expand drug detoxification and treatment programmes in Mandu.

2. Establish a needle-exchange programme.
Notes
Overview

What this unit is about
This unit describes the background and special considerations associated with studying men who have sex with men (MSM). It explains sampling and surveillance methods and recommends specific surveillance methods for this group. The unit ends with a case study concerning MSM and specific study issues.

Warm-up questions
1. True or false? Because men who have sex with men are homosexual, there is no risk that HIV will spread to the rest of the population, including women.
   - True
   - False
2. List two common points of access where MSM can be found.
   a. 
   b. 
3. Because MSM are often hard to reach because of discrimination and stigmatisation, two successful sampling methods in this group are _____________________ and _____________________.
4. What are some of the ethical issues to consider when conducting HIV surveillance of MSM?

Introduction

What you will learn
By the end of this case study, you should be able to:

- describe the special considerations associated with surveillance in men who have sex with men
- list the possible organisations that can assist in surveillance of MSM
- describe options for sampling and surveillance methods among MSM.

Background

Definitions
The term men who have sex with men describes a type of behaviour, as opposed to a specific group of people. MSM include self-identified gay and bisexual men, as well as men who engage in male-male sex who identify as heterosexual.

Another group that has historically been included in MSM are those individuals who are transgendered. 'Transgender' is an umbrella term that generally refers to biological males who have undergone or are in the process of undergoing treatment to make them
anatomically female. In some cultures, particularly in Asia, there are also culturally endorsed roles for persons identifying as neither male nor female. These people are considered a third gender. 

Many transgendered persons, because of their marginalisation from mainstream society, have few options for employment and are, consequently, employed in the sex industry and other service-oriented jobs. 

In some countries, male-to-male sex happens within well-defined gay communities. These communities are often served by health clinics and other institutions that cater to gay men and can be used as sentinel sites. Elsewhere, however, MSM do not identify themselves as gay. In these locations, male-to-male sex is clandestine and there are no easily accessible clinics or other sentinel sites for communities of these MSM. 

Role of MSM in the HIV epidemic 
Men who have sex with men represent a substantial proportion of the Asian HIV epidemic. The HIV prevalence among MSM may be experiencing rapid increases. Additionally, some research indicates that bisexual activity is more common in Asia than in other parts of the world. 

MSM can be exclusively homosexual and have sex only with men. They can also be bisexual and have sex with both men and women. When developing the sampling frame, it is important to note that in many societies, men who have sex with men may also have sex with women. 

In general, the risk of HIV transmission in anal sex between men is greater than the risk of transmission in vaginal sex between men and women. This is what puts MSM at higher risk in general. Men who have sex with both men and women may represent an important bridge group between a sub-population at high risk for HIV infection and a larger population at lower risk for infection. 

In Asia, marriage pressure (that is, the phenomenon of family pressure on sons to marry in order to provide stability for parents and the continuation of the family name) may be greater than in other regions. Marriage pressure may be a factor in the higher rates of bisexual behaviour seen in Asia. 

Prevalence of HIV among MSM 
The following table illustrates the range of HIV prevalence among MSM in Asia and includes HIV prevalence-trend data for some locations. The rapid rise in prevalence in many of these locations is cause for concern and illustrates the need for behavioural and serological surveillance among MSM.
Table 4.1

**HIV prevalence among MSM in Asia**

<table>
<thead>
<tr>
<th>Location</th>
<th>%</th>
<th>Sample*/Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dhaka, Bangladesh</td>
<td>0.4</td>
<td>Sentinel Surveillance/2005</td>
</tr>
<tr>
<td>Kathmandu, Nepal</td>
<td>3.9</td>
<td>Sentinel Surveillance/2005</td>
</tr>
<tr>
<td>Bangkok, Thailand</td>
<td>17.3</td>
<td>1121 TLS/2003</td>
</tr>
<tr>
<td></td>
<td>28.3</td>
<td>400 TLS/2005</td>
</tr>
<tr>
<td>Beijing, China</td>
<td>0.8</td>
<td>325 RDS/2004</td>
</tr>
<tr>
<td></td>
<td>4.6</td>
<td>427 RDS/2005</td>
</tr>
<tr>
<td>HCMC, Vietnam</td>
<td>6</td>
<td>208 CV/20002</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>600 Snowball/2004</td>
</tr>
<tr>
<td>Phnom Penh, Cambodia</td>
<td>14</td>
<td>206 TLS/2000</td>
</tr>
<tr>
<td></td>
<td>**</td>
<td>305 RDS/2005</td>
</tr>
<tr>
<td>Shenzhen, China</td>
<td>0.7</td>
<td>113 TLS/2002</td>
</tr>
<tr>
<td></td>
<td>1.3</td>
<td>267 TLS/2004</td>
</tr>
</tbody>
</table>

* RDS= Respondent-Driven Sampling, TLS= Time-Location Sampling, CV= Convenience Sampling
** Not available

**Role of MSM in HIV surveillance**

HIV surveillance of men who have sex with men (MSM) is critical in all countries. Data throughout the developing world indicate increasing HIV prevalence among MSM populations. Overall, however, routine surveillance among MSM is sporadic at best, creating the potential for prevalence to rise even higher while going undetected.

The purposes of HIV surveillance in MSM are:

- to monitor disease occurrence and its antecedents
- to obtain data to use in planning and evaluating prevention and care programmes
- to advocate for prevention resources
- to improve the health, social welfare and equal rights of MSM.

Table 4.2 summarises how HIV is affecting MSM throughout the world.

Table 4.2

**HIV Burden among MSM**

<table>
<thead>
<tr>
<th>Region of the world</th>
<th>MSM HIV Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>MSM are the most affected population</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td>News Zealand</td>
<td></td>
</tr>
<tr>
<td>Most Western European nations</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>Depending on the country, MSM may constitute a large proportion of persons affected by HIV</td>
</tr>
<tr>
<td>Latin America</td>
<td></td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>Little or no data exist on the burden of HIV among MSM</td>
</tr>
<tr>
<td>North Africa</td>
<td></td>
</tr>
<tr>
<td>Middle East</td>
<td></td>
</tr>
</tbody>
</table>
Bridges and overlap with other populations
In Asia, as in the rest of the world, a proportion of MSM also have sex with women. Some research indicates that MSM in Asia may have a higher proportion of bisexual behaviour than in other regions. The potential for MSM to bridge HIV infection to heterosexual women is an issue deserving monitoring and investigation. Surveys of MSM should always ask about all types and genders of partners MSM may have. MSM can also be members of other high risk populations covered in this module. MSM are found among IDUs, STI clinic patients, out-of-school youth, prisoners and sex workers. Being a member of two or more high risk groups increases HIV infection risk for MSM.

Conducting Formative Research
Formative research is necessary in order to characterise the range and diversity of MSM populations in the area of interest. Attention should be paid to the behaviours MSM engage in, their overlap with other high risk populations and their geographic concentrations. In addition, determining the extent to which MSM identify as gay or non-gay is crucial. This research will help to identify the various points of access and places where potential surveillance among MSM can be conducted.

Pre-surveillance assessment
Prior to beginning surveillance, you should conduct a pre-surveillance assessment to identify your data needs and determine which sub-populations and geographic locations to include.

Steps in the pre-surveillance process include:

• identifying a co-ordinating and decision-making body
• agreeing on the purpose of surveillance
• establishing criteria for selecting sub-populations and geographic coverage areas for surveillance
• gathering information to guide survey implementation and to help you decide which sub-populations and geographic areas to include in surveillance and which variable to collect
• finalising sub-population and geographic selection.

Consider where to find MSM
To facilitate access to MSM and to ensure proper use of surveillance data, alliances should be formed with the organisations and individuals that are trusted by the MSM community. Additionally, if they exist, enlisting the support of the current prevention programmes for MSM can help establish the infrastructure for the surveillance system.

Surveillance activities should enlist the assistance of:

• health authorities
• social services
• MSM groups
• gatekeepers, such as gay activists and religious leaders
• organizations that represent MSM interests
• existing public health prevention programmes.
Surveillance officers should also enlist the support of those whom the community trust as sources of information. These individuals include:

- natural leaders of the MSM community (asking around can usually easily elicit names of MSM leaders)
- owners of MSM businesses/venues (such as saunas and bars)
- employees of MSM businesses/venues (such as bars, dance clubs, hair salons).

It is important to remember that alliances need to be viewed as mutually beneficial. You should exercise caution and not alienate community gatekeepers. Mapping the geography of the MSM community is an essential part of surveillance for this group, as for any other hard-to-reach group.

A key issue for preliminary investigation is to determine to what extent MSM can be found in venues that are identifiable and accessible to the investigators. In some areas there may be no such venues, with MSM only accessible through their personal social networks. These distinctions are keys to choosing the appropriate sampling methodology.

**Conducting ethnographic mapping**

Conduct [*ethnographic mapping*](#) to create a comprehensive description of:

- the social geography of MSM
- the places where MSM congregate
- time periods when MSM congregate.

This information is crucial to choosing a sampling method and for creating a sampling frame.

In terms of access in countries with well-defined gay communities, points of contact include:

- restaurants
- gay-identified bars
- dance clubs
- gyms
- parks
- bathhouses
- social organizations
- other *cruising areas*.

Cruising areas are public spaces, such as parks, public restrooms, bathhouses, dance clubs, and railway stations, where MSM meet, congregate and arrange and/or engage in sexual activity.

Other points of access may be through gay newspapers, magazines or gay-focused services, clinics specialising in MSM health and internet chat rooms. In contrast, MSM venues in countries without well-developed gay communities will be more difficult to
identify. Some MSM do not congregate in particular locations. They may be deliberately elusive due to stigmatization of homosexual behaviour.

Organisations providing HIV prevention or AIDS care services to MSM should not be included as venues, as such inclusion has the potential to inflate estimates of HIV infection and/or HIV risk behaviour.

**Selecting a Sampling Method**

While surveillance of MSM may be more difficult than surveillance of female sex workers, the methods for approaching surveillance efforts are similar.

As with surveys of other hard-to-reach populations, getting a representative sample is difficult. There is no clear *sampling frame* and many studies have relied on various *non-probability sampling* methods. Because these samples are not representative, it is difficult to use them to compare indicators over time. Two methods that have successfully been used to monitor HIV prevalence and risk behaviours in MSM are:

- *time-location sampling* (TLS)
- *respondent-driven sampling* (RDS).

In some circumstances, neither TLS nor RDS will be appropriate for MSM in your area. In this case, using traditional *snowball sampling* may be the only appropriate method to use. Figure 4.1 on the next page will help you select an appropriate sampling method for MSM in your area.

**Figure 4.1**

**Appropriate sampling methods for MSM**
Male sex workers
In areas where MSM sell sex to other men, sampling techniques used for sex workers may be more appropriate and effective for this sub-population. Please refer to Unit 2 (Sex workers) for further information.

Measures
Comprehensive HIV surveillance among MSM includes surveillance of:

- HIV infection
- STI infection
- risk behaviour(s)
- partner characteristics.

The ideal surveillance system should also measure specific healthcare outcomes and societal attitudes and practises. Moreover, surveillance should describe the diversity of male-to-male sexual practises, their potential for HIV transmission and their potential for bridging to other populations.

Biological measures
Measuring HIV sero-prevalence among MSM is an integral component of surveillance. The high sexual risk among MSM also makes STI testing a useful indicator for surveillance (see Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups for a description of the available STI tests).

The biological measures to include in surveys of MSM are similar to those for female sex workers and may include:

- syphilis
- gonorrhea (urethral, rectal and pharyngeal)
- chlamydia (urethral, rectal and pharyngeal)
- herpes simplex virus type-2 (HSV-2).

In areas where there may be suspected overlap between MSM and IDUs, hepatitis C virus (HCV) may also be a useful biological marker. Tests for HCV may be expensive.

In Asia, hepatitis B virus (HBV) is often acquired perinatally or from child-to-child contact in household settings, and is thus not as reliable a marker for injection drug use as it is in other regions.

Behavioural measures
Measuring changes in sexual behaviour among MSM helps to explain trends in HIV and STI sero-prevalence data.

Behavioural surveillance of MSM attempts to determine:

- the frequency of unprotected sex
- the characteristics of partners of MSM
- the frequency of injection drug use.
Behavioural surveillance of MSM may collect information on:

- condom use
- number of partners
- type of partners
- frequency of unprotected insertive anal intercourse (UAI)
- frequency of unprotected receptive anal intercourse (URAI)
- STI treatment-seeking
- migration patterns
- marital status
- history of sex work
- HIV test-seeking and result-seeking
- history of imprisonment
- injecting drug use
- contact with sex workers
- MSM venues.

When conducting behavioural surveillance of MSM, specific indicators may include:

- percent of MSM reporting the use of a condom the last time they had sex with a male partner (UNGASS)
- percent of MSM who have had anal sex with more than one male partner in the last 12 months (MEASURE)
- percent of male sex workers reporting the use of a condom with their most recent client (UNGASS).

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

- United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.

- Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among MSM. These guidelines are available online at: http://www.fhi.org.

- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practices). The
formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area.

**Special Ethical Considerations**

Due to the covert nature of life for many MSM in many developing countries, MSM are a **vulnerable population**. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of confidentiality or inadvertent identification as an MSM
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicised results
- physical abuse
- imprisonment.

Certain considerations must be taken into account when attempting surveillance in these populations, including:

- the stigma associated with being a MSM, which prevents many from being open about their sexual orientation
- the illegal status of male-to-male sex in many countries, which results in discrimination by the general population and police harassment.

Language, social perspective and taboos surrounding homosexual activity exist in many countries. These can affect the completeness of surveillance systems and the quality of the data.

**Assuring confidentiality**

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country’s laws that may complicate participation. These may include:

- laws prohibiting homosexual activity
- laws prohibiting injection drug use
- laws requiring reporting of individuals with HIV infection.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise them. Explaining these issues to them is part of the informed consent process. Steps you can take to minimise threats to confidentiality may include:

- conducting surveillance among MSM anonymously
- conducting interviews with MSM in private settings
- limiting access to any identifying information to authorised personnel
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.
Summary

MSM include self-identified gay and bisexual men, men who have engaged in male-male sex but identify as heterosexual, and transgendered persons. MSM are at high risk of acquiring HIV and other STIs due to their high sexual risk. Men who have sex with men may make up a substantial proportion of HIV burden in Asia. Behavioural and HIV sero-surveillance of MSM is particularly important in countries where little is known about MSM. Respondent-driven sampling (RDS) and time-location sampling (TLS) are well-suited for sampling MSM when MSM have either identifiable venues or robust social networks. As MSM are often stigmatised, special ethical issues must be considered when conducting surveillance among this group.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of MSM?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods have been used to sample MSM?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of MSM?
5. In the past five years, has the prevalence of HIV among MSM increased, decreased or remained about the same?

Apply what you have learned/case study

Biological and sero-surveillance of MSM in Millao, Malanka

Part 1: Collecting information to plan surveillance activities

Millao, a cosmopolitan city with a population of three million, is the capital of Malanka, an island nation in South-East Asia.

Since Millao is the financial and cultural centre of the country, many men are drawn to the city. Although homosexuality is officially prohibited, Millao has an active selection of venues catering to MSM, including saunas and dance clubs.

Annual sentinel surveillance for the past five years has found an increase in the incidence of rectal gonorrhoea among male STI clinic attendees in Millao. The Ministry of Health is concerned that there may be an undetected epidemic of STI and HIV among MSM.
Because homosexuality is illegal in Millao, MSM are often discriminated against and harassed by local police. As a result, MSM mistrust local officials. For this reason, the Ministry of Health has, in the past, had difficulty conducting biological and behavioural surveillance among MSM.

This year, the Ministry of Health has decided to conduct biological and behavioural HIV/STI surveillance of MSM in Millao. As the HIV surveillance officer of Millao, you are tasked with designing and conducting this activity.

1. What information is required for planning the survey?

2. How will your office obtain this information?

Part 2: Building key alliances with community networks involving men who have sex with men

In order to plan for the survey, you will need to begin to understand the range of MSM sub-populations, the local vocabulary used to describe the MSM sub-populations, the venues where MSM congregate, and ways to identify gatekeepers. As you do not know how many MSM live in Millao or where they congregate, you decide to conduct research to determine where and when MSM congregate and in what numbers, as well as other patterns of MSM activity in Millao. Information can be obtained from websites, through interviews, through ethnographic mapping and by observation.

3. Describe how you would conduct research as the first part of designing a comprehensive HIV surveillance effort for MSM.

4. How would you gain the trust of members of the MSM community?

Part 3: Mapping the MSM network and choosing a sampling approach

Enlisting the support of influential MSM in Millao, you form partnerships with local NGOs working with the MSM community and establish a working group or a community advisory board (CAB) to help gain access to other MSM. You can gain the trust of members of the community by letting them know that data are used for advocacy and for designing and delivering education and outreach. You can also work with local law enforcement agencies to ensure that police do not harass MSM who participate.

Through formative research, you find an extensive local MSM scene. After conducting focus-group discussion and in-depth interviews with MSM, you find out that MSM in Millao congregate in a wide range of venues. Sex takes place in some of these venues, which include saunas, gyms, dance clubs and public parks.

5. What sampling scheme is most appropriate?

6. What are the advantages and disadvantages of time-location sampling (TLS)?

Part 4: Collecting biological and behavioural data

You decide to conduct HIV prevalence and risk-behaviour surveys of MSM every other year, using a time-location sampling method. There are many advantages and
disadvantages of TLS. Although TLS requires mapping and time-consuming ethnographic work and may only reach a subset of MSM, it allows for a probability sample of hidden or ‘floating’ MSM.

7. What biological variables do you include?

8. What behavioural variables do you include?

9. What additional steps are needed to test for HIV?

10. What are some of the special ethical considerations for this surveillance activity?

Part 5: Analysing and disseminating data

You decide to assess the prevalence of HIV, syphilis, gonorrhoea, chlamydia and HSV-2, the types and number of partners, and the frequency of unprotected anal sex.

To acquire this data, you will need to obtain voluntary informed consent from MSM who agree to participate in the study. Ethical issues you should consider include maintaining participants’ confidentiality and ensuring that interviewers are sensitive to this issues facing MSM. Additionally, as you will be testing for HIV, you should establish a mechanism in which persons who test positive for HIV are referred to treatment and counselling.

This study produces the following results:

- HIV prevalence was 9%.
- Syphilis (TPHA) prevalence was 14.0%.
- HSV-2 prevalence was 20%.
- Gonorrhoea prevalence was 5%.
- Chlamydia prevalence was 1%.
- 65% of MSM report unprotected anal sex with male partners.
- Some MSM engage exclusively in homosexual activity, while others consider themselves to be heterosexual and are married.

11. Describe how you would use the data collected to develop MSM-focused prevention programmes?

Part 6: Epilogue

Millao has a large population of men who have sex with men, including male sex workers, transgendered individuals, men who have sex with men and identify as homosexual and men who are married and identify as heterosexual. Because homosexuality is prohibited, men who have sex with men in Millao can be fearful of the authorities and often do not seek medical care when needed. MSM in Millao are at high risk of acquiring and transmitting HIV. Some MSM have high partner turnover and low condom use; many do not seek treatment for STIs or other health problems; many are injection drug users and many have been incarcerated. Targeted interventions are needed to promote safe sex practises among MSM in Millao.
Based on these findings, the Ministry of Health directs the HIV programme manager to initiate the following interventions:

1. Engage peer and NGO outreach workers to educate MSM about the need for consistent condom use with non-regular and regular partners.

2. Distribute condoms to MSM through peers, NGO workers and STI clinics in the red light district.

3. Organize education and outreach programmes to encourage MSM to seek treatment for STIs.
Overview

What this unit is about

This unit describes the background and special considerations associated with studying mobile populations. It explains sampling and surveillance methods and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following terms is used to describe voluntary migrants, and which terms are used to describe involuntary migrants?
   a. refugees
   b. displaced persons
   c. mobile populations
   d. none of the above.

2. True or false? Both biological and behavioural surveillance on migrant workers should be conducted regularly every year.
   True False

3. Of the following, which is not a reason why migrants are especially vulnerable to HIV?
   a. Female migrants may sell ‘survival sex’ when they have no other source of income.
   b. Migrants usually have only one sexual partner.
   c. Migrants have limited access to healthcare.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.

4. List two sub-groups that can be considered mobile populations.
   a.
   b.

5. Which type of migration occurs regularly in the South-East Asia region and usually involves young people who move from low-prevalence areas to high-prevalence areas and eventually return home?
   a. ‘circular’ or ‘oscillating migration’
   b. gross migration
   c. step migration.
Introduction

What you will learn

By the end of this unit, you should be able to:

• describe the special considerations associated with surveillance in mobile populations
• distinguish between the various types of mobile populations
• describe options for sampling and surveillance methods among mobile populations.

Background

Definitions

This unit focuses the special issues involved with conducting behavioural surveillance and HIV sero-surveillance in mobile populations. ‘Mobile populations’ is the term used to refer collectively to groups of people who move from one place to another. They may move temporarily, seasonally or permanently, and for either voluntary or involuntary reasons. Migration is one of many social factors that have contributed to the HIV epidemic. Migration refers to people who move from one area to another, and does not imply permanent resettlement. Many migrant groups with increased risk of HIV are temporary migrants and may move for only a few weeks at a time.

Migration can be divided into two broad categories:

• voluntary and job-related migration (includes truckers, miners, sex workers, fishermen, military personnel, etc.)
• involuntary (includes refugees, trafficked sex workers, and internally displaced people).

Please note that although military personnel may be considered mobile persons, the special considerations associated with studying military personnel are discussed in Unit 8.

There are many people who are involuntary migrants, including refugees and internally displaced persons (IDPs). By legal definition, refugees are persons who are outside their country of nationality and who are unable or unwilling to return to that country due to a well-founded fear of persecution because of race, religion, political opinion or membership in a social group. This definition only includes persons who have been displaced from their homeland and have sought refuge in a second country. Internally displaced persons are persons who have left their homes due to civil unrest, natural disasters, political and/or religious persecution, but have stayed in their homeland and have not sought sanctuary in another country.

According to the Internal Displacement Monitoring Centre (IDMC) of the Norwegian Refugee Council (NRC) more than two-thirds of Asia’s three million internally displaced people are in South Asia. As of 2006, the number of IDPs in Asia varied, including the following examples:

• India: at least 600,000 internally displaced persons (IDPs)
• Bangladesh: 500,000 IDPs
Nepal: 100 000 – 200 000 IDPs
Myanmar: 500 000 IDPs
Indonesia: 150 000 - 250 000 IDPs
Sri Lanka: 600 000 IDPs.

Types of migration
Although there are many different types of migration, a common mode of migration in South-East Asia is circular or oscillating migration. This type of migration is characterized by young men and women leaving their rural communities to work in urban areas or construction sites. They return home periodically, depending on the distances involved. Over the past century, migration has become common among rural men seeking employment in urban centres. Today, young women commonly migrate from rural areas to seek employment as domestic helpers or factory workers in urban centres.

Some examples of migration are the following:

- married men who relocate from rural to urban areas for seasonal or long-term jobs and may move with or without their families
- young single men and women who migrate from rural to urban areas for industrial jobs, often living in dormitories or other group housing
- single and married women who travel weekly or monthly from rural to urban areas to work as domestic helpers.

In addition to persons moving out of their homes to work elsewhere, migrants also include people in the transportation industry, such as truck drivers and merchant seamen, who travel frequently across long distances.

The mobile populations include many groups, such as the following:

- persons (for example, salesmen and short distance truckers) travelling between home and business locations daily or weekly, away from home and family for short durations
- long-distance transportation workers who are away from home for several months, but do not necessarily establish permanent residences
- merchant seamen.

Additionally, civil strife, political tension and natural disasters, to the extent they reduce economic opportunities for young people in their rural homes, often result in migration.

Role of mobile populations in the epidemic
Mobile populations are at high risk for both acquiring and transmitting HIV and STIs. Mobile persons often serve as a bridge between female sex workers and the general population. Additionally, due to migration patterns, mobile populations often bring HIV from high-prevalence areas to low-prevalence areas. Studies in several countries have demonstrated the importance of major transportation corridors in the spread of HIV. The role of migration in the spread of HIV has been described primarily as a result of men becoming infected while they are away from home, often by contact with infected
sex workers, and infecting their wives or regular partners when they return. From an epidemic-spread perspective, this pattern is most critical to identify when there are sufficient high risk networks at these migrants’ point of origin to sustain a local epidemic (for example, if wives are also engaging in selling sex in their home villages/towns while their husbands are away).

Migrants are especially vulnerable to HIV infection for a number of reasons, including the following:

- many migrant workers travel to, reside in and work at locations where much risky behaviour is occurring, including multiple sex partners and drug use
- female migrants may sell 'survival sex' when they arrive at a new location and have no other sources of income
- migrants have limited access to health services, including HIV services.

Work-related migration often creates an imbalance in the ratio of women to men which results in the sharing of partners and an increased demand for sex workers. Long-distance truck drivers or persons in other occupations that entail long travel away from home are often the clients of female sex workers more frequently than the general population.

Many forms of sex work are common in border towns and port areas where truckers travel. This sex work is often based in bars, nightclubs and brothels. It is also common for sex workers to have sex with drivers in their trucks as they wait in lines to load or unload cargo or get proper documentation. Sex workers in some countries are also highly mobile.

Sex is not the only common medium of HIV transmission among migrants. Both male and female migrants are often at risk for parental transmission because of injection drug use, traditional medical practices and unsafe therapeutic injections. The trafficking of illegal drugs is also an important driver of the epidemic among migrants.

**Prevalence of HIV among mobile populations**

Limited data are available in South-East Asia on the prevalence of HIV infection among mobile populations. A 2002 study conducted by Family Health International in the Achham district of Nepal found that international migrants had the highest rate of HIV infection (3.7%), followed by internal (3%) and non-migrant sub-groups (0.7%). According to the sentinel surveillance data conducted by the National AIDS Control Organisation of India, the median HIV prevalence among truck drivers in 2006 was 2.4%.

**Examples of mobile populations and migrants**

There are many different groups that are mobile or are migrants. The employment-oriented seasonal and short-term migration of Nepalese youth and young adult men to the cities of Nepal, to India, and to other countries is emerging as a major factor in driving the HIV epidemic in Nepal. Young and mobile men, who tend to be away from home for periods ranging from a few months to a few years, are likely to be involved in casual sex with non-regular partners, including sex workers.

In the Indian state of Tamil Nadu, the government, community groups and other development partners confronted the epidemic after studies found that 30% of truck
drivers reported sex with a female sex worker in the preceding 12 months. Just over half had used a condom the last time they had paid for sex. Sex work appears to be a common feature in most of these studies.

Figure 5.1 shows the migration of Indian population from areas of low prevalence to states where the HIV prevalence is high. In many of the northern states, the HIV prevalence among high risk groups is less than 5%. Numerous migrants from those states moved to areas where HIV prevalence in antenatal clinics is above 1%, constituting a generalized epidemic.

Role of mobile populations in surveillance
There is a large—and increasing—number of migrant workers moving from rural villages to cities, as well as to other countries in the South-East Asia region. However, many countries do not have a surveillance system to capture the magnitude of this migration, the flow pattern, or the profile of who is migrating. Existing HIV surveillance does not capture people’s home communities and the key sites where they aggregate in host communities. Thus, there is a gap in our knowledge of the prevalence of and trends in HIV among the mobile populations. This unfortunately has the effect of giving the wrong impression that some countries with large migrant communities and with high HIV prevalence are actually low-prevalence countries.

Figure 5.1
Indian population movement from low to high-prevalence regions

Conducting Formative Research

Formative research will be necessary to design the survey or study best suited to the group, given the range of possibilities. Formative research will also help to identify the various points of access to the groups and places where surveys and studies could be conducted. Which migrant groups you survey will depend on the specific situation in your country or region.

Listed in Table 5.1 below are recommendations for proposed surveillance methods for mobile populations.

Table 5.1
Recommendations for proposed surveillance methods for mobile populations

1. Conduct formative research to map mobile populations and to categorize the sub-populations in the region by patterns of movement and probability of transmission.
2. Prioritize the populations and geographic areas for conducting surveillance, based on potential for epidemic impact.
3. Develop definitions for mobile populations (truck drivers, miners, construction workers, sailors, fishermen and others) in regions prioritized for surveillance.
4. Build key alliances with community networks involved with mobile populations (for instance, employers and border patrol).
5. Gain collaboration of existing prevention programmes, if they exist.
6. Design surveys or studies.
7. Collect HIV sero-prevalence data, behavioural data and STI data.
8. Analyse and disseminate data.

Pre-surveillance assessment

The first step in planning HIV surveillance in mobile populations is to gain an understanding of the population or populations in your area through formative research. Conducting a pre-surveillance assessment will help you determine the diversity of mobile sub-populations, identify key indicators to measure and determine the geographic areas and venues where mobile persons may be found in high numbers.

A critical component of formative research is gaining an understanding of the patterns of movement and the volume of people travelling. This will help you determine epidemic impact and subsequent prioritization of surveillance groups/areas.

Consider where to find mobile populations

Conducting surveillance in mobile populations requires gaining access to the full range of sub-populations in the area. Due to the diversity of these sub-populations, locating all areas where mobile persons can be found and gaining access to these persons is challenging. You can locate and access mobile persons by:

- visiting the venues where they congregate/work
interviewing and working with persons who have regular contact with mobile persons

HIV prevalence in mobile populations may be highest in well-travelled border towns and ports. These towns and ports, therefore, may be appropriate and convenient sites for surveillance. Possible locations where mobile persons may be found in high numbers include:

- truck stops and roadside hotels
- brothels in border towns or near construction, mining and/or fishing areas
- highway STI clinics
- health clinics operated by construction or mining companies.

A pre-step for deciding on a sampling method is to decide whether to sample at the point of origin or the point of destination for the migrants/mobile populations. This will depend on the aggregation of people at one end or the other, as well as whether the epidemic impact is being assessed for a particular geographic region, that is the point of origin or the point of destination.

The Family Health International (FHI) report *Protecting People on the Move: Applying Lessons Learned in Asia to Improve HIV/AIDS Interventions for Mobile People* further discusses how to identify sites that fuel the spread of HIV or create conditions that make mobile people vulnerable to HIV. This report is available online at: http://www.fhi.org/en/HIVAIDS/country/Asia/res_PeopleonMove2006.htm.

The Fafo Institutes for Labour and Social Research and Applied International Studies have developed methods of accessing hidden populations such as exploited migrants and trafficked persons. Further information is available online at: http://www.fafo.no/indexenglish.htm.

**Forming alliances**

The next steps will involve forming and maintaining alliances with the organisations and individuals that are trusted by the segment of the migrant community in which you are interested, such as:

- border patrol, immigration police, customs agents, police and harbour masters
- employers
- employment agencies
- bar tenders
- union officials
- operators of truck stops, fish markets or other places where these groups may congregate
- local community leaders (for example, the town mayor and the department of transportation).

Forming alliances is an ongoing process that must be developed over time and will help in each stage of preparing for surveillance. When planning and implementing
surveillance activities, it is important to understand the power structures that influence the movement and behaviour of mobile populations. It will also be helpful to enlist the support of the managers of any currently existing intervention programmes for migrant workers and populations. This will be extremely helpful in setting up the infrastructure for the surveillance system and disseminating results of the surveillance activity.

Community approval
Community approval promotes trust and confidence among community members who will be involved. It also reflects respect for local community customs. Given this, it is recommended that second-generation surveillance involve regular consultation from the community. Community advisory boards, made up of various leaders, can promote consultation, input and advice on the design and implementation of surveillance. Below is a list of potential members for a community advisory board for HIV surveillance among migrant workers at a large manufacturing plant. The actual composition of a board will depend on the characteristics of the community and the nature of the surveillance activity, but it may include some of the following:

- union leaders
- employers
- employee occupational health centre workers
- employees elected by co-workers at large
- designated employee safety officers
- factory floor managers
- factory owners
- occupational health nurses
- occupational health academic faculty.

Conduct ethnographic mapping
Ethnographic mapping entails the creation of a comprehensive description of the population with respect to:

- the places where mobile populations may be found
- time period
- types of mobile populations and sub-populations in your area.

This information can inform you as to where and when mobile persons can be found and recruited for surveillance activities, and what sub-populations can be found in different areas.

Identifying the migrant populations that are of greatest interest to you and the best ways to approach these groups is an important first step, and the core of your formative research. Table 5.2 lists some examples of what migrant groups might be useful for particular communities and how to access the populations.
Table 5.2

Choosing a migrant population to survey based on community characteristics: some examples

<table>
<thead>
<tr>
<th>Sample community characteristics</th>
<th>Migrant population to survey</th>
<th>How to access the population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Town with large worksites, such as construction sites or manufacturing plants</td>
<td>Migrant workers in construction site or manufacturing plant</td>
<td>Companies can often provide access to employees through their occupational medicine departments</td>
</tr>
<tr>
<td>Port cities</td>
<td>Long-distance truck drivers</td>
<td>Surveys of truckers as they wait in line</td>
</tr>
<tr>
<td>Rural areas that border the sea or a large inland lake</td>
<td>Merchant seamen</td>
<td>Union records</td>
</tr>
<tr>
<td></td>
<td>Fishermen</td>
<td>Systematic survey of boats as they return to port</td>
</tr>
</tbody>
</table>

The examples in the table above deal with men who have migrated away from their homes for work and are at risk of acquiring HIV, typically from sex workers. On the other hand, sex workers are often economic migrants as well, who will leave poorer areas to work in places with greater affluence and more ready cash. Sex workers will often cross borders or even continents.

Examine STI clinics

You may also find mobile persons in large numbers at STI clinics.

- Some STI clinics are located along major trucking routes.
- Other STI clinics do not specifically cater to mobile persons, but do include a high number among their patients.

If these STI clinic clients are to be considered for surveillance of mobile populations, occupational information must be systematically and routinely recorded.

Select a Sampling Method

Sampling methods

Methods for surveillance in migrants are similar to those used in other high risk populations in this module. These methods include:

- HIV prevalence studies
- surveillance for STIs
- behavioural surveys to identify social, behavioural and biomedical risk factors associated with HIV transmission.
There is no particular ‘best’ sampling method for use in all situations. In some situations, when neither TLS nor RDS is appropriate, a facility-based sampling method may be the most viable option. The best way to sample these groups will depend on which specific groups of workers you wish to survey and where the best places to find them are.

The following table summarizes some of the possible methods of surveying various migrant groups.
Table 5.3

Examples of possible methods of surveying various migrant groups.

<table>
<thead>
<tr>
<th>Migrant group</th>
<th>Possible survey methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Truck drivers/assistants.</td>
<td>• Simple random sampling, cluster sampling or systematic sampling, if trucking companies provide lists of their employees.</td>
</tr>
<tr>
<td>Miners, factory and construction workers.</td>
<td>• During regular occupational health check-ups.</td>
</tr>
<tr>
<td></td>
<td>• If housed by a company, lists or maps can be used for simple random sampling or multi-stage cluster sampling.</td>
</tr>
<tr>
<td>Self-employed (for example, truck drivers and fishemen).</td>
<td>• Time-location sampling (for example, truck drivers stopping for dinner along a specific highway).</td>
</tr>
<tr>
<td>Merchant sailors.</td>
<td>• Simple random sampling (for example, if a list of seamen exists at a union hall).</td>
</tr>
</tbody>
</table>

An example, sampling migrant workers

An important element of these studies relates to sexual networks and sexual behaviours of migrant workers. Also, much of the surveillance needs to be based at the workplace, not just in neighbourhoods where workers live. Migrant workers are often introduced to new patterns and norms of sexual behaviour and use of the sex facilities through colleagues in the workplace.

Thus, to provide a good sampling frame for migrant populations, the following steps are suggested:

- List all working sites of migrants by geography or time location; for example, all large industrial facilities with dormitories for migrant workers or all highway stops that cater to long-distance truck drivers.
- Based on HIV prevalence or the potential for instituting prevention programmes, choose the type of site of interest to you. Select sites for surveillance from the list you generate. If the numbers of persons working at the sites is small (for example, fishing boats or trucks), you may need to include the entire target population in the sample. If there are multiple large sites, you can pick one or two randomly, depending on sample size calculations.
- At selected sampling sites, take all or select systematically some respondents for interview.

Measures

Both behavioural and biological measures of HIV, STI and risk behaviours can be collected in a variety of ways. The frequency of surveillance among mobile populations and migrants will depend on what is being measured and the characteristics of the population.
Collecting the biological specimens for surveillance will depend on what is available to the surveillance team in your region and what is acceptable in the context of cultural and societal norms.

**Biological measures**

As in most other surveillance systems, biological specimens should be drawn for testing for prevalence of HIV and other STIs. The high sexual risk among mobile persons also makes STI testing a useful and feasible indicator for surveillance. For a description of the available STI tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups.

- Syphilis testing is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.
- Accurate tests for gonorrhoea and chlamydia are expensive and usually require a urine specimen.
- HSV-2 testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.

If, during formative research, you found that some mobile persons also inject drugs, biological markers of injection drug use include hepatitis B core antibody (HBcAb) and hepatitis C virus (HCV) antibody. Tests for HCV may be expensive.

**Behavioural measures**

Measuring changes in sexual behaviour among mobile populations helps explain trends in HIV and STI prevalence data. Among mobile persons, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Several international organisations have sought to standardize a set of “core” or basic indicators of HIV risk among mobile populations (truck drivers, in particular). These include:

- correct identification of ways of preventing the sexual transmission of HIV and rejection of major misconceptions about HIV transmission (UNGASS)
- condom use at last sex with a non-marital, non-cohabiting partner (MEASURE)
- correct identification of the use of condoms as means of protection against HIV infection (MEASURE)
- sex with a sex worker in the last 12 months (MEASURE)
- condom use at last sex with a sex worker, of those who report having had sex with a sex worker in the last 12 months (MEASURE)
- reported symptoms of STIs in the last 12 months and seeking care at a service provider with personnel trained in STI care (MEASURE).

These basic indicators may be supplemented with local measures of particular importance in your area (as determined by your formative research phase). These additional indicators may include:
• knowledge of HIV and STIs
• number of sex partners, types
• condom use with sex partners
• sex with other men
• injection drug use
• history of genital ulcer disease or genital discharge
• STI treatment-seeking history and places where care is sought
• marital status/regular partnership status
• basic demographic characteristics
• the length of time spent away from home/regular sex partners
• where they travel and how often
• whether they cluster in communities that mimic their home/living conditions, types of social support.

Reference to indicators
Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

• United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
• Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV including indicators that are key to the spread of HIV among FSWs. These guidelines are available online at: http://www.fhi.org.
• The HIV/AIDS Survey Indicators Database of MEASURE DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practices). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Special Ethical Considerations
There are special ethical issues you must consider when conducting surveillance activities in mobile populations. Being identified as HIV-infected or an injection drug user could result in firing or deportation.

Also, you should consider your ability to obtain true informed consent when mobile persons may be coerced to participate or not participate by their employer.

Assuring confidentiality
Confidentiality protects subjects from adverse consequences that may arise from
participating in a study or survey. If a person’s HIV infection becomes known, he or she may suffer discrimination or stigma, or even be subject to criminal charges in some situations. Be aware of any particular provisions in your country’s laws that may complicate participation. These may include:

- laws prohibiting men to have sex with men
- laws prohibiting injection drug use
- laws requiring reporting of individuals with HIV infection
- laws that protect study results from legal proceedings that could result in jail or deportation.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimize them. Explaining these issues to them is part of the informed consent process.

Summary

Mobile populations are at high risk both for getting and transmitting HIV and STIs and often serve as a bridge between female sex workers and the general population. Methods for surveillance in migrants are similar to those used in other high risk populations in this module. Surveillance among mobile populations should be conducted on a regular basis every year and should include biological and behavioural measures. The best way to sample these groups will depend on which specific groups of workers you wish to survey and the places you can find them.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this appendix. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

1. List migrant/mobile populations at high risk in your country.

2. Does your country conduct behavioural and/or sero-surveillance of mobile populations (such as, truckers)?

3. In your country, who are the gatekeepers of this population?

4. In your country, what methods have been used to sample mobile populations?

5. In your country, what behavioural and biological measures have been used when conducting surveillance of mobile populations?

6. In the past five years, has the prevalence of HIV among mobile populations increased, decreased or remained about the same?
Apply what you have learned/case study

Biological and Behavioural Surveillance Among Truck Drivers in Nodesh

Part 1: Collecting information to plan surveillance activities

Bangalay, with a total population of 15 million, is the capital of the South-East Asian country of Nodesh. Jawara, the northernmost province, borders Serosia and is thought to be a common drug trafficking area. Bantak, to the south, is the country’s major deep-water port and a docking place for merchant marines, cruise ships and local fishing vessels.

Sero-prevalence surveys conducted in Bangalay have consistently found a low HIV prevalence. However, similar surveys conducted over the past five years have found that prevalence levels of HIV among injection drug users in Jawara and STIs among female sex workers in Bantak are rising at an alarming rate.

The Nodeshi Minister of Health, concerned that HIV will spread from these high risk groups to the general population, advises the regional HIV programme manager to investigate the spread of HIV in the country.

The HIV programme manager decides to focus on truck drivers because of the role the trucking industry plays elsewhere in the spread of HIV and the documented high risk behaviours of truck drivers globally. She decides to undertake a combined biological/behavioural survey among truck drivers in Nodesh, and holds a meeting with her HIV surveillance team to plan for the survey.

1. What information is required for planning the survey?
2. How might the HIV surveillance team obtain this information?

Part 2: Choosing a sampling approach

To obtain background information for designing a behavioural survey, the HIV surveillance team reviews several documents, including published literature, reports of NGOs, reports from trucking companies and clinic records from roadside STI clinics. Interviews of key informants are conducted using open-ended questions. Several key informants are also contacted, including the owners and managers of several trucking companies, truck drivers and helpers, the Ministry of Transport, representatives of the trucking union and staff of roadside STI clinics.

Through discussions with key informants and a review of the available literature, the surveillance team discovers that there are 140 trucking companies in Nodesh, employing approximately 20,000 truck drivers. All trucking companies have offices in Bangalay, where truck drivers must report on a frequent basis to receive their trip assignments.
The HIV surveillance team also discovers that there are three main categories of trucking companies and that, due to union negotiations, each trucking company serves either:

- a long-distance route between Bangalay and the northern district of Jawara, which borders Serosia
- a medium-distance route between Bangalay and the deep-water port of Bantak in the south of the country
- local routes between Bangalay and the surrounding areas.

The HIV surveillance team conducts a census of the trucking companies in Nodesh to determine which companies employ which types of drivers (long-distance, medium-distance, or local) and how many truckers each company employs. The surveillance team learns that 20 companies employ a total of 10,000 long-distance drivers, 100 companies employ a total of 4,000 medium-distance drivers and 20 companies employ a total of 6,000 local-route drivers.

3. What is an adequate sample size to detect an increase in consistent condom use (defined as use of condoms during every episode of vaginal intercourse during the preceding three months) with sex workers from 10% in the current year to 20% if the survey is repeated in two years? (Refer to table with the sample size options).

The most conservative sample size to detect an increase of 10 percentage points (10%-20%) in the proportion of truckers who reported consistent condom use (with 80% power of detecting a change of this magnitude at the 95% confidence level) is 395 truckers per survey year. The final sample size is rounded to 400 per survey year.
4. What sampling scheme can be used to select representative respondents to be included in the survey?

Part 3: Sampling and collecting biological and behavioural data
A variety of sampling approaches are appropriate for sampling truck drivers in Nodesh. Because the team was able to construct a list of all of the trucking companies, as well as information on how many drivers each company employs, the HIV surveillance team decides to employ probability-proportional-to-size (or PPS) sampling scheme, in which types of truck drivers are sampled proportionate to the size of the different groups of truck drivers (long-distance, medium-distance, or local).

In stage 1, the team stratifies the sampling by category of truck driver. To ensure that the sample reflects the actual composition of the truckers, the required number of truckers from each category is estimated:

- 200 long-distance drivers should be in the sample (as 50% of drivers are long-distance drivers)
- 80 medium-distance drivers should be in the sample (as 20% of drivers are medium-distance drivers)
- 120 local-route drivers should be in the sample (as 30% of drivers are local-route drivers).

In stage II, the survey team determines that their budget allows them to make 40 sampling trips and survey 10 truck drivers per trip. Based on this estimate, and considering that each company employs only one type of driver, all 20 long-distance trucking companies are contacted; eight medium-distance companies are randomly selected; and 12 local-route companies are contacted.

With help from the selected trucking companies, the surveillance team randomly selects ten truck drivers from each selected trucking company. A total of 400 truckers are successfully recruited.

5. Describe how you would randomly sample 10 truck drivers from each company.

6. What behavioural variables should be collected?

7. What biological variables should be collected?

Part 4: Collecting survey information
Between January and April 2006, the team of field workers visit the selected trucking company's office at the Bangalay truck stand to recruit subjects. The Bangalay truck stand is selected as the best site for recruitment, as all companies have offices at the Bangalay truck stand and all drivers must visit the office to receive their trip assignments. Assuring the participants that confidentiality will be maintained, the field workers explain the purpose of the study to the drivers and obtain their verbal informed consent.

Members of the surveillance team escort the recruited drivers to the local roadside STI clinic for biological and behavioural data collection.
Male clinic staff members collect urine and blood samples from participants, which are then tested for:

- HIV-1
- Herpes simplex virus-2 (HSV-2) - a marker of lifetime sexual risk, for example, multiple sex partners
- syphilis
- gonorrhoea
- Hepatitis C - a marker for injection drug use.

Interviewers administer semi-structured questionnaires to the truck drivers to assess their sexual and injecting risk behaviours. Variables collected included:

- socio-demographic information (age, marital status, employment history, etc.)
- alcohol and drug use
- types of female sex partners in the past year
- MSM activity
- condom use
- history of diagnosis with STI, current symptoms of STI
- injection drug-use behaviours (types of drugs injected, frequency, needle-sharing and use of sterile equipment).

The survey produces the following biological results:

- HIV prevalence: 2.75% (11/400)
- HSV-2 prevalence: 40% (160/400)
- syphilis prevalence: 5% (20/400)
- gonorrhoea prevalence: 3% (12/400)
- Hepatitis C prevalence: 12% (48/400).

The survey produces the following behavioural results:

Risky sexual behaviour is common, with few truckers reporting consistent condom use, despite having high numbers of sexual partners. Both premarital and extramarital sex are common. Both married and non-married truckers report multiple sex partners, often with FSWs.

Nearly 10% report male-male sex ever and fifteen percent report injection drug use within the last year. Overall, condom use with non-marital partners is low. Only 20% report they ever used a condom and 5% consistently used condoms with non-cohabitating, non-marital partners. No subject having had sex with another man reports using condoms.

Marked differences are found between the three categories of truckers.

**Long-distance drivers (n = 200):**

- mostly single, young
- high rates of injection drug use
• reported sharing of syringes and other injection equipment
• some sexual contact with FSW along trucking route
• 24% prevalence of hepatitis C (48/200)
• 5% prevalence of HIV-1 (10/200)
• three cases of hepatitis C/HIV co-infection.

Medium-distance drivers (n = 80):

• single and married
• high level of interaction with FSW in port of Bantak
• high prevalence of HSV-2 (80%), gonorrhoea and syphilis
• no reported injection drug use
• 1.25% HIV prevalence (1/80)
• Most with HIV also had HSV-2; many also had other STIs.

Local-route drivers (n = 120):

• mostly married (many with multiple wives and/or regular sex partners in different locations)
• little contact with sex workers
• high prevalence of untreated gonorrhoea and syphilis
• no reported injection drug use
• no HIV cases.

8. What interventions should be initiated based on these results?

Part 5: Epilogue

Findings of this study are consistent with the results of other studies. Most truck drivers surveyed engaged in high risk behaviours and many did not have their last genital symptoms treated.

Given the very low levels of HIV in Nodesh, targeting truck drivers with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Nodesh Minister of Health directs the HIV programme manager to implement the following measures:

a. To create 100% condom-use campaigns in port-area brothels; engaging peers and NGO outreach workers to educate truck drivers about consistent condom use with sex workers and regular partners.

b. To establish harm-reduction programmes for IDUs and provide sterile injecting equipment to IDU truck drivers at the large truck stops along the Bangalay-Jawara trucking routes.

c. To establish workplace-based STI screening and HIV education for local-route drivers.

d. To improve the service provided at roadside STI clinics by ensuring drug supply and training staff on proper STI management.
Overview

What this unit is about
This unit describes the background and special considerations for conducting behavioural and biological HIV surveillance among out-of-school youth.

Warm-up questions
1. Out-of-school youth may include which sub-populations?
   a. street children
   b. child labourers
   c. adolescent sex workers
   d. married adolescents
   e. all of the above.

2. True or false? By targeting youth through behaviour-change campaigns, several countries have successfully decreased national HIV prevalence levels.
   True          False

3. List three possible places where you would expect to find large numbers of out-of-school youth.
   a. 
   b. 
   c. 

4. What are two reasons why out-of-school youth may be considered a vulnerable population?
   a. 
   b. 

Introduction

What you will learn
By the end of this unit, you should be able to:

- understand the diversity of out-of-school youth
- understand the role of out-of-school youth in the HIV epidemic
- describe options for sampling of out-of-school youth for surveillance
- describe the special ethical considerations associated with conducting HIV surveillance activities in out-of-school youth.
Background

Barriers to education

In some of the countries most affected by HIV/AIDS, many children and adolescents are not in school. Factors that can contribute to children not attending school include:

- Economic hardship—due to unaffordable school fees (such as tuition, books, uniforms, etc.), some families are not able to afford sending their children to school.
- Household obligations—some families rely on older children to do housework, childcare or work outside the home to supplement family income.
- Gender discrimination—families may not believe that educating girls is important.
- Insufficient or inappropriate education facilities—lack of schools or shortage of trained teachers may narrow educational opportunities.
- Poor infrastructure—poor roads and/or transportation systems may prevent youth from getting to school.
- National policies may prevent some persons from attending school; for example, policies may prohibit pregnant girls or persons without birth certificates from attending school.
- The lure of cities—youth may run away from families in rural areas.
- Social conflict and emergencies—natural disasters and political conflicts may disrupt school schedules.
- Orphan status—parents may have died from AIDS.

In many countries, females are less likely to attend school than males.

- Girls are more likely than boys to be kept at home when there is a need for household help, particularly when there are sick members in the family or younger siblings who need care.
- Because of economic or cultural beliefs, families may choose to send only their male children to school.
- Girls marry at a young age, which in most cases permanently disrupts their education.

Definitions

In the South-East Asia Region, out-of-school youth (OSY) include diverse sub-populations. For the purpose of this unit, we consider OSY to include children and adolescents from the ages of 15 to 24 who are not currently enrolled in formal education. They may have completed school, may have dropped out of school, or may never have started school. The experiences of OSY vary greatly—they may work in factories, sell goods in markets, work on farms, stay at home to do housework or child-rearing, engage in prostitution, live and work on the streets, or be unemployed.

Sub-populations of out-of-school youth

OSY often live under challenging conditions and are marginalized from mainstream services and society. In South-East Asia, OSY at risk of HIV infection can be grouped into one or more of the sub-populations discussed in Table 6.1.
### Table 6.1
**Sub-populations of out-of-school youth**

<table>
<thead>
<tr>
<th>Group</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street children</td>
<td>Includes orphaned, homeless, runaway or neglected children who live chiefly in the streets without adequate protection, supervision or direction from responsible adults.</td>
</tr>
<tr>
<td>Child labourers</td>
<td>Includes children who are paid to do work that is physically, mentally or morally exploitative and harmful in its own right, or because it blocks their access to education. These children often migrate from rural areas to cities to work.</td>
</tr>
<tr>
<td>Adolescent sex workers</td>
<td>Includes any person under the age of 18 involved in the sex industry. Adolescent sex workers often do not have the ability to resist sexual aggression or demand that their clients use condoms.</td>
</tr>
<tr>
<td>Married adolescents</td>
<td>Includes girls who are married before the age of 18 due to family traditions. Due to household responsibilities, married adolescents generally do not attend school.</td>
</tr>
</tbody>
</table>

### Role of OSY in the HIV epidemic
Youth who do not attend school have a higher risk of acquiring HIV, as they:

- do not receive reproductive health education and other school-based services
- may have low self-esteem
- are not exposed to the structure that the school environment would otherwise provide
- face stigma and discrimination, which prevent them from adopting risk-reduction behaviours
- are more likely to experiment with drugs and alcohol
- may be sexually exploited, trafficked or involved in the sex industry.

In the Asia-Pacific region, it is estimated that over two million young people aged 15-24 years live with HIV, with widening epidemics in many countries in the region. Young people are often more likely than their elders to engage in high risk behaviour, making them more susceptible to the risk of infection. Reasons for increased risk-taking behaviour among youth include:

- lack of information
- peer pressure
- inability to calculate risk
- low perception of risk
- economic pressures
- inability to refuse unprotected sex
- limited availability of or access to condoms
- lack of youth-friendly services.

The types of risks and social factors underlying HIV infection among OSY categories differ, as outlined in Table 6.2 below.
Table 6.2
The vulnerability of OSY to HIV

<table>
<thead>
<tr>
<th>Group</th>
<th>Risk and social factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street children</td>
<td>• are often sexually active</td>
</tr>
<tr>
<td></td>
<td>• may have multiple sex partners, including female sex workers</td>
</tr>
<tr>
<td></td>
<td>• may provide sex in exchange for money</td>
</tr>
<tr>
<td></td>
<td>• may be sexually abused</td>
</tr>
<tr>
<td></td>
<td>• may inject drugs</td>
</tr>
<tr>
<td></td>
<td>• have less access to prevention information through schools</td>
</tr>
<tr>
<td></td>
<td>• may be involved in gangs and/or drug trafficking</td>
</tr>
<tr>
<td></td>
<td>• generally don’t receive appropriate medical care.</td>
</tr>
<tr>
<td>Child labourers</td>
<td>• have less access to prevention information through schools</td>
</tr>
<tr>
<td></td>
<td>• may be sexually abused in the workplace</td>
</tr>
<tr>
<td></td>
<td>• may be involved in sex work.</td>
</tr>
<tr>
<td>Adolescent sex workers</td>
<td>• may not have the right or ability to resist sexual aggression</td>
</tr>
<tr>
<td></td>
<td>• are often obliged to take multiple clients each day</td>
</tr>
<tr>
<td></td>
<td>• are young and physically immature, which, combined with the physical trauma of aggressive or repeated intercourse, makes them especially susceptible to contracting and spreading HIV.</td>
</tr>
<tr>
<td>Married adolescent women</td>
<td>• may not be able to control a husband’s infidelity or resist sexual abuse</td>
</tr>
<tr>
<td></td>
<td>• younger women are more susceptible to contracting STIs due to immature genital tracts</td>
</tr>
<tr>
<td></td>
<td>• have less access to prevention information through schools.</td>
</tr>
</tbody>
</table>

By targeting youth through behaviour-change interventions, several countries have successfully decreased national HIV prevalence levels. To create appropriate interventions, HIV surveillance of high risk youth is crucial.

Prevalence of HIV among OSY

Overall, the prevalence of HIV among out-of-school youth varies by country and region, as illustrated by the following data:

- In Nepal, 11% of the reported HIV cases are among youth younger than 19 years of age.17
- A study among FSWs in India indicate that the highest HIV sero-prevalence was among the younger sex workers (<20 years of age), with 12% testing HIV-positive.18
- In Bangkok, Thailand, the prevalence of HIV among MSM aged 22 years or younger has risen from 13% in 2003 to 22% in 2005.19
- In Indonesia, the prevalence levels of STIs and HIV/AIDS infection among street youth are unknown, but it is estimated that in Jakarta, one in every seven street children has a history of STIs.
- In Myanmar, the prevalence of HIV among young people aged 15-24 was found to be 2.2% in 2005, compared to a national adult HIV prevalence of 1.3%.20
Role of OSY in surveillance

In South-East Asia, people between the ages of 10 and 24 are one of the fastest-growing groups of new HIV infections. It is crucial to identify and track high risk groups within this population. Because of the high risk behaviour and ability to make long-lasting behavioural changes, many special programmes and interventions are specifically targeted toward out-of-school youth, including:

- mass media campaigns
- promotion of youth-friendly health services
- condom use promotion and life skills education
- voluntary counselling, testing and STI treatment.

Because young people are often powerful agents for change when given the appropriate tools and support, it is crucial to have surveillance in place that will help monitor any specific behaviour changes observed in these groups.

Overlap with other populations

In many areas, young people constitute a significant percentage of FSWs, IDUs and MSM. For example:

- In Cambodia, Laos, Myanmar, and Vietnam, between 60% and 70% of sex workers are younger than 25 years of age.
- In Central Asia, up to 25% of IDUs are estimated to be less than 20 years old.
- In Indonesia, 70% of injecting drug users are younger than 25 years.
- Many clients of sex workers are also young. Data from behavioural surveys conducted in India and Nepal found that between 17% and 70% of the clients of sex workers are young, with the majority aged 20-24 years.
- In Myanmar, sentinel surveillance conducted between 1989 and 2003 found that 41% of FSWs age 15-24 were HIV positive.  

Conducting Formative Research

The first step in planning HIV surveillance in OSY is to gain a better understanding of the sub-populations of OSY in your area.

Pre-surveillance assessment

Pre-surveillance assessment activities are conducted to identify key indicators to measure the diversity of the sub-groups of OSY and the geographic areas and venues where OSY may be found in high numbers. The aims of the pre-surveillance process include:

- exploring the diversity and types of OSY
- agreeing on the purpose and uses of surveillance data for OSY programmes
- identifying a co-ordinating or decision-making body
- selecting which specific OSY sub-groups to include
- delineating the geographic coverage areas
- selecting which indicator variables to collect (behavioural and biological).

Because OSY are composed of a number of different sub-groups, HIV prevalence may differ considerably among different groups existing relatively close to one another within
a given country, or even within a given city. Identifying points of access and forming alliances with organizations and persons trusted by the different OSY sub-groups will help you more fully understand the culture and diversity of OSY in your area.

**Consider where to find OSY**

Surveillance requires gaining access to a full range of OSY and areas where OSY can be found. This may be difficult when considering each sub-group’s different characteristics. Findings from the pre-surveillance assessment should prove helpful in focusing the search. To facilitate locating and accessing OSY, consider:

- identifying and interviewing persons known to have regular contact with OSY
- visiting areas where they are known to congregate
- collaborating with organisations that provide education, food and/or shelter to OSY, such as religious organisations and civil society organisations.

Possible organisations that can help you locate and access OSY include:

- the United Nations Children’s Fund (UNICEF)
- the United Nations Populations Fund (UNFPA)
- the Red Cross and Red Crescent societies
- Save the Children
- the World Association of Girl Guides and Girl Scouts
- the Boy Scouts
- OXFAM International
- local sports clubs.

Other OSY sub-groups, such as child sex workers, factory workers and soldiers, may require more extensive formative assessment before they are located. These sub-groups may be more easily accessed by forming key alliances with adults or older youth who are in charge. Some examples are:

- influential current and former sex workers, factory workers
- police
- leaders of youth gangs
- handlers or other *gatekeepers*, such as pimps, madams, brothel managers and owners, and factory supervisors
- governmental and non-governmental organisations conducting youth-targeted HIV prevention and care programmes
- national and international advocacy groups dealing with OSY issues.

These people and organisations can also assist later in implementing surveillance activities. For example, former adolescent sex workers can be hired and trained as recruiters or to conduct interviews in difficult-to-access areas.

**Conduct ethnographic mapping**

*Ethnographic mapping* entails the creation of a comprehensive description of the population with respect to:
• the places OSY can be found
• time periods of high and low volume of OSY
• types of OSY sub-groups found in a particular area.

This comprehensive description is used to broadly guide where and when OSY can be found and recruited for surveillance activities, and what sub-groups can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a sampling frame or comprehensive roster representing OSY or a particular sub-group in your area. This sampling frame provides the basis for some probability-based sampling methods.

The locations where OSY spend most of their time will differ by sub-group, and will be dependent on the particular sub-group of interest. To locate OSY, identify areas where young people tend to congregate. These include:

• parks
• markets
• beaches
• train and bus stations
• street corners
• movie theatres
• sports fields
• shelters.

Depending on the focus of the surveillance, other sub-groups, such as OSY sex workers, intravenous drug users or factory workers may be included. In these cases, consider:

• brothels
• sex trade areas
• bars and discos
• massage parlours
• areas where people gather to use, sell or buy drugs
• truck stops
• factories employing youth workers
• households.

Due to various legal issues surrounding many of the sub-groups, it is unlikely that there is any formal registration system for OSY. However, depending on each country or region, OSY may be registered as sex workers or labourers. Rosters of OSY may also be available from NGOs, religious organisations and other agencies that provide services to OSY. It is important to note that these lists are rarely separated into adult and youth categories, making it difficult to obtain a representative sample.

**Select a Sampling Method**

Hard-to-reach populations, such as out-of-school youth, may be sampled using either probability sampling or non-probability sampling (also referred to as 'convenience sampling'). Depending on the organisation, accessibility, and the extent that OSY are networked, different sampling methods may be more or less feasible. Although non-
probability sampling, such as snowball sampling, is easier to conduct than probability sampling (since a sampling frame is not needed), data collected through non-probability methods can introduce bias into the data. This can occur due to a number of reasons, such as differences in HIV prevalence or risk behaviours between different sub-populations within a group or between the sub-groups themselves. Probability and quasi-probability sampling methods can be used to obtain more representative samples of OSY.

Not all out-of-school youth are difficult to access. Many OSY are married and/or live with relatives. These youth can be sampled using conventional sampling techniques. To obtain an accurate list of OSY, review recent survey results from Demographic Health Surveys (DHS), or Behavioural Surveillance Surveys (BSS). These surveys often contain a comprehensive listing of household members and can be used to help create a sampling frame. Conducting a pre-surveillance assessment will help you identify the sub-groups of OSY in your area and will provide information on how they can best be accessed and sampled.

Probability sampling techniques like time-location sampling (TLS) and respondent-driven sampling (RDS) may be used to sample hard-to-reach OSY like street children.

**Time-location sampling**

Time-locations sampling (TLS) may be used to sample OSY when OSY tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets and transportation centres. In TLS, the sites known to be frequented by OSY (found through ethnographic mapping or pre-surveillance activities) are used to develop a sampling frame from which a probability sample of sites and time periods are chosen. Because the locations where OSY congregate may change over time, you should develop a new sampling frame for each round of surveillance.

**Respondent-driven sampling**

Certain OSY sub-populations do not congregate in identifiable and accessible locations, and are not adequately represented by TLS. Respondent-driven sampling, an adaptation of chain-referral sampling, is based on a dual incentive structure in which participants are rewarded for being interviewed and for recruiting their peers. When using RDS to sample hard-to-reach or mobile OSY, incentives should not be too weak or too strong.

- If incentives are too weak, participants may feel the compensation is not worth the time it would take to recruit their peers.
- If incentives are too strong, bias can be introduced, as the participants may try to keep the incentives distributed solely within their own peer group.

Food items are often used as incentives when conducting RDS among children and adolescents. Organizations working with street children can help you determine appropriate incentives.

As the definition of OSY may vary, your inclusion and exclusion criteria should be very clear in the first wave of recruitment so that youth understand which other youth to recruit.
Priorities for local AIDS control efforts

The PLACE (Priorities for Local AIDS Control Efforts) protocol is a new rapid assessment tool used to identify high transmission areas that formalize the collection of information in high-transmission areas. PLACE use key informants to identify locations where people meet new sex partners, then interviews people at the site to characterize the site in each area and map sites. PLACE also interviews individuals socialising at the site to describe the characteristics of the people at the site.

Figure 6.1 will help you select an appropriate method for sampling out-of-school youth in your area.

Figure 6.1
Selecting sampling methods for out-of-school youth

![Diagram showing selection process]

Additional information on the sampling methods that may be used to sample out-of-school youth are discussed in Module 5: Surveillance of HIV Risk Behaviours.

Measures

Biological measures
Measuring HIV prevalence among OSY is an integral component of surveillance. The high sexual risk among many of the sub-groups makes STI testing a useful and feasible indicator for surveillance (see Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups for a description of the available STI tests).

- Syphilis testing is often the most efficient biological indicator of unprotected intercourse because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.
• Accurate tests for gonorrhoea and chlamydia are expensive and usually require a urine, rectal or pharyngeal specimen.

In areas where there is suspected overlap between OSY and intravenous drug users, biological markers may include hepatitis C virus (HCV).

**Behavioural measures**

Measuring changes in sexual behaviour among OSY helps explain trends in HIV and STI prevalence data. Among OSY, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Indicators that assess sexual risk include:

• correct identification of ways of preventing the sexual transmission of HIV and rejection of major misconceptions about HIV transmission
• age of sexual debut
• condom use during last sex with a non-regular sex partner
• the use of transactional sex.

In areas where there is suspected overlap between OSY and other high risk groups (for example, FSWs, MSM, or IDU), consider using indicators that assess high risk behaviours among these groups.

The indicators that may be appropriate in situations where there is suspected overlap between out-of-school youth and other high risk groups are presented in Table 6.3 on the next page.

**Table 6.3**

*Additional indicators to include when there is suspected overlap between OSY and other high risk groups*

<table>
<thead>
<tr>
<th>Group</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex workers (FSWs)</td>
<td>• venue of sex work</td>
</tr>
<tr>
<td></td>
<td>• number of paying customers</td>
</tr>
<tr>
<td></td>
<td>• condom use with paying customers</td>
</tr>
<tr>
<td>Injection drug users (IDUs)</td>
<td>• frequency of injection drug use</td>
</tr>
<tr>
<td></td>
<td>• sharing of needles, syringes or other injecting equipment</td>
</tr>
<tr>
<td></td>
<td>• types of drugs injected</td>
</tr>
<tr>
<td></td>
<td>• history of imprisonment</td>
</tr>
<tr>
<td>Men who have sex with men (MSM)</td>
<td>• number of male sex partners</td>
</tr>
<tr>
<td></td>
<td>• frequency of unprotected anal intercourse (UAI)</td>
</tr>
<tr>
<td></td>
<td>• frequency of unprotected receptive anal intercourse (URAI)</td>
</tr>
</tbody>
</table>

**Reference to indicators**

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:
• United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.

• Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV including indicators that are key to the spread of HIV among IDUs. These guidelines are available online at: http://www.fhi.org.

• The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Special Ethical Considerations
Because OSY are young and often involved in activities such as prostitution or child labour, they are often stigmatized and considered a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

• loss of anonymity (such as inadvertent identification as a drug user, sex worker or undocumented labourer)
• inadvertent disclosure of HIV status
• negative reaction and backlash in response to publicized results.

It may also be difficult to obtain true informed consent, due to the lower education and literacy levels common among OSY.

Assuring confidentiality
Anonymity protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country’s laws that may complicate participation. These may include:

• laws prohibiting working under a certain age
• laws prohibiting sex work or sex work under a certain age
• laws prohibiting drug use
• laws requiring reporting of individuals with HIV infection.

People asked to participate in a survey or study should understand potential threats to their anonymity. They should also understand the steps that the investigators will take to minimize them. Explaining these issues to them is part of the informed consent process.

Steps you can take to minimize threats to anonymity may include:

• conducting anonymous interviews with OSY in private settings
• collecting no identifying information about OSY
• limiting access to all information study data to authorized study personnel only
• keeping study documents in a locked, limited-access room
• having all staff sign confidentiality forms and undergo training in research ethics.

**Working with adolescents**

Different countries have different laws and standards about when an adolescent can participate in research involving sexual behaviours. There are also different laws regarding the age of majority and when parental consent is required. Familiarise yourself with these laws in your country as part of your initial formative research efforts. Generally, surveillance tries to minimize the number of participants in the age range 15-18, and avoids including those under 15. If it is necessary to include children under the age of 15, special guidance on research with children should be sought.

Emancipation of minors is a process that occurs when a court (or another body given that authority) declares that someone who is still a minor is nevertheless to have the legal rights of an adult, and to be free of any authority from their parent or other legal guardian. Each country has its own laws regarding the emancipation of minors, and many countries deem a minor to be automatically emancipated if they marry. It may be necessary to check your country’s laws regarding parental consent and the age of majority, as some OSY may be considered minors, and obtaining consent from their parents may be difficult.

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to persons participating in research involving human subjects. The Declaration of Helsinki provides ethical guidance for research activities involving minors. Further information is available at: http://www.wma.net/e/policy/b3.htm.

**Summary**

In the South-East Asia Region, *out-of-school youth* include diverse sub-populations, including street children, child labourers, adolescent sex workers, married adolescents and child soldiers. As people between the ages of 15 and 24 are the fastest growing group of new HIV infections, it is crucial to identify and track high risk groups within this population. Depending on the organization and accessibility of out-of-school youth in your area, different sampling methods may be more or less feasible. Additionally, appropriate behavioural indicators will vary depending on the situation and sub-populations of OSY in your area. You should be aware that different countries will have different laws and standards about when an adolescent can participate in research involving sexual behaviours, and when parental consent is required. If you plan to include children under the age of 15 in your surveillance activities, you should seek special guidance on research with children.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.
Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of out-of-school youth?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods have been used to sample out-of-school youth?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of out-of-school youth?

5. In the past five years, has the prevalence of HIV among out-of-school youth increased, decreased or remained about the same?

Apply what you have learned/case study

Conducting behavioural surveillance among street youth in Indam, Serosia

Part 1: Collecting information to plan surveillance activities

Indam City, with a total population of 5 million, is the economic and administrative capital of Serosia, a large South-East Asian country.

In 2005, data from STI surveillance found that number of new diagnoses of chlamydia among teens had doubled since 2000. Alarmed by these results, the Serosian Ministry of Health developed a package of youth-targeted evidence-based interventions to reduce HIV, including a national multi-media prevention campaign composed of billboards, leaflets, and radio and television broadcasts.

The Commissioner of Public Health for the Indam Metropolitan area is alarmed by recent NGO reports that an increasing number of street youth, some as young as 15, are presenting at urban public health centres with STIs and symptomatic HIV infection. She worries that the interventions and media campaign might not be reaching the street youth and/or have not been effective in preventing HIV infection among these youth.

The Indam Commissioner of Public Health directs the HIV Programme Manager to undertake a survey of street youth in Indam to determine the sexual and injecting behaviours of these youth and to assess whether they have been exposed to the multi-media HIV prevention campaign. She holds a meeting with her team of epidemiologists and social workers to plan for the survey.

1. What information is required for planning the survey?

2. How will the Indam HIV team obtain this information?
Part 2: Building key alliances with community networks involved with street youth

Prior to conducting the survey, the HIV team needs to conduct pre-surveillance activities (such as ethnographic mapping) to decide who they want to survey, where these youth can be found, what questions to ask and the ethical considerations of undertaking such a survey.

To obtain background information for designing a behavioural survey, the HIV team reviews several documents, including peer-reviewed articles, government reports, NGO reports, clinic records of the public and private clinics and reports from the police department. Several key informants are contacted, including current and former street youth, railway station employees, police, NGO managers and outreach health workers. The HIV team collects information on the locations where street youth sleep, work, and congregate and the public health services and NGOs operating in the area.

Through discussions with current and former street youth, the HIV team realizes that the street youth are highly distrustful of outsiders, including researchers, and are fearful that involvement in research activities may lead to the destruction of their illegal squatter settlements and/or their arrest. The team decides that in order to access street youth, they must enlist support of gatekeepers whom the street youth know and trust.

3. Who are important gatekeepers that can help the HIV team gain access to the street youth in Indam City?

4. What actions can the HIV team take to address the street youths distrust?

Part 3: Choosing approaches to behavioural survey

Through discussions with current and former street youth and managers of NGOs working with street youth, the HIV team learns that many of the street youth are organized in cliques (or groups), with certain cliques (or groups) living and working as a team. Using the contacts of the current and former street youth the HIV team meets with ‘senior’ street youth who have influence among other street youth.

The HIV team also meets with NGO managers and the police in the area.

A briefing meeting is organized, at which the HIV programme manager informs the stakeholders about the need for and purpose of the behavioural survey. The expected outcome of the survey is explained to the audience.

With a verbal assurance of the cooperation of the stakeholders and assurance from the police not to arrest street youth participating in the survey or destroy their settlements, the HIV team is now set to move to the next step.

5. What sampling methods are appropriate for sampling street youth in Indam City?

6. What are the advantages and disadvantages of each approach?

7. How would the HIV team construct their sampling frame?

8. What kinds of incentives should the HIV team offer to the street youth who participate in the survey?
Part 4: Collecting behavioural data

The HIV team considers their sampling options and determines that they could:

1) conduct targeted sampling
2) conduct time-location sampling at the locations where street youth congregate
3) use snowball sampling
4) conduct respondent-driven sampling.

The team weighs the pros and cons of each approach. The team considers the following:

- Targeted sampling requires knowing the venues and then developing a sampling frame based on quotas, but is not a probability based sampling method.
- Snowball sampling is easier to conduct and requires less recourse than time-location sampling or respondent-driven sampling, because it does not require a sampling frame. Like targeted sampling, snowball sampling is not a probability based sampling method.
- RDS and TLS are probability-based sampling methods that have more external validity than either snowball sampling or targeted sampling.

Given that street youth sleep, work and congregate in identifiable and accessible locations, the availability of adequate resources, and the strengths of time-location sampling as a probability sampling method, the team decides to conduct TLS to obtain a representative sample of street youth in Indam City.

The HIV team constructs a list of sites where street youth live, work and meet. These sites include squatter settlements where many street youth sleep, bus stations, train stations, busy intersections and markets where street youth beg and hawk goods, and parks where street youth congregate. The team then visits these venues and count the number of street youth present at the venues at specific times. The team statistician determined that the HIV team needs to survey a total of 600 street youth; thus, the HIV team decide to use a two-stage cluster sampling design. In stage I, 20 locations are randomly selected using a list of random numbers. In stage II, a fixed number of 30 street youth are selected from each selected site at a randomly selected three-hour time period on a randomly selected day of the week.

Although the HIV team discuss providing financial incentives, for ethical reasons they decide to give a packet of biscuits and a hot meal as the incentive to participate.

9. What behavioural variables should be collected?

Part 5. Results

At the randomly selected locations and times, trained interviewers explain the purpose of the study to the youth and obtain verbal consent. Confidentiality is assured. The interviews are conducted in privacy and in a non-coercive manner. Personal identifiers are not collected.

Trained interviewers administer a pre-tested, semi-structured questionnaire to
recruited youth to assess HIV risk behaviour, HIV-related knowledge and exposure to interventions.

The questionnaire includes queries on demographics and the context of street life, including age, gender, household information, lifetime years on streets, literacy and educational information, including current school attendance, and highest grade completed. Participants are asked about lifetime history of sexual intercourse, age of first intercourse, frequency of condom use, if they had ever exchanged sex for money, if ever experienced any kind of sexual abuse in streets, if experienced any kind of sexual abuse in home, and alcohol and illicit drug use. Youth are asked about the number of sexual partners they had in the previous year, whether they were diagnosed with any STIs, and whether they had any unprotected sex under influence of drugs or alcohol. HIV-related knowledge and information included items asking about any HIV testing history and whether they could correctly identify condom use as a means of preventing HIV transmission. To assess the youths’ recognition of and exposure to HIV prevention interventions, including the prevention campaign by the national mass media, campaign logos and campaign audio recordings are presented to participants along with control HIV/STI prevention logos and audio recordings. Participants are asked which logos they had previously seen and which audio recordings they had previously heard. Those surveyed are also asked about their health-seeking behaviour and the frequency with which they utilized public health centres.

Data are entered in a database, cleaned and analysed using the statistical software STATA. A summary of the results is presented to the Indam City Public Health Commissioner.

Although the study cannot afford to provide HIV or STI testing, referrals and vouchers for these services are offered to all street youth who participate in the survey.

The survey produces the following results.

Demographics

- The sample included 600 street youth (480 boys and 120 girls).
- Median age of those who participated was 16 years (range 12-19).
- Boys were significantly older than girls (median age 17 vs. 14, p<.01).
- Girls were more likely in contact with their family than boys (p<0.05).
- Most respondents lived on the street or in illegal squatter settlements.
- Only 6% (36) of respondents had electricity at the location where they spent the last night.
- 45% (267) of respondents were literate (50% of boys; 22.5% of girls).
- 5% of those surveyed reported having run away from home as a result of sexual or physical abuse in their home (girls more frequently reporting this occurrence, p<0.05).
- 10 reported having run away from home because of a forced marriage (girls more frequently reported this occurrence, p<0.05).

Sexual behaviours

- A significantly higher proportion of boys (67%) than girls (30%) reported ever having had sexual intercourse (p<0.01)
• Median age of sexual debut was 15 for boys and 13 for girls.
• Females reported more sexual partners in last year than males.
• 15% of female respondents reported having performed sex or sexual favours for money within the previous year, compared to only 4% of male respondents.
• An additional 10% of female respondents reported having exchanged sex for food or other goods, mostly with other street youth.
• 5% of male respondents reported having provided female street youth with food or protection in exchange for sex or sexual favours.
• 11% of female respondents reported having been raped while living on the streets.
• 26% of those who were sexually active reported history of condom use “in general,” while 72% reported using a condom during most recent sexual intercourse.

Drug use
• Alcohol was the substance most frequently used within the year by boys (85%) and girls (79%).
• Girls were less likely to report having used marijuana, inhalants and/or methamphetamines in the last year (p<0.05).
• Injection drug use was reported by only two participants (1.2%), both male.

HIV knowledge
• Nearly all respondents had heard about HIV/AIDS, but only 32% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
• 56% of respondents believed that they would never get HIV
• 11% of the participants reported having been tested for HIV; only one respondent reported that he/she was HIV-infected.

Exposure to interventions
• Only 12% of those surveyed had been exposed to the government’s mass-media HIV prevention campaign.
• All those who had been exposed to it had heard the radio component of the campaign.
• Nearly all of the youth surveyed knew the locations of the public health centre that served street youth; yet only 10% reported having utilized these services.
• Fear of being arrested or “sent home” was the most commonly cited reason why street youth did not utilize public health services.

10. Based on the community survey, what are the main factors that put street youth at risk of transmitting and acquiring HIV?

11. What interventions should be initiated based on these results?

Part 7: Epilogue
Based on the community survey, street youth were highly at risk of acquiring and transmitting HIV; HIV-related knowledge was low, many female street youth had performed sex work, had been raped or abused; many children had run away from home to escape abusive relationships or forced marriages. Injection drug use was low, although glue sniffing was common. Street youth did not utilize the public health centres, although
they knew they existed. Urgent targeted interventions were needed to increase safe sex practises and HIV-knowledge among street youth in Indam.

Based on these findings, the public health commissioner of Indam directs the HIV programme manager to initiate the following interventions:

1. design interventions specifically targeted at street youths
2. engage peers and NGO outreach workers to educate street youth about HIV/STI transmission and prevention
3. disseminate “best practices” to researchers and practitioners that have worked with street youth across different cities
4. work with local police and public health centres to establish times when street youth can visit public health centres without fear of being arrested or persecuted.
Overview

What this unit is about

This unit describes the background and special ethical considerations associated with conducting HIV surveillance among prisoner populations. It presents sampling options and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following is a reason for high HIV prevalence among prisoners?
   a. the over-representation of injection drug users among prisoners
   b. male-to-male sex during long periods of incarceration
   c. sexual relations between prison staff and prisoners
   d. high concentration of female sex workers in some prisons
   e. the sharing of needles for drug use in prison
   f. all of the above.

2. True or false? The most practical way to collect information on HIV prevalence in prisons is to use the mandatory screening programmes when prisoners are admitted.
   True  False

3. What is the simplest form of sampling that can be used if you are surveying prisoners who are already incarcerated?
   a. cluster sampling
   b. systematic random sampling
   c. snowball sampling
   d. time-location sampling.

4. True or false? High HIV prevalence among prisoners is a result of HIV infection both before and after entering the criminal justice system.
   True  False

5. Cohort studies provide the most exact measurements of incidence. However, they require the studied groups to be relatively stationary. Which of the following groups can be surveyed using cohort studies?
   a. street-based sex workers
   b. migrant workers
   c. prisoners
   d. refugees.

6. Because of their inability to give truly voluntary ___________, prisoners are a vulnerable population and need special ethical protection.
Introduction

What you will learn

By the end of this unit, you should be able to:

- understand the factors that contribute to the high prevalence of HIV among prisoners
- describe options for sampling and surveillance methods within prison populations
- describe the special ethical and legal considerations associated with surveillance in prisoner populations.

Background

Definition

Both male and female prisoners are at a higher risk for HIV infection.

For the purpose of this unit, we define a prisoner as any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial or sentencing. We use the term ‘prison’ broadly for any place of detention, including:

- police stations and jails
- centres for pre-trial and convicted prisoners
- centres for juvenile offenders
- centres for illegal immigrants and/or asylum seekers
- penal colonies
- mandatory re-education and rehabilitation centres (such as, those for drug users and sex workers).

Role of prisoners in the HIV epidemic

There are multiple and powerful factors contributing to the high prevalence of HIV in prisons. These include:

- the high concentration of arrested injection drug users (IDUs) and female sex workers (FSWs)
- consensual and non-consensual male-to-male sex, especially during long periods of incarceration
- syringe sharing with multiple injectors
- tattooing with unsafe needles (theoretically, although clearly a risk for HBV and HCV).

Furthermore, HIV prevention measures, such as the provision of condoms, are uncommon in prisons. Additionally, although injectable drugs, such as heroin, are available in some facilities (usually illegally), access to sterile injection equipment is limited.

Female prisoners are often incarcerated for sex work. For this reason, female prisoners often have a higher prevalence of HIV than male prisoners. Additionally, sexual relations between correctional staff and female prisoners may contribute to the high prevalence of HIV among female prisoners.
Prevalence of HIV among prisoners

HIV *sero-prevalence* levels have reached alarming levels in many prison populations in Asia and elsewhere in the world. The high HIV *prevalence* levels among prisoners are the result of both the high rates of HIV infection before persons enter prison and of high transmission rates within prisons. Transmission within prisons is likely the result of both high risk sex and the sharing of needles for injection drug use.

HIV transmission in prisons has been reported in many countries all over the world. However, the infrequency of these reports has led to the belief that HIV transmission rarely occurs among prisoners. A more likely explanation for the lack of these reports is that sero-prevalence studies are more difficult to conduct in prisons than in community settings, due to the difficulty of gaining access to prison populations.

In South-East Asia, the prevalence of HIV infection among prisoners varies by country and region. Consider the following examples:

- the HIV prevalence among prisoners in Indonesia is between 8.6% and 15.4% (2002)
- in 2003, HIV prevalence among prisoners in Jakarta, Indonesia was 17.65%\(^22\)
- in India, only one national study of HIV prevalence in prisons has been conducted, finding that 1.7% of all prisoners and 9.5% of female prisoners were HIV-infected
- in 2003, in Amristar Central Jail in India, 1.8% of male prisoners were found to be HIV-infected
- a 2001-2002 study conducted among a cross-section of prisoners in Bangkok, Thailand found an HIV prevalence of 25.4%\(^23\)
- in Thailand, India and Indonesia, the HIV prevalence in prisons is between two and 15 times greater than in the general population.

Figure 7.1 shows the prevalence of HIV among prisoners in Jakarta and West Java, Indonesia between 1999 and 2003.

**Figure 7.1**

*HIV prevalence in prisons in DKI Jakarta and West Java, Indonesia, 1999-2003*

As shown in the figure above, the prevalence of HIV among prisoners in Jakarta and West Java, Indonesia has fluctuated in recent years.

**Bridges and overlap with other populations**

Prisoners overlap with other high risk groups, including IDUs and FSWs. Due to the often-illegal nature of sex work and injecting drug, sex workers and IDUs may be concentrated in prisons and jails.

Also, upon release, prisoners may transmit HIV acquired during their incarceration to others, acting as a bridge between a high risk group and the general population. Failure to address the HIV transmission that occurs in prisons may undermine the success of HIV prevention programmes targeted at the general population.

**Conducting Formative Research**

The first step in planning HIV surveillance among prisoners is to gain an understanding of the population. You will need to gaining access to information on the prison system and obtaining authority or permission to conduct surveillance activities in prisons.

**Pre-surveillance assessment**

As access to prisoners is regulated, you must obtain permission from governmental authorities and/or prison administrators before conducting any surveillance activities.

Building key alliances with the community networks involved with prisoners, including the Ministry of Justice, prison administration and staff, and healthcare workers at prisons will help you design and conduct surveillance activities. Prison wardens are important gatekeepers who can provide access to prisoners.

Conducting a pre-surveillance assessment will help you identify key indicators to measure, the diversity of the sub-populations of prisoners and the infrastructure and procedures of prisons for surveillance purposes.

A pre-surveillance assessment will help you answer the following questions.

- What are the different types of facilities for incarceration in your country (for example, in city, sub-national and national-level jails, prisons and penitentiaries)?
- What are your country’s policies for testing prisoners for HIV at each level?
- Are HIV-infected prisoners kept at separate facilities?
- Are prisoners routinely screened on admission or at some other time during incarceration?
- Are surveys of currently incarcerated prisoners feasible and ethical?
- Are surveys of prisoners at the time of or immediately following release feasible?
- What are the relationships between the locations of prisons and the geographic areas from which prisoners originate?

Other organizations or individuals may also be helpful, such as:

- correctional officers
- human rights organisations
• prisoner rights organizations
• health or social services programmes for prisoners (if they exist).

**Selecting a Sampling Method**

Some countries have mandatory HIV testing for prisoners upon entry. If all persons entering prison undergo mandatory screening for HIV and the data are available to surveillance staff, sampling is not necessary.

In counties where mandatory HIV testing is not the norm, and for more complex surveys (such as surveys of prisoners who are currently incarcerated or surveys of prisoners at the time of release), some form of random sampling may be appropriate. One approach, for example, is to conduct a combined biological and behavioural survey on a consecutive or systematic sample of prisoners after their intake or at an initial health assessment. As with all surveillance activities, to be effective, surveillance must be regular and ongoing.

Sampling methods well-suited for use among prisoners include:

• **cluster sampling**
• **stratified random sampling**
• **systematic random sampling**.

Further information on these sampling methods can be found in Module 5: Surveillance of High risk Behaviours.

**Measures**

Ideally, sero-prevalence studies should be combined with behavioural surveillance. This will allow you to understand the behaviours that affect the prevalence of HIV, STIs and parenterally transmitted infections.

Surveys that specifically collect behavioural and biological information on HIV, STI and risk behaviours should be done with informed consent. The focus of the behavioural questions may vary, based on the gender of the prisoner population, as summarized in Table 7.1.

**Table 7.1**

**Focus of behavioural surveillance, by prisoner gender**

<table>
<thead>
<tr>
<th>Prisoner gender</th>
<th>Focus of surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>• injection drug use before and during incarceration</td>
</tr>
<tr>
<td></td>
<td>• male-to-male sex in prison</td>
</tr>
<tr>
<td></td>
<td>• heterosexual sex before incarceration</td>
</tr>
<tr>
<td>Female</td>
<td>• injection drug use before and during incarceration</td>
</tr>
<tr>
<td></td>
<td>• heterosexual sex before and during incarceration</td>
</tr>
</tbody>
</table>
Biological measures

Measuring HIV sero-prevalence among prisoners is an integral component of surveillance. The high sexual risk among prisoners also makes STI testing a useful and feasible indicator for surveillance (see Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups for a description of the available STI tests).

Because prisoners may have injected drugs prior to or during their incarceration, laboratory tests for hepatitis C virus (HCV) may be a useful biological measure.

Possible biological measures to include when conducting surveillance among prisoners are presented in Table 7.2.

Table 7.2

<table>
<thead>
<tr>
<th>Biological measure</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Syphilis</td>
<td>Syphilis testing is often the most convenient and efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.</td>
</tr>
<tr>
<td>Gonorrhoea</td>
<td>Accurate tests for gonorrhoea are expensive and usually require a urine specimen.</td>
</tr>
<tr>
<td>Chlamydia</td>
<td>Accurate tests for chlamydia are expensive and usually require a urine specimen.</td>
</tr>
<tr>
<td>Herpes simplex virus type 2</td>
<td>HSV-2 testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.</td>
</tr>
<tr>
<td>Hepatitis C virus (HCV)</td>
<td>HCV is a good marker for injection drug use.</td>
</tr>
</tbody>
</table>

In rare cases, urine specimens may also be tested for the presence of opiates and methamphetamines.

Behavioural measures

Behavioural measures should focus on sexual and parenteral risk behaviours. Because sex workers and injection drug users may be present in high numbers in jails and prisons, measures used in community-based surveys of these populations may be appropriate when conducting behavioural surveillance among prisoners. Further information on the behavioural measures used in surveys of sex workers and injection drug users are discussed in Unit 2: Sex Workers and Unit 3: Injection Drug Users.

Standard or basic indicators that assess HIV risk among prisoners include:

- having received HIV testing in the last 12 months and knowing the results (UNGASS)
- correctly identifying ways of preventing the sexual transmission of HIV and rejecting major misconceptions about HIV (UNGASS)
• correctly identifying condom use as means of protection against HIV infection (MEASURE)
• having had sex with a non-marital, non-cohabiting partner in the last 12 months, of all respondents reporting sexual activity in the last 12 months
• having had sex with a sex worker in the last 12 months (MEASURE)
• engaging in commercial sex work in the past 12 months
• engaging in anal sex with more than one male partner in the last 12 months, of all men surveyed who have sex with a male partner
• engaging in injection drug use in the past 12 months
• sharing needles, syringes or other injecting equipment the last time they injected drugs.

These basic indicators may be supplemented with local measures of particular importance in your area (as determined by your formative research phase). These additional indicators may include:

• reason for incarceration
• drug use (injection and non-injection)
• marital status
• occupation before incarceration
• term of sentence (years or months)
• history of attending drug abuse treatment clinic.

Reference to indicators
Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

• United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
• Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among FSWs. These guidelines are available online at: http://www.fhi.org.
• The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviours relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.
Estimating incidence
Because prisoners are a relatively stationary group, calculating the incidence of HIV in prisons may be possible. Cohort studies provide the most exact measurements of incidence, but are only possible if correctional staffs allow public health workers access to prisoners for HIV testing during their incarceration. A few studies have surveyed prisoners as they are released and calculated the incidence of HIV in prisons. Additionally, recidivists (persons who are repeatedly arrested for criminal behaviour) form dynamic cohorts for HIV incidence studies. Ideally, incidence studies should be combined with behavioural surveillance to aid in understanding the specific risk behaviours contributing to HIV incidence.

Tuberculosis testing
The prevalence of tuberculosis (TB) is up to 100 times higher in prisons than in the general population. HIV/TB co-infected persons are more likely to progress to active TB disease than are persons infected with TB alone. Additionally, studies have shown that infection with TB enhances replication of HIV and may accelerate the progression of HIV infection to AIDS.

If you suspect high rates of HIV/TB co-infection among prisoners in your country, you should consider entrance-point tuberculin skin testing of prisoners and periodic testing of prisoners and prison staff. This testing is done for clinical purposes in order to identify and treat individuals with latent and active TB and to control TB transmission in prisons. However, results from these surveys can be used for TB prevalence estimates.

Special Ethical Considerations
Conducting HIV surveillance among prisoners raises a number of ethical and legal issues.

Special protections for persons who are the subjects of biomedical and behavioural research are listed in the Helsinki Declaration, issued by the World Medical Association. This document is available at www.wma.net/e/policy/b3.htm. The Helsinki Declaration states that:

*Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.*

As prisoners are unable to give true voluntary and informed consent, they are a vulnerable population and need special ethical protection.

Because of their unique situation, special efforts are required to ensure the privacy, rights and safety of prisoners participating in HIV testing, the provision of adequate care if they are found to be infected and the safety and security of the staff conducting the study. Most prevalence studies require that the investigators alert the potential study participants to the possible consequences, legal or otherwise, of admitting drug use or
having sex in prison. Furthermore, some institutional review boards require the input of a prisoner advocate.

**Informed consent**

When conducting HIV testing among prisoners, you must determine whether the testing is being done for clinical reasons or for surveillance reasons. Mandatory testing of all entering prisoners is performed for clinical reasons. Local laws and regulations cover how this type of testing is to be done. Informed consent is required when conducting prevalence studies and other activities involving the non-routine collection of data. All data-collection activities other than mandatory testing usually require informed consent.

In every area of life, prisoners bargain for privileges and better conditions. Because of their incarceration, prisoners are under unique constraints that affect their ability to make a truly voluntary and un-coerced decision about whether to participate as research subjects. For this reason, many countries have prohibited all research involving prisoners. In settings where research involving prisoners is allowed, it is important to take special precautions when obtaining informed consent from prisoners.

**Assuring confidentiality**

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. The confidentiality of medical information in the prison setting is virtually impossible to maintain.

Prisoners asked to participate in surveillance activities should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimize these threats. Explaining these issues to them is part of the informed consent process.

Steps you can take to minimize threats to confidentiality may include:

- conducting interviews with prisoners in private settings
- keeping the names of the prisoners separate from the data collected about them
- limiting access to any identifying information to authorized study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Although it is uncommon in South-East Asia, some correctional facilities isolate HIV-infected prisoners from the general prison populations. In settings where HIV-infected prisoners are kept in separate facilities or areas than uninfected prisoners, ensuring confidentiality is not possible.

If the correction facility has isolation for HIV-infected prisoners, then:

- prisoners must be informed about the treatment options available in the facility
- prisoners must be made aware of who has access to their medical records
- prisoners’ rights must be evaluated and monitored by institutional review boards (IRBs).
When confidentiality cannot be guaranteed and the potential harm of being identified as HIV-infected is severe, *unlinking anonymous testing* (UAT) may be a more desirable option. By design, UAT precludes the disclosure of participants' names or other identifying information. Module 3: HIV Sero-Surveillance covers the methods of UAT in detail.

**Summary**

Multiple factors contribute to the high prevalence of HIV in prisons, including the high rates of HIV infection before entering prison and HIV transmission within prisons. Because sex work and injection drug use are illegal in many countries, high numbers of these groups may be present in prisons.

Prisoners are considered a vulnerable population due to their possible inability to give true informed consent. The sampling method best suited for sampling prisoners in your area will depend largely on your country's policies regarding mandatory HIV testing. Behavioural and biological measures to include when conducting HIV surveillance among prisoners should focus on the markers of sexual and injecting risk behaviours.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to.

**Small group discussion**

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of prisoners?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods have been used to sample prisoners?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of prisoners?
5. In the past five years, has the prevalence of HIV among prisoners increased, decreased or remained about the same?

**Apply what you have learned/case study**

**Biological and behavioural surveillance of prisoners at Millao Central Prison, Malanka**

**Part 1: Mandatory HIV testing**

Millao, a city with a total population of 12 million, is the capital of Malanka, an island nation in South-East Asia. The HIV surveillance team of the National AIDS Control Programme (NACP) recently received a report from an NGO that found previous incarceration to be the strongest predictor of HIV infection among males in Millao. The NGO is concerned that prisoners released are a potential source of HIV infection to the community.
The surveillance team, in collaboration with the Ministry of Justice, decides to conduct a sero-prevalence assessment of prisoners at Millao Central Prison. Millao Central Prison is the largest adult male correctional facility in Malanka and houses prisoners from all regions of Malanka. It is estimated that approximately 50% of all prisoners are incarcerated on drug-related offences. The minimum stay for the prison is 12 months; persons sentenced to less time are held in local jails.

Recently, the prison began HIV, STI, hepatitis C and drug testing of all prisoners upon arrival. A routine physical test is performed and blood and urine samples are collected from all newly arriving prisoners. Blood samples are tested for HIV, hepatitis C and syphilis, and urine samples are tested for chlamydia, opiates and methamphetamines.

Because all new prisoners are screened for HIV, STIs and hepatitis C at intake, the HIV surveillance team decides to analyse data from all prisoners arriving at the prison between January and June 2006.

A total of 700 adult male prisoners are included in the sample and produce the following biological results:

- 77 (11%) prisoners test positive for chlamydia.
- 35 (5%) are HIV infected.
- 21 (3%) are reactive to syphilis
- 189 (27%) are reactive to HSV-2
- 84 (12%) are reactive to hepatitis C
- 385 (55%) test positive for opiates
- 70 (10%) test positive for methamphetamines.

Biological data suggest that persons entering prison were engaged in risky sexual and injecting behaviours prior to their incarceration. To determine whether this is true, the HIV surveillance team decides to investigate the details of sexual and injecting risk behaviour of these prisoners prior to their incarceration.

1. What are the possible approaches to conducting a behavioural survey among prisoners at Millao Central Prison?
2. What are some of the ethical issues you must consider prior to conducting a behavioural survey in a prison population?
3. What behavioural variables should be collected?

Part 2: Collecting behavioural data
After carefully considering the pros and cons of various sampling approaches, the HIV surveillance team decides to conduct a detailed behavioural survey to assess the 700 prisoners’ pre-incarceration sexual and injecting behaviour. Although blood and urine are routinely collected at intake, behavioural data are not similarly collected. In addition, they wish to do follow-up HIV testing to measure HIV incidence in the prison.

Informed consent is required before prisoners can participate in this study. Some of the ethical issues facing the HIV surveillance team are:
• the inability of prisoners to give true informed consent
• issues surrounding confidentiality
• issues around giving incentives for participating.

The HIV surveillance team approach the 700 male prisoners who arrived at Millao Central Prison between January and April 2006 (35 of whom tested positive for HIV) and explain the purpose of the behavioural survey. After receiving assurance that confidentiality will be maintained, 525 prisoners (25 of whom are HIV infected and 500 of whom are HIV uninfected) provide informed consent and agree to participate in the survey. The HIV surveillance team administers a baseline questionnaire that includes the following variables:

• socio-demographic information-
  • age
  • marital status
  • occupation prior to incarceration
  • monthly income
  • residence prior to incarceration.

• arrest/incarceration information-
  • type of offence (drug-related or not)
  • duration of sentence
  • past history of incarceration.

• injecting behaviour-
  • which drugs
  • sharing of injection equipment.

• sexual behaviour-
  • sex with steady and casual partners
  • sex with sex workers
  • sex with other men
  • condom use.

Researchers find that the behavioural data support the biological data.

• Nearly 50% of respondents are incarcerated on drug-related charges.
• 38% of respondents injected prior to incarceration.
• Heroin was the most commonly injected drug.
• 22% reported having shared injection equipment (such as needles, syringes, etc) in the month prior to their incarceration.
• Most respondents (82%) reported having visited female sex workers in the year prior to their incarceration.
• 95% reported unprotected sex in the past year.
• 6% reported sex with men before incarceration.
• 80% of the HIV positive inmates have a history of previous incarceration compared to 30% of HIV-negative inmates.
Although the survey data suggest that many inmates could have been infected during previous incarcerations, risk behaviours outside of prison are also high. The HIV surveillance team decides to assess the incidence of HIV inside Millao Central Prison.

4. Describe how the HIV surveillance team could measure HIV incidence among Millao Central Prison inmates.

5. What behaviours could explain the increase in HIV among the prisoners?

Part 3: Estimating incidence

To determine the incidence of HIV during incarceration in the Millao Central Prison and the behaviours related to infection, the HIV surveillance team follows the 500 HIV-uninfected prisoners and the 25 HIV-infected prisoners for 12 months. After 12 months, the 500 uninfected prisoners are re-tested for HIV and their in-prison risk behaviours are assessed. The in-prison risk behaviours of the 25 HIV-infected prisoners are also assessed.

Behavioural data from follow-up surveys produce the following results.

Of the 25 HIV infected prisoners:

- 72% (18/25) inject heroin while in prison, all 18 report sharing needles and other injection equipment.
- 28% (5/18) of the men who inject heroin in prison are also engaged in unprotected male-male sex while in prison.

Of the 500 HIV-uninfected prisoners:

- 15% (75/500) inject heroin while in prison, all of whom report sharing needles and other injection equipment due to the unavailability of sterile injecting equipment
- 5% (25/500) inject heroin, share injecting equipment and engage in unprotected male-male sex while in prison
- 5% (25/500) do not inject heroin but do engage in unprotected male-male sex while in prison
- 4% (20/500) sero-converted in the 12-month period-
  - 18 reported injecting while in prison (HIV incidence among injectors 24% per year)
  - two reported male-male sex but no drug injecting (HIV incidence among those reporting male-male sex but no drug injection 8% per year).

The HIV surveillance team concludes that many prisoners who are uninfected when they enter Millao Central prison are contracting the virus while incarcerated through sharing of injection equipment with HIV infected injectors and, to a lesser extent, through unprotected male-male sex.

6. What interventions should be initiated based on these results?
Part 4: Epilogue

Based on these findings, the National AIDS Control Programme directs the Ministry of Justice to increase the funding for prison-based drug treatment programmes and HIV interventions. The NACP directs the Ministry of Justice to consider the following options and consider the feasibility of implementing them:

- to establish drug treatment and methadone programmes for IDU prisoners
- to provide prison-based HIV education
- to initiate anti-retroviral therapy for prisoners with HIV clinical stages 3 and 4.
Overview

What this unit is about
This unit describes the background and special considerations associated with conducting behavioural and HIV sero-surveillance among uniformed personnel, such as police and members of the military. It explains sampling and surveillance methods and recommends specific surveillance methods for this group.

Warm-up questions
1. List three reasons why uniformed personnel are at increased risk of HIV infection.
   a.
   b.
   c.

2. Access to uniformed personnel is usually restricted. Military officials, such as senior commanders and medical officers, are important ___________ who can provide access to uniformed personnel.

3. ___________ is required when conducting HIV prevalence studies and other activities involving the non-routine collection of data.

4. List two methods that may be used for sampling uniformed personnel.
   a.
   b.

Introduction

What you will learn
By the end of this unit, you should be able to:

- describe the special considerations associated with surveillance of uniformed personnel
- describe options for sampling and surveillance methods among uniformed personnel.

Background

Definitions
For the purpose of this unit, uniformed personnel include members of the armed services, police forces, border guards, guards at correctional facilities and other law enforcement officers.

Role of uniformed personnel in the HIV epidemic
Throughout the world, uniformed personnel are often at especially high risk of contracting HIV and AIDS. In many countries, HIV prevalence is much higher among uniformed personnel than it is in the general populations.
Uniformed personnel are at increased risk of acquiring HIV because they are:

- usually young and sexually active
- often away from home
- susceptible to peer pressure
- inclined to feel invincible and to take risks
- surrounded by opportunities for casual sex
- in possession of disposable income or have access to material resources
- frequently the clients of female sex workers
- high prevalence of STIs.

Furthermore, deployment to conflict areas increases their chances of acquiring HIV.

This is because of:

- the possibility of infection through exposure to traumatic injuries requiring transfusion of HIV-infected blood
- the frequent absence of adequate HIV testing and monitoring equipment in conflict areas.

It has been well documented that the presence of STIs increases the risk of transmitting and acquiring HIV infection. Peacetime STI infection rates in military personnel are two to five times higher than in the civilian population.

**HIV prevalence among uniformed personnel**

The prevalence of HIV among military recruits in South-East Asia varies by country and region. As access to uniformed personnel is usually restricted, data on the prevalence of HIV among this population is scarce in many countries.

Consider the following examples:

- in Myanmar, approximately 1.6% of new military recruits tested positive for HIV in early 2004
- in Thailand, HIV prevalence among army conscripts decreased from 4% in 1993 to 1.9% in 1998
- according to UNAIDS, in Cambodia, 12 to 17% of the armed forces were estimated to be HIV-infected in 1999, compared with 3.7% among the general population.
As shown in figure 8.1, the HIV prevalence among Royal Thai Army conscripts has significantly decreased between 1991 and 2002.

Figure 8.1. HIV prevalence among Royal Thai Army conscripts, classified by their longest residency during the two years prior to recruitment.

Role of Uniformed Personnel in Surveillance

Military recruits

Young males who are conscripted or volunteer for military service may, in some countries, be considered relatively representative of other young males, especially if military service is mandatory. Biological and behavioural data collected from military personnel at recruitment can be used to approximate a broad cross-section of the general young male population for surveillance purposes.

Sero-prevalence data from military recruits can be used to gain an understanding of the epidemic in different geographic areas. When prevalence data are linked to recruits’ area of residence, data may be analysed using geographic information systems (GIS) to gain information about trends in the epidemic in different geographic areas.

Incidence estimates

Because of their young age, the prevalence of HIV among new male recruits may serve as a proxy for HIV incidence among similarly aged men in the general population.

Repeated annual testing of uniformed personnel can provide information on the HIV incidence among uniformed personnel during their period of service.

Bridges with other populations

Uniformed personnel *bridge* with many other high risk groups. They are often the clients of *female sex workers*. Furthermore, some groups of uniformed personnel may be more likely to have sexual relations with female prisoners, refugees and other displaced persons, who themselves may be at high risk.

Additionally, many countries contribute personnel to United Nations peacekeeping operations. These operations often occur in areas of high HIV prevalence. Uniformed personnel infected with HIV while serving in UN peacekeeping operations in areas of high HIV prevalence may act as a bridge, bringing HIV back to their home countries.

Finally, many military personnel are married or marry shortly after their discharge from service. The wives of military and former military personnel may also be at high risk of HIV infection.

Conducting Formative Research

The policies governing the testing of uniformed personnel vary by country. Whereas some countries, such as Thailand, have mandatory HIV testing of military recruits, others, such as India, do not.

The first step in planning HIV surveillance in uniformed personnel is to identify the various points of access, locations of uniformed personnel, barracks and health clinics used by military and police and other places where surveillance can be conducted.

Listed in Table 8.1 below are recommendations for proposed surveillance methods for military, police and law enforcement personnel.

Table 8.1

**Recommendations for proposed surveillance methods, uniformed personnel**

1. Form a collaborative group with the command structure of the organisation which you are targeting. Build key alliances with command structure for uniformed personnel, including command staff and medical officers at clinics caring for these persons.
2. Conduct a situation analysis.
3. Conduct formative research to identify the groups of members of uniformed services at highest risk of HIV infection.
4. Understand the definition of uniformed personnel and what groups might be included in your country.
5. Assess the infrastructure of military and law enforcement authorities for surveillance purposes.
6. Gain collaboration of existing personnel delivering public health interventions, if applicable.
7. Design surveillance approach.
8. Collect HIV sero-prevalence data, behavioural data and STI data.
9. With the collaboration of the uniformed service analyse and disseminate data.
Pre-surveillance assessment

Conducting a pre-surveillance assessment will help you identify key indicators to measure the diversity of the sub-populations of uniformed personnel and the infrastructure available for surveillance purposes.

A pre-surveillance assessment will help answer the following questions.

- What are the different types of uniformed personnel in your country (for example, military personnel and police officers)?
- Are there HIV/AIDS policies in place for the uniformed service(s)?
- What are your country’s policies for recruiting uniformed personnel?
- Is military service mandatory or voluntary?
- Are uniformed personnel routinely screened for HIV at recruitment or at any other time during their service?
- Are surveys of uniformed personnel feasible and ethical?
- Are surveys of uniformed personnel at time of discharge feasible?

Building key alliances

Access to uniformed personnel is usually restricted. Senior commanders and medical officers are important gatekeepers who can provide access to uniformed personnel. Prior to beginning surveillance activities, the surveillance team will need to form alliances at the highest levels, with the Ministry of Health and the Ministry of Defence for armed services, or with the Ministries of Interior or Justice for police. It will also be helpful to enlist the support of those operating the current medical care and public health intervention programmes that exist for these populations. This will be helpful in setting up the infrastructure for the surveillance system.

Selecting a Sampling Method

Many countries have routine physical examinations for uniformed personnel. As part of these examinations, HIV testing may be required. This is the ideal situation and allows for non-biased estimates of HIV prevalence.

In situations where no routine testing exists, however, surveys can be done as repeated cross-sectional studies in a random sample of personnel. Another option (though a less desirable one) is to conduct surveys of persons seeking treatment for STIs at military clinics.

When routine testing is done, prevalence surveys can be combined with behavioural survey methods to produce a more complete understanding of HIV, STIs and risk behaviours in these populations. Sampling is desirable because it may be logistically difficult for HIV surveillance programmes to reach all uniformed personnel.

Uniformed personnel may or may not be tested for HIV on a regular basis. Table 8.2 summarizes what you should do in each case.
Table 8.2
Recommended type of sampling, depending on whether uniformed personnel are routinely tested for HIV

<table>
<thead>
<tr>
<th>Routine testing</th>
<th>Sampling options</th>
<th>More information</th>
</tr>
</thead>
</table>
| Yes             | • Use all the data available.  
• Choose a survey period of a few months. | • The advantage of choosing a shorter survey period is that you may be able to ask additional behavioural questions. |
| No              | • Conduct a survey of a random sample.  
• Try to access persons through medical clinics. | • Because lists of personnel likely exist, random sampling methods can be quite straightforward:  
• ask individual service members to participate (with their commanders’ permission)  
• surveys can include biological and behavioural variables  
• if repeated regularly, surveys can provide good monitoring systems for HIV, STI and behavioural risks  
• An alternative is clinic-based surveys:  
• survey all individuals seeking care, or just one category of sub-set (for example, those who have STI symptoms)  
• people who are sick are more likely to seek care, so this will likely lead to overestimation of the true prevalence. |

When uniformed personnel are not routinely tested for HIV, the following random sampling methods may be appropriate.

*Systematic sampling* - Every nth person is sampled from a sampling frame after a random start. Systematic sampling is often used instead of simple random sampling when the sampling list is long or the desired sample size is large, or when access is to a clinic. Random sampling may be difficult due to a lack of computerized personnel lists and due to security concerns.

*Cluster sampling* - When it is difficult or impossible to make a list/sampling frame of each individual in the target population, you can develop a sampling frame of some larger unit. These are called clusters or primary sampling units. You can then sample in stages by first sampling clusters and then sampling people within the clusters. Cluster sampling is the most common method of sampling in surveys. It has the advantage that the sampling frame is not required to be a list of every person in the target population. Instead, a sampling frame of clusters is required. A cluster is any aggregate of the population of interest (for example, recruitment centres, military units, military bases or camps). Once the clusters are selected, you are required only to list people in the...
selected clusters. All members of the target population still have a chance of being sampled (a non-zero probability) as long as all the clusters within which the target population is found are included in the list of clusters.

**Stratified sampling** - Stratification is the classification of a survey population into sub-groups or strata on the basis of selected characteristics (such as members of the army, navy, police force or air force). Stratified sampling is the selection of separate (that is, independent) samples from each stratum.

**Measures**

Both behavioural and biological information on HIV, STI and risk behaviours can be collected in a variety of ways with a focus on sexual transmission and risk. However, it is important to note that there may not be enough time, ability or organisational interest to conduct behavioural surveillance in these settings. Ideally, surveillance among uniformed personnel should be conducted on a regular basis, every year.

**Biological measures**

Measuring HIV sero-prevalence among uniformed personnel is an integral component of surveillance. The high sexual risk among uniformed personnel also makes STI testing a useful and feasible indicator for surveillance (see Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups for a description of the available STI tests).

Possible biological measures to include in addition to HIV testing when conducting surveillance among prisoners are presented in Table 8.3.

**Table 8.3**

**Possible biological measures**

<table>
<thead>
<tr>
<th>Biological measure</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Syphilis</td>
<td>Syphilis testing is often the most convenient and efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.</td>
</tr>
<tr>
<td>Gonorrhoea</td>
<td>Accurate tests for gonorrhoea are expensive and require a urine specimen.</td>
</tr>
<tr>
<td>Chlamydia</td>
<td>Accurate tests for chlamydia are expensive and require a urine specimen.</td>
</tr>
<tr>
<td>Herpes simplex virus type 2</td>
<td>HSV-2 testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.</td>
</tr>
</tbody>
</table>

**Behavioural measures**

Measuring changes in sexual behaviour among uniformed personnel helps explain trends in HIV and STI prevalence data. Among uniformed personnel, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted toward promoting safe behaviour in this group.
Several international organisations have sought to standardize a set of “core” or basic indicators of HIV risk among uniformed personnel. These include:

- percent of respondents who received HIV testing in the last 12 months and who know the results (UNGASS)
- percent of respondents who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV (UNGASS)
- percent of respondents who have had sex with a non-marital, non-cohabiting partner in the last 12 months (MEASURE), and
  - the number of respondents who report using a condom the last time they had sex with a non-marital, non-cohabiting partner.
- percent of respondents reporting they had sex with a sex worker in the last 12 months (MEASURE), and
  - the number of male respondents reporting condom use the last time they had sex with a sex worker
- percent of respondents who have had anal sex with more than one male partner in the last 12 months (MEASURE), and
  - the percent of men or their partners who used a condom at last anal sex with a male partner
- percent of respondents with a self-reported STI (urethral discharge).

These basic indicators may be supplemented with local measures of particular importance in your area (as determined by your formative research phase). These additional indicators may include:

- perceptions of self and/or partner risk
- type of partner(s) (including sex workers)
- alcohol and drug use
- migration, mobility
- STI treatment-seeking
- marital status
- history of deployment to conflict or refugee areas.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the following websites:

- United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.
Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises or situations). The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

**Special Ethical Considerations**

**Counselling and testing**
Providing HIV counselling and testing, and referrals to care/treatment for those HIV infected should be considered where feasible. Doing this provides many benefits over just doing surveillance. Uniformed personnel can be trained to provide counselling and testing—skills which can be integrated into regular service provision once the survey is over. Individuals can be offered their HIV test results, giving them the opportunity to present for care. Choice and confidentiality are of the utmost importance. Survey participants should be always given the opportunity to decline any or all participation in the survey or knowing their HIV test results.

**Informed consent**
When conducting HIV testing among uniformed personnel, you must determine whether the testing is being done for clinical reasons or for surveillance reasons. Mandatory testing of all new recruits is performed for clinical reasons. Local laws and regulations cover how this type of testing is to be done. However, there is no reason not to use data obtained from mandatory screening for estimating the prevalence of HIV among new recruits. Informed consent is required when conducting prevalence studies and other activities involving the non-routine collection of data. All data-collection activities other than mandatory or clinical testing usually require informed consent.

Uniformed personnel are under unique constraints because of the hierarchical structure of uniformed services. The subordinate position of some uniformed personnel may affect their ability to make a truly voluntary and un-coerced decision whether or not to participate as research subjects. It is important to take special precautions when obtaining informed consent from uniformed personnel.

**Assuring confidentiality**
*Confidentiality* protects subjects from the negative consequences that may arise from participating in a study or survey. The confidentiality of medical information of uniformed personnel may be difficult to maintain.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimize them. Explaining these issues to them is part of the informed consent process.
Steps that you can take to minimize threats to confidentiality may include:

- conducting interviews with uniformed personnel in private settings
- keeping names of persons separate from the data collected about them
- limiting access to any identifying information to authorized study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Some countries exclude HIV infected persons from serving in the military and/or police force. In settings where HIV infected persons are excluded from service, ensuring confidentiality may not be possible.

When confidentiality cannot be guaranteed, the potential harm of being identified as HIV-infected is severe and blood specimens are routinely collected for other purposes, such as syphilis screening, unlinked anonymous testing (UAT) may be desired. By design, UAT precludes the disclosure of participants’ names or other identifying information. Module 3: HIV Surveillance covers the methods of UAT in detail.

**Summary**

Throughout the world, uniformed personnel are among the most susceptible populations to HIV. They are at high risk of infection because they are often away from home and surrounded by opportunities for casual sex, often with female sex workers. Where military service is mandatory, young male recruits may be considered relatively representative of other young males. Many countries have routine physical examinations for uniformed personnel, including routine HIV testing. Although this information is collected for clinical purposes, collecting this information for surveillance purposes allows for a non-biased estimate of HIV prevalence. It should be noted that uniformed personnel are under unique constraints because of the hierarchical structure of uniformed services. It is important to take special precautions when obtaining informed consent from uniformed personnel.

**Exercises**

**Warm-up review**

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

**Small group discussion**

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of prisoners?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods have been used to sample prisoners?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of prisoners?
5. In the past five years, has the prevalence of HIV among prisoners increased, decreased or remained about the same?
Apply what you have learned/case study

HIV Surveillance in Serosia’s Armed Forces

Part 1: Collecting information to plan surveillance activities

The current HIV prevalence in the general populations of Serosia is one percent. Serosia does not currently test military recruits for HIV, nor does it periodically test servicemen. As a pilot initiative, an Army base in the port city of Bantak performed unlinked anonymous HIV testing on leftover sero-specimens collected between May and December of last year and published the results. Results of this pilot programme found an HIV prevalence of 5.5% among the 214 military personnel included in the sample.

The Defence Minister considers that the containment of HIV/AIDS is a top priority in combat preparation, and is alarmed at the high rates of HIV found in last year’s survey.

The Minister feels that it is crucial to have knowledge about the health status of the military personnel, not only to avoid a sudden incapacity in terms of military readiness due to AIDS, but also to allow the evaluation of the troops’ capacity to help each other in cases of blood transfusions necessary in surgery procedures imposed by the theatre of operations and/or other catastrophes. The Minister calls on the Director of Epidemiology and Surveillance for the Ministry of National Defence to design a sero-behavioural survey to gain an understanding of the epidemiological profile of HIV prevalence in the Serosian military population. It is the Minister’s hope that results from this survey will facilitate policy making, the creation of recruit entry criteria, medical-services planning, and HIV prevention training activities.

5. What information is required for planning the survey?

6. How will the epidemiology and surveillance team obtain this information?

Part 2: Choosing a sampling approach

Prior to conducting the proposed surveillance activity, the surveillance team must conduct formative research to catalogue the various points of access, locations of uniformed personnel, and health facilities used by military personnel. The surveillance team conducts a pre-surveillance assessment to assess the infrastructure available for surveillance purposes and to determine if military personnel are routinely tested for HIV.

Because the surveillance team is conducting this surveillance activity on behalf of the Ministry of National Defence, they have access to this usually restricted-access population. Prior to beginning surveillance activities, the surveillance team enlists the support of the directors of the various military medical centres.

The surveillance team decides to include 600 male military personnel aged 18 years and above. There are over 50 military installations in Serosia. The country is divided into three military regions:

- Northern Regions: 10 bases
- Central Regions: 25 bases
• Southern Region: 15 bases
• Each military base houses one division of 5,000 men.

The team decides that it is not necessary to include personnel from all installations, but that it is necessary to have the sample reflect the relative military strength of each region.

3. What sampling approaches are appropriate for obtaining a representative sample of military personnel?

Part 3: Collecting biological and behavioural data
A variety of sampling approaches are appropriate for sampling military personnel in Serosia. As military personnel are not routinely tested for HIV, universal testing using unlinked anonymous testing is not possible. However, a cross-sectional survey can be conducted in a random sample of personnel.

The surveillance team opts for a two-stage cluster sampling design. They stratify the bases by region and select every fifth base. Because lists of the military personnel associated with each base are available, the team then randomly selects 60 respondents from each of the 10 selected military bases.

Northern District - 120 participants
Tapang - Air Base for the Northern District ............... (60)
Idupur - Army Base for the Northern District ............ (60)

Central District - 300 participants
Indam - National Army Training Centre .................... (60)
Indam - National Air Force Training Centre ............. (60)
Indam - National Special Forces Training Centre ...... (60)
Villipur - Air Base for the Central District ............... (60)
Villipur - Army Base for the Central District ............ (60)

Southern District - 180 participants
Bantak - Bantak Naval Centre .............................. (60)
Bantak - Army Base for the Southern District .......... (60)
Bantak - Air Base for the Southern District ............. (60)

4. What biological and behavioural information should the epidemiology and surveillance team collect?

5. What are some of the ethical considerations for this surveillance activity?

Part 4: Analysing and disseminating data
The surveillance team decide to collect information on the social and demographic characteristics of the population to be studied and assess the sample's HIV related risk behaviour and their knowledge, attitudes and practices regarding HIV/AIDS. To determine the prevalence of HIV and syphilis in the military population, the surveillance team decide to collect blood samples and provide confidential syphilis testing and HIV rapid testing, and provide referrals to treatment to those who are found to be infected.
With input from behavioural scientists, statisticians, and epidemiologists, MNDS and WHO-SEARO, the surveillance team develop a questionnaire based on Serosia’s Demographic Health Survey (DHS). The final version of the questionnaire was pre-tested. Feedback and comments were also obtained from counsellors conducting the survey.

The surveillance team discuss the many ethical issues related to conducting research among military personnel. Because this surveillance activity involves the non-routine collection of data, informed consent must be obtained from all persons from whom data would be collected. Recognising that military personnel may be under unique constraints because of the hierarchical structure of uniformed services, the HIV surveillance team take special precautions when obtaining informed consent from uniformed personnel. Counsellors from the surveillance team explain the purpose and procedures of the survey, as well as the HIV testing procedures to the potential participants in group settings. All participants are told that they can choose to participate or not without any negative consequences. After the group presentation, each potential participant is briefed again in private and questions are addressed by the counsellor. At this time, the volunteer is given a copy of the consent form to review, fill out and sign. All participants are given a copy of the written consent form to keep for future reference.

Counsellors administer face-to-face interviews in private, using a standard, structured questionnaire conducted with consenting male military personnel. Blood samples are taken by finger-prick for linked, confidential HIV rapid testing, and from dry blood spots (DBS). Results are given to those who choose to receive them and referrals to care are made where indicated.

This surveillance activity produced the following results.

Social and Demographic information:
- A total of 600 male military personnel from 10 military installations were included in this survey
- Median age of respondents was 26 years
- The majority of respondents were married (56%, 336/600).

HIV Prevalence:
- Of the 600 samples tested, 18 (3%) appeared positive for HIV-1 antibodies
- The prevalence of HIV was significantly higher among personnel from the three military installations in the port city of Bantak in the Southern Province (12/180, 6.7%), compared to personnel from the Northern and Central Provinces, (1.4%)
- Prevalence of syphilis antibodies was 7% (42/600), increasing by age and correlated to HIV-1 positive serology (p=0.001) and with 24% (10/42) active cases.

HIV-related risk behaviour:
- 42% (252/600) of respondents reporting that they had sex with a sex worker in the last 12 months
- Nearly all interactions with sex workers occurred at brothels located near the military bases
• 62% (156/252) of the respondents who reported having sex with a sex worker reported using a condom the last time they had sex with a sex worker
• No injection drug use was reported.

**HIV-related knowledge and attitudes:**

• 32% (192/600) of respondents reported having been previously tested for HIV testing, although only 60% (115/192) of those previously tested reported knowing the test result
• Nearly all (88%, 528/600) respondents correctly identified consistent condom use as a way of preventing the sexual transmission of HIV.

**6. What interventions/programmes should be developed based on these results?**

**Part 5: Epilogue**

The results of this surveillance activity confirm the results of last year’s study that found HIV prevalence among military personnel to be significantly higher than that of the general population. The majority of the military personnel included in the survey were married, and many reported extramarital sex with a sex worker within the previous 12 months. Although most respondents were correctly able to identify condom use as a method of preventing the transmission of HIV, many respondents did not use a condom the last time they had sex with a sex worker.

The surveillance team present the following recommendations to the Defence Minister:

1. provide more confidential voluntary counselling and testing at military health centres
2. provide treatment and care for personnel found to be HIV-infected
3. work with brothels near military bases to establish 100% condom programmes.
Notes
Module 6: Surveillance of Populations at High Risk for HIV Transmission

• Sometimes referred to as 'at-risk groups' or 'most at-risk populations,' members of high risk groups are at increased risk of passing HIV on to others, or to contracting HIV from others.

• In Asia, populations at increased risk include the following: sex workers (SWs), injection drug users (IDUs), men who have sex with men (MSM), mobile populations, out-of-school youth, prisoners, and uniformed personnel.

• Populations at increased risk play a central role in the spread of HIV infection. At the beginning of an HIV epidemic, the first infections appear in these groups, because they have higher risk behaviours. These behaviours include:
  • having sex without using a condom (unprotected sex) with multiple partners and/or having a high number of new partners, and
  • injecting drugs with shared needles.

• Understanding the spread of HIV in high risk groups is essential. Surveillance data can contribute to advocacy for improved care and treatment for most at-risk populations and to evaluate the success of HIV and STI control programmes.

• The first step in planning HIV surveillance in high risk populations is to gain an understanding of the populations. Pre-surveillance assessment activities are conducted to identify key indicators to measure, the diversity of the sub-populations and the geographic areas and venues where high risk populations may be found in high numbers.

• There are several conventional probability sampling methods that can be used for sampling most at-risk populations. As many populations at increased risk are hard-to-reach populations, respondent-driven sampling (RDS) and time-location sampling (TLS) are ideally suited for surveys of high risk groups.

• RDS combines the methods of snowball sampling with a mathematical model in a way that weighs the sample to compensate for the non-random way it was collected. It is an experimental sampling method that does not require a sampling frame. It is especially good for finding hard-to-reach groups, which are small compared to the general population.

• TLS, which is also called time-venue, time-space or venue-day-time sampling, combines the methods of targeted sampling and cluster sampling in a way that produces a probability sample. TLS requires extensive ethnographic mapping to prepare a sampling frame that captures the variability in the time and location of behaviours and the number of group members.

• The selection of indicators for surveying high risk groups should be determined by the country’s data needs. The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area.

• Behavioural surveillance indicators should measure behaviours that are key to the spread of HIV and that are targeted by HIV prevention programmes, including:
  • behaviours that increase the chance that an uninfected person will come into contact with an infected person, and
  • behaviours that increase the chance that HIV will be transmitted if contact with an HIV infected person occurs.

• There are a number of choices to make about which biological measures to use in surveys of high risk groups. Choices include HIV, which is almost always
included, and other infections that are markers of behaviours associated with HIV transmission.

- Rates of acute STIs are often used as a proxy for the presence of sexual behaviours that could result in the transmission of HIV.
- Groups at high risk for parenterally acquiring HIV, such as injection drug users, have increased risk of other blood-borne infections. Hepatitis C virus is the blood-borne infection most typically measured.
- Many high risk groups are marginalized, and sometimes their behaviour is illegal. It is important to understand your country’s laws regarding sex work, injection drug use, and laws requiring reporting of individuals with HIV infection, as these laws may complicate the participation of some at-risk populations.


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ACASI: Acronym for 'audio computer-administered self-interview'.

Accuracy: Refers to how well the sample reflects (nearest to the truth) the study population.

Advanced HIV Disease: The late stage of HIV infection that includes development of one or more opportunistic illnesses (illnesses that occur because of low levels of CD4 lymphocytes). Advanced HIV Disease is the term now used for AIDS in updated WHO Guidelines.

AIDS: 'Acquired Immunodeficiency Syndrome.' See Advanced HIV Disease.

BED capture-EIA test: This test detects an antibody to a small HIV protein, gp41. It was first tested in HIV types B, E and D, hence its name BED.

Behavioural surveillance: Surveys of HIV related behaviour that involve asking a sample of people about their risk behaviours, such as their sexual and drug-injecting behaviour.

Bias: A systematic error in the collection or interpretation of data.

Biological surveillance: Surveillance that involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses, such as sexually transmitted diseases and tuberculosis.

Bridging populations: Persons in high risk sub-populations who interact with people of lower risk in the general population, making it more likely that the HIV epidemic shifts from the concentrated to the generalized population.

Bivariate analysis: One of the main types of behavioural surveillance analysis that is performed to determine whether one variable is related to the distribution of another. For example, there might be an association between a respondent’s age (the explanatory variable) and their use of condoms (the outcome variable). Variables are associated if the value of one tells you something about the value of another. Statistical tests in bivariate analysis determine whether any observed difference reflects a true difference, or may be due to chance.

BSS: Acronym for ‘behavioural surveillance survey.’

CAPI: Acronym for 'computer-assisted personal interview.'

CASII: Acronym for 'computerized assisted survey instruments.'

Census sampling: Every unit, or case, is measured for the entire population. A de facto census allocates persons according to their location at the time of enumeration.
A *de jure* census assigns persons according to their usual place of residence at the time of enumeration.

**Chain referral sample**: Any sampling method wherein participants refer other potential participants for inclusion in the sample. There are several types of chain referral sampling methods, most of which are non-probability samples. Examples of chain referrals include RDS, network sampling, random walk and snowball sampling.

**Chancroid**: An acute, sexually transmitted, infectious disease of the genitalia caused by the bacteria *Haemophilus ducreyi*. The infection produces a genital ulcer that may facilitate the transmission of HIV.

**Characteristic**: A definable or measurable feature of a process, product, or variable.

**Chlamydia trachomatis**: The most common sexually transmitted bacterial species of the genus Chlamydia that infects the reproductive system. Chlamydia infection causes infection of the cervix of women and the urethra of men and is frequently asymptomatic. If left untreated, it can cause sterility in women.

**Clinic-based surveys**: Surveys that use samples that have been selected in clinical facilities, such as STI or drug treatment clinics. The most common type of the clinic-based surveys that are done using biological markers, such as HIV infection, is clinic-based sentinel sero-surveillance.

**Cluster**: Any aggregate of the population of interest (for example, departments, villages, health facilities, etc.)

**Cluster sampling**: The population of interest is broken into groups or clusters and a sample of clusters is randomly selected.

**Cohort studies**: Cohort studies follow a group of initially uninfected people over time, and test them repeatedly. Cohort studies follow a well-defined group of people with a common experience or exposure, who are tested repeatedly over a long period of time.

**Community-based surveys**: Surveys that use samples that have been selected from non-clinical settings. They often include high risk groups, such as sex workers or truck drivers, who are not included in clinic-based surveys. As with clinic-based surveys, the most common type of community-based survey is called 'repeated cross-sectional community-based sentinel sero-surveillance.'

**Community sites**: Locations in the community, such as households or brothels.

**Concentrated HIV epidemic**: The epidemic state in which HIV has spread to a high level in a defined sub-population but is not well established in the general population. (HIV prevalence is consistently >5% in at least one defined sub-population and is <1% in pregnant women in urban areas.)
**Confidence interval**: The compound interval with a given probability, for example, 95% that the true value of a variable such as mean, proportion, or rate is contained within the limits.

**Confidentiality**: Protecting information that concerns a study participant or patient from release to those who do not need to have the information.

**Consecutive sampling**: This sampling method consists of sampling every patient who meets the inclusion criteria until the required sample size is obtained or the survey period is over. While this method is not strictly a probability sample, it is easier to use and offers less occasion for sampling bias.

**Convenience sampling**: The selection of entities from a population based on accessibility and availability. Available participants may be people on the street, patients in a hospital or employees in an agency. This type of sampling does not generally represent the population of interest and is best used in the exploratory stage of research.

**Coupon**: Used in RDS studies to provide incentives to participants. Coupons in RDS can be used both to track participation for reimbursements and to link the recruiters to the recruits. Other methods may use coupons to encourage participation, much like the advertisements placed in popular clubs or bars. Some coupons may have two parts that can be easily separated. One part of the coupon serves as the referral coupon, which the recruiter uses to recruit a peer into the study. The other part of the coupon serves as the payment coupon. It is kept by the recruiter and he or she will use it to claim an incentive for having recruited a peer into the study. Both parts of the coupon have the unique identification number of the recruitee printed on them. The dual system eliminates the need to collect names for incentive collection.

**Coupon rejecters**: People who are offered a coupon by a recruiter, but decline to take it.

**Cross-sectional survey**: A survey that is conducted over a given period of time, such as during a single year, rather than over an extended period of time.

**Cruising area**: Cruising areas are public space, such as parks, public restrooms, bath houses, dance clubs and railway stations where MSM meet, congregate and arrange and/or engage in sexual activity.

**CSW**: Acronym for ‘commercial sex worker.’

**Descriptive statistics**: Used to describe the basic features of the data, they provide simple summaries about the sample and the measures.

**DHS**: Acronym for ‘demographic and health surveys.’

**Differential recruitment**: Recruiters successfully bring recruits in at different rates.

**Disinhibition**: Poor decision-making when considering risk-taking behaviours.


**Emic:** Refers to accounts, descriptions, and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the members of the population of interest.

**Enumeration units:** The sampling units from the final stage of a multistage sampling design. See 'Listing units.'

**Epidemic:** The occurrence of a disease (or other health-related event) at a greater than expected level of increase to a baseline. For example, the high prevalence of HIV found in many parts of the world today, including sub-Saharan Africa, Latin America and South and South-East Asia.

**Equilibrium:** In RDS, the point in the recruitment process where a variable is not expected to change by more than 2 percent with each successive wave.

**Ethnographic assessments:** Ethnographic assessments are written analyses of the cultural practices, beliefs and behaviours of a particular culture, network or sub-group.

**Ethnographic mapping:** Collecting information on the geographic location, temporal movement of and interactions among members of the study population.

**Etic:** Refers to accounts, descriptions and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the community of scientific observers.

**External validity:** The ability to make inferences from the study sample to the population of interest.

**Sex workers:** Persons who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings. These may include ‘direct’ or ‘formal’ sex workers, who are sometimes included in registries and often found in brothels, and ‘indirect’ or ‘casual’ sex workers, who do not engage in sex work full time and are unlikely to be included in registries. The term ‘sex worker’ can be used to refer to female, male and transgendered sex workers.

**Formative research:** Research conducted before the study begins. Researchers use qualitative methods, such as focus groups, in-depth interviews, mapping or observations of the target population and the individuals who work with them to assure that the research team sufficiently understands the community.

**Gatekeepers:** Persons who can provide access to a high risk population. Examples are a brothel owner who can provide access to female sex workers, or a prison warden who can provide access to prisoners.

**General population surveillance:** Surveillance that measures HIV risk behaviours in a sample of people selected to represent the people living in a region or nation. The surveillance can be restricted to certain ages (for example, young people aged 15-24) or genders.
**Generalisability**: The results from the sample are the same as the results we would have obtained had we tested every person in the study population (that is, the results from the sample are generalisable to the study population).

**Generalized HIV epidemic**: The epidemic state in which HIV is firmly established in the general population. (HIV prevalence is consistently >1% in pregnant women.)

**Geographical Information System (GIS)**: System of hardware, software and procedures designed for integrated storing, management, manipulation, analysing, modelling and display of spatially referenced data for solving planning and management problems.

**Gonorrhoea**: An infection caused by *Neisseria gonorrhoeae* bacteria. Although gonorrhoea is considered primarily a sexually transmitted infection, it can also be transmitted to newborns during the birth process.

**Grey literature**: Material that is not published in easily accessible journals or databases. Besides programme evaluations, government surveillance reports and programme planning documents mentioned earlier, it includes the abstracts of research presented at conferences, and unpublished theses and dissertations.

**Hard-to-reach populations (HTRP)**: Groups of people linked by behaviours, socioeconomic situations or societal structures, who for various reasons (e.g. law, stigma) refrain from involvement in the legal economy and other aspects of the majority social institutions. Includes but is not limited to: IDUs, MSM, FSW and undocumented migrants.

**Hepatitis B virus (HBV)**: The causative agent of hepatitis B. The virus is transmitted by sexual contact, the use of contaminated needles and instruments and by contaminated serum in blood transfusion. The infection may be severe and result in prolonged illness, destruction of liver cells, cirrhosis or death.

**Hepatitis C virus (HCV)**: The causative agent of hepatitis C. This virus is transmitted largely by the use of contaminated needles and instruments and by blood transfusions. The disease progresses to chronic hepatitis in up to 50% of the patients acutely infected.

**Herpes simplex virus 1 (HSV-1)**: A virus that causes cold sores or fever blisters on the mouth or around the eyes, and can be transmitted to the genital region.

**Herpes simplex virus 2 (HSV-2)**: A virus causing painful sores of the anus or genitals. While this is a sexually transmitted infection, it may be transmitted to a newborn child during birth from an infected mother.

**Herpes viruses**: A group of viruses that includes herpes simplex type 1 (HSV-1), herpes simplex type 2 (HSV-2), cytomegalovirus (CMV), Epstein-Barr virus (EBV), varicella zoster virus (VZV), human herpes virus type 6 (HHV-6), and HHV-8, a herpes virus associated with Kaposi’s sarcoma.

**High risk group surveillance**: Surveillance that measures HIV risk behaviours in groups whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring
and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic.

**High risk group:** A group in the community with an elevated risk of disease, often because group members engage in some form of risky behaviour.

**High risk heterosexuals (HRH):** Includes and is not limited to: mobile populations, uniformed personnel and sex partners of other/most-at-risk populations MARPs.

**HIV:** See 'Human Immunodeficiency Virus.'

**Homophily:** In Respondent-Driven Sampling (RDS), a measure of the tendency of people to connect to other people like themselves.

**Human Immunodeficiency Virus (HIV):** A retrovirus that causes AIDS by infecting T-cells of the immune system.

**IDU:** Acronym for ‘Injection (or intravenous) drug user.’

**Incentive:** A reward or reimbursement given to participants in a study. In RDS surveys, there are typically two levels of incentive: primary incentive and secondary incentive. A participant receives the primary incentive for enrolling in the study and completing an interview. The same participant receives secondary incentive(s) for recruiting his or her peers into the study. Incentives are not absolutely necessary in every situation and should be determined during formative research.

**Incidence:** A measure of the frequency with which an event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.

**Indicator:** Specific data that are gathered to measure how well a prevention or treatment programme is doing. Defines an aspect of behaviour that is key to the spread of HIV. Indicators provide a way to track changes in behaviours over time and provide a way to compare levels of risk behaviours between different population groups.

**Information bias:** Error that results from people who have a disease being misclassified as not having the disease.

**Informed consent:** The permission granted by a patient or a participant in a research study after he or she has received comprehensive information about a research study or medical procedure. Informed consent protects the person’s freedom of choice and respects his or her autonomy with regard to decisions affecting his or her body and health.

**In-group affiliation:** In Respondent-Driven Sampling (RDS), what homophily measures (group similarity based on ethnicity, age, socio-economic status and so forth).
Injection drug users: Also called ‘intravenous drug users,’ they are persons who use or have used needles or syringes to inject drugs. Injection drug use is considered a high risk behaviour.

Institutional sampling: Individuals in an institution, such as prison, are sampled.

Internal validity: The absence of substantial differences between groups at baseline; the absence of substantial difference of attrition rates between groups at follow-up.

Internally displaced persons (IDP): IDPs are persons who have left their homes due to civil unrest or natural disasters, but have stayed in their homeland and have not sought sanctuary in another country.

Interviewer error: Problems stemming from the actions and behaviours of the person doing the interview.

Intradermally: Injected into the layers of the skin.

Intramuscularly: Injected into a muscle.

Intravenously: Injected into a vein.

Involuntary migrants: Involuntary migrants include persons who have migrated away or have been displaced from their home countries due to an established or well-founded fear of persecution, or have been moved as a result of deception or coercion.

Listing units: The sampling units from the final stage of a multistage sampling design. See enumeration units.

Key informants: Members of the target group, who can often become informal assistants.

Kick-off meeting: A meeting you host for community members who may in turn become seeds for the Respondent-Driven Sampling (RDS) survey. The purpose of the meeting is to educate seeds on study goals and process, inform seeds of their importance to the success of the study and encourage the seeds to be enthusiastic.

Lessons learned: Information from actual studies that will help you make decisions when planning your study.

Low level epidemic: The epidemic state in which HIV has never spread to significant levels in any sub-population, although HIV infection may have existed for many years. (HIV prevalence has not consistently exceeded 5% in any defined sub-population or in the general population.)

Markov process: A mathematical theory that provides a probabilistic description of the state of a system at any future time. The Markov process is especially relevant to RDS
because of the nature of the recruitment process, whereby a chain of peers recruiting peers is monitored through a coupon mechanism.

**MARP**: Acronym for most-at-risk population. A group within the community with an elevated risk of disease, often because group members engage in some form of high risk behaviour.

**Masking**: Describes the behaviour of reclusive respondents, people who do not want to be found.

**Men who have sex with men (MSM)**: Men who have sex with men (MSM) are one of the highest risk groups in the Americas, Asia, Europe and Oceania. For the purposes of this manual, we also consider male sex workers, transvestites and transgendered persons (*hijra*) in the MSM category.

**MICS**: See ‘Multiple Indicator Cluster Survey.’

**Mobile populations**: The term used to refer collectively to groups of people who move from one place to another (migrants). They may move temporarily, seasonally, or permanently and for either voluntary or involuntary reasons.

**Monitoring and Evaluation (M&E)**: Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.

**MSC**: See ’multi-stage cluster sampling.’

**Multi-stage cluster sampling (MSC)**: Two or more stage sampling. Final units from selected clusters may be randomly selected.

- Simple two-stage cluster sampling
- Probability proportional to size sampling (PPS) is used when all clusters do not have the equal probability of being selected in the sample. PPS is a class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable.

**Multivariate analysis**: One of the main types of analysis conducted in behavioural surveillance that is performed to look at the influence of at least two variables on another variable. Since relationships between variables are often complex and interwoven, Multivariate techniques can pinpoint the individual effects of several explanatory variables on an outcome variable, which may be related to each other.

**Needs assessment**: A systematic examination of the type, depth and scope of a problem.

**Network**: This sampling method may be used for groups whose members are socially linked. Ego-centred network sampling is based on random, representative or any other form of quota sampling. Full relational network sampling begins with identification of individuals (seeds) who act as entry points to the network.
NGO: Acronym for ‘non governmental organisation.’

Non-probability sampling: The sampling units are selected through a non-randomized process; therefore, the probability of selecting any sampling unit is not known.

Non-random mixing: The tendency of people to associate preferentially with others who are like themselves.

Operational definitions of target populations: Definitions that are operationally useful for sampling and fieldwork purposes. For example, a definition that clearly identifies what constitutes a sex worker, in terms of duration of selling sex, form of payment, type of venue where they work, etc.

Operations manual: A document that describes every step to be taken during the implementation of a survey or study. Ideally, it provides standard operational procedures for every foreseeable occurrence.

Out-of-school youth (OSY): Include children and adolescents who are not currently enrolled in formal education. They may have completed school, may have dropped out of school, or may never have started school.

Over-sampling: A sample may obtain more members of a particular sub-group than their representation in the target population warrants. In some cases, over-sampling is carried on purpose to learn more about a small sub-group, such as female injection drug users in communities that are predominantly male.

p24 antigen: A protein that appears in the serum of infected individuals approximately one week before HIV antibodies appear, or about 14 days after actual infection. In very large sero-surveys, persons who tested negative for HIV antibody can be retested for p24 antigen.

Parameter: The summary numerical description of variables about the target population.

Parenteral transmission: Transmission of an infectious agent through blood. Parenteral transmission of HIV can occur from the sharing of injection drug equipment, from transfusions with infected blood or blood products, or from needle stick injuries.

Participant observation: A qualitative research method in which direct observation is carried out over a period of time, and which is understood and accepted by the group being observed.

Payment coupon: Kept by the recruiter. He/she will use it to claim an incentive for having recruited a peer into the study.

Period prevalence: Refers to prevalence over a period of time, such as a six-month period.
PLACE: See ‘Priorities for local AIDS control efforts.’

PLWHA: Acronym for ‘Persons living with HIV/AIDS.’

Point prevalence: Refers to prevalence at a single point in time.

Population: The entire set of individuals to which findings are to be extrapolated.

PPS: See ‘Probability proportional to size sampling.’

Precision: Refers to how well the results can be reproduced each time the survey is conducted.

Pre-survey assessment: Describes a set of activities that occur prior to beginning formal HIV and behavioural surveillance in high risk groups. These activities include developing detailed plans and reviewing and collecting information that will help in planning and designing surveillance activities.

Prevalence: The proportion of a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Primary incentive: The incentive a participant gets for enrolling in the study and completing an interview.

Primary sampling units: A sampling frame of a larger unit. When it is difficult or impossible to make a list/sampling frame of each individual in the target population, we can develop a sampling frame of some larger unit; that is, clusters or primary sampling units. We then sample in stages by first sampling clusters and then sampling people within the clusters.

Priorities for Local AIDS Control Efforts (PLACE): A new, rapid assessment tool used to identify high transmission areas, which formalizes the collection of information on high transmission areas. PLACE uses key informants to identify sites where people meet new sex partners, then interviews people at the site in order to characterise the site in each area and map sites, and, finally, interviews individuals socialising at the site to describe the characteristics of the people at the site.

Probability proportional to size sampling: A class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable.

Probability sampling: All sampling units in the study population have a known, non-zero probability of being selected in the sample, usually through a randomized process.

Protocol: The detailed plan for conducting a research study or other activities in which specific steps are required, including surveillance activities.
**Purposive sampling**: A non-random sampling method that involves choosing respondents with certain characteristics.

**Qualitative research**: Research that focuses on the characteristics or quality of things, rather than the quantity. The sample included qualitative research is usually much less used than that included in quantitative research.

**Quantitative research**: Research that focuses on quantity of things, rather than the quality. Quantitative research has powerful tools for the analysis of numbers, but researchers know that the things counted are often qualitative categories or definitions.

**Questionnaire faults**: Problems with the way questions are phrased, set out and ordered, which lead to misunderstandings of the questions.

**Random walk**: A variation of link-tracing sampling procedure in which the respondent is asked to give the names of other members of a hidden population. From that list, one is selected randomly, located and added to the sample. The process is repeated for a desired number of waves. (S.K. Thompson et al.)

**Random error**: Also called non-systematic error. This is the type of error that results from chance and leads to imprecise results.

**Rapid assessment and response (RAR)**: A method that is used to assess the nature and extent of a public health problem and to suggest ways to address the problem. RAR is not designed as a surveillance tool, but as a way to assess a situation quickly, and bring in resources to address it.

**RDS**: See 'Respondent-driven sampling.'

**RDSAT**: Respondent-driven sampling analysis tool (a freeware software package for analysing RDS samples.)

**Referral coupon**: Used by the recruiter to recruit a peer into the study.

**Refugees**: By legal definition, refugees are persons who are outside their country of nationality and who are unable or unwilling to return to that country. They cannot return due to a well-founded fear of persecution because of race, religion, political opinion or membership in an ethnic or social group.

**Reliability**: Refers to how reproducible a result is from repeated applications of a measure to the same subject.

**Representativeness**: The degree to which the sample truly reflects the study population (that is, whether it is representative of the study population).

**Resource assessment**: A component of rapid assessment and response (RAR), a systematic examination of the response (funds, people, buildings, knowledge) that is either available or required to solve the problem.
Respondent-driven sampling (RDS): A sampling technique that does not require a sampling frame. It is an adaptation of a non-probability sampling method (snowball sampling) and is based on the assumption that members of the sub-population themselves can most efficiently identify and encourage the participation in surveillance of other sub-group members. RDS starts with initial contacts or ‘seeds’ who are surveyed and then become recruiters. Each of these recruiters is given coupons to use to invite up to three eligible people that he/she knows in the high risk group to be interviewed. The new recruits bring their coupon to a central place where they are interviewed. The recruits then become recruiters. This occurs for five to six waves. Both the recruits and the recruiters are given incentives to encourage participation.

Safety protocol: A study document that describes how to deal with field incidents or adverse events.

Sample: A selected subset of a population. There are specific types of samples used in surveillance and epidemiology such as convenience, systematic, population-based and random.

Sampling bias: Also called selection bias. This refers to errors in sampling that decrease accuracy and lead to incorrect estimates. We also use the term ‘biased samples’ to mean that errors were made in choosing the people in the sample.

Sampling element: Individual member of the population whose characteristics are to be measured. See ‘Sampling unit.’

Sampling error: The part of the total estimation error of a parameter caused by the random nature of sampling.

Sample frame: A list of units from which a sample may be selected. A sample frame is a fundamental part of probability sampling.

Sampling units: Refers to individual members of the population whose characteristics are to be measured. See ‘Sampling element.’

Sampling variation: Difference between the estimate you measure in a sample and the true value of the variable in the study population.

Second-generation surveillance: Built upon a country’s existing data collection system, second-generation HIV surveillance systems are designed to be adapted and modified to meet the specific needs of differing epidemics. This form of surveillance aims to improve the quality and diversity of information sources by developing and implementing standard and rigorous study protocols, using appropriate methods and tools. Second generation surveillance refers to activities outside of those activities generally considered to be a part of routine case surveillance such as case reporting and sentinel sero-surveys and uses additional sources of data to gain additional understanding of the epidemic. It includes biological surveillance of HIV and other STIs (Sexually transmitted infections), as well as systematic surveillance of the behaviours that spreads them.
Secondary incentive: The incentive a participant gets for recruiting his or her peers into the study.

Seeds: Non-randomly selected (by the investigators) members of the target population who will initiate the Respondent-Driven Sampling (RDS) recruitment process. From each seed, a recruitment chain is expected to grow.

Sero-prevalence surveys: Surveys that estimate HIV prevalence by testing blood for HIV antibody.

Sentinel populations: Populations that are subject to sentinel surveillance activities. They may not necessarily be representative of the general population, but rather they might be the first affected by HIV. Examples include sexually transmitted infection patients or truck drivers.

Sentinel sites: Facilities such as STD (Sexually transmitted disease) clinics, antenatal care clinics, blood donation centres, drug treatment programs, prisons and needle exchange programs.

Sentinel surveillance: A surveillance system in which a pre-arranged sample of reporting sources at 'watch post' or 'sentinel' sites agrees to report all cases of one or more notifiable conditions. Often designed to provide an early indication of changes in the level of disease. Depending on the nature of the population surveyed, these data may be representative of the general population, or they may simply give more detailed information about the populations tested.

Sexually transmitted infection (STI): Diseases that are spread by the transfer of organisms from person to person during sexual contact.

Simple random sampling (SRS): Sampling where everyone has an equal chance of being randomly selected (a non-zero probability) and we know what that chance is.

Snowball sampling: Relies on informants to identify other relevant study participants in a chain referral pattern. Informants (seeds) who meet inclusion criteria are identified. This sampling design is based on chain referral and relies on the seed(s) to identify other relevant subjects for study inclusion. Those other subjects may identify other relevant subjects for inclusion. Snowball sampling is useful for studying populations that are difficult to identify or access. Representativeness is limited.

Social influence: Mild peer pressure from the recruiter who will receive a secondary incentive for recruiting his/her peers.

Social network: Members of a peer group who know each other.

Socio-metric stars: Seeds who are not only willing to recruit their peers, but are well-regarded by their peers and have a lot of them. Such seeds are more likely to influence others to be recruited into the study.
SRS: See 'Simple random sampling'

Standard error: Estimate of precision in probability sampling that can be used to construct a range of values within which the true population measure is likely to fall. We usually want to be 95% sure that the true population measure lies in our range.

Standardized testing algorithm for recent HIV sero-conversion (STARHS): A calculation for measuring new infection that uses a single blood test. STARHS uses the results of two EIA tests, one highly sensitive and another modified to be less sensitive. The less sensitive EIA test is called the 'detuned' assay.

Statistics: A branch of applied mathematics concerned with the collection and interpretation of quantitative data and the use of probability theory to estimate population parameters.

Steering method: In Respondent-Driven Sampling (RDS), using additional methods to recruit a special sub-population of interest; for example, providing an extra coupon to be used only to recruit female IDUs.

Stigma: A mark of disgrace or shame. For example, in some societies, being infected with HIV causes a person to be stigmatized.

STI: See 'Sexually transmitted infection.'

Strata: A sub-group in stratified sampling.

Strategic information (SI): Refers to any data collected by surveillance or monitoring and evaluation of a programme or system. Includes, but is not limited to, process indicators, output indicators and surveillance data.

Stratification: The classification of a survey population into sub-groups or strata on the basis of selected characteristics.

Stratified and constant incentives: In a study of SWs, a constant incentive level was considered too low to attract the more hidden SWs who earned a higher income. The research team considered using a stratified incentive process. The SWs received an incentive based on the type of sex work they did. For instance, a street-based SW received a $5.00 incentive, while a call-girl-type SW received a $10.00 incentive.

Stratified sampling: The selection of separate (independent) samples from each stratum. When the population consists of distinct sub-groups, (for example, age groups or regions) we may need to make precise estimates of our indicators for each sub-group. If this is the case, we use stratified sampling. First we calculate the required sample size for measuring our indicator, then define the sub-group (strata) and randomly sample the calculated sample size in each stratum. Since we want to make precise estimates of our indicator for each stratum, our sample size will be much larger than if we just wanted an estimate for the entire population. We can combine strata estimates to
obtain a population estimate for our indicators. However, this requires that we know the proportion of the population in each strata.

**Subcutaneously**: Injected below the skin.

**Surveillance**: The systematic, regular and ongoing collection and use of data for public health action.

**Surveillance sites**: The places from which case reports are obtained. This includes sites at which universal reporting and sentinel reporting are done. These may be healthcare facilities or other locations at which sero-surveys are conducted.

**Survey population**: The target population modified to take into account practical considerations (for example, all commercial sex workers in a city over the age of 15, excluding those who are based at home, as they cannot be accessed).

**Syphilis**: A sexually transmitted disease resulting from infection with the bacterium *Treponema pallidum*. Syphilis can also be acquired by newborns from their mothers during pregnancy.

**Systematic sampling**: When we construct the sampling frame, as in simple random sampling (that is, we make a list of everyone in the target population) but rather than selecting names or random numbers, we sample people at regular intervals down the list. For this scheme to work you need to ensure that the list is not ordered in any way that would bias those who are selected in the survey.

**Systematic sampling**: Every $k$th unit is sampled from a sampling frame after a random start. Systematic sampling is often used instead of SRS when the sampling list is long or the desired sample size is large.

**Target population**: The group that meets a survey's measurement objective (for example, all commercial sex workers in a city).

**Targeted sampling**: Targeted sampling uses pre-existing indicator data (qualitative and quantitative) to construct a sampling frame from which recruitment sites are then randomly selected. Qualitative indicator data includes ethnographic data and key informant interviews. Types of quantitative indicator data include cases of HIV/AIDS and STIs, admissions to drug treatment and population characteristics from census data. There are several limitations: 1) indicator data may not be useful in characterising the target population; 2) sampling may be biased and difficult to replicate; 3) geographic areas may not be sampled in proportion to the number of members in the population of interest; 4) the population of interest may not be sampled in proportion to the intensity of risk behaviour and 5) the probability of selecting a member of the population of interest may not be known.

**TB**: Tuberculosis.

**Time-location sampling (TLS)**: Similar to conventional cluster sampling, but gets around the problem of clusters that are not stable (that is, clusters where the number and type
of people vary by, for example, time of day). Time-location sampling allows the same site to be included in the sample frame more than once (for example, at different times of the day or different days of the week).

**Transgendered persons:** Persons who identify with or express a gender and/or sex different from their biologic sex.

**Transition probability:** The likelihood that a person will change from one state to another, for example becoming HIV positive.

**Univariate analysis:** The most basic, yet often the most important, type of behavioural surveillance analysis, because it shows the distribution of each variable. Most of the indicators defined for behavioural surveillance purposes are calculated through univariate analysis. They would include variables like the proportion of young men who have had sex with more than one partner during a given time period. When trends are analysed, statistical techniques are used to calculate how likely it is that changes in the proportions could have occurred by chance, or whether observed changes are likely to reflect real changes.

**Universal conscription:** Military conscription in which all physically able men between certain ages (for example 17-28) must perform military service.

**Unlinked anonymous testing (UAT):** Testing that occurs when a sample of blood that was originally collected for other purposes is tested for HIV after being anonymised. The person whose blood is taken does not know that his/her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to them.

**Unprotected sex:** Having sex without using a condom.

**Validity:** The validity of a measure is the extent to which it actually measures what it is suppose to measure. The truth.

**Values:** Magnitude of measurements (statistics).

**Variable:** Any characteristic or attribute that can be measured.

**Venue:** Locations in the community, such as bars or brothels.

**Venue-based sampling (brick and mortar sites):** Recruit respondents in places and at times where they would reasonably be expected to gather. The venues act as screeners in identifying potential respondents. Venue-based sampling requires comprehensive formative research.

**Voluntary migrants:** Often referred to as 'economic migrants.' The term 'voluntary migrants' refers to people who temporarily work or travel away from their homes.

**Volunteerism:** A term to describe overly cooperative subjects, leading to a potential bias if such cooperative people differ from the rest of the population of interest.
The CDC Global AIDS Program (GAP)
The CDC Global AIDS Program (GAP) Surveillance team is developing an interactive sampling selection tool for use in surveillance study sampling design. Proper sampling design is critical to the success of your study. The tool is scheduled to become available in 2007. The date of release and the URL will be announced by various means, through CDC-GAP and WHO regional offices.

Family Health International (FHI)
Family Health International has pioneered ways to curtail the spread of HIV/AIDS. Many of the HIV prevention “best practices” in use today have emerged from FHI’s work in more than 60 countries.
www.fhi.org/en/HIVAIDS

HIV/AIDS Survey Indicators Database
The HIV/AIDS Survey Indicators Database is overseen by a technical advisory committee that includes representatives from USAID, UNICEF, CDC, UNAIDS, WHO, US Census Bureau, Family Health International, MEASURE Evaluation, The Synergy Project, and MEASURE DHS+ (the implementing organisation). USAID is currently the primary funder for the initiative, with UNAIDS and UNICEF providing additional support. There are 180 surveys available in the database.

Multiple Indicator Cluster Survey (MICS), UNICEF
The Multiple Indicator Cluster Survey (MICS) is a household survey programme developed by UNICEF to assist countries in filling data gaps for monitoring the situation of children and women. It is capable of producing statistically sound, internationally comparable estimates of these indicators.
www.childinfo.org.

Respondent-Driven Sampling (Cornell)
Defines RDS and provides information on minimum data requirements, sampling references, intervention references and downloads.

Respondent-Driven Sampling Field Experiences Message Board
A respondent-driven sampling site where people can share questions and receive answers in real time. The Board is not monitored; so it relies on people checking in for now. It requires registration. You will be alerted to new postings if you choose. Feel free to share the web site with other RDS users or others who might be interested.

UNAIDS (Joint United Nations Programme on HIV/AIDS)
As the main advocate for global action on HIV/AIDS, UNAIDS leads, strengthens and supports an expanded response aimed at preventing the transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to...
HIV/AIDS and alleviating the impact of the epidemic. UNAIDS compiles epidemiological fact sheets about each country involved in HIV/AIDS prevention programmes, as well as specific populations.


**United Nations General Assembly Special Session on HIV/AIDS (UNGASS)**

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: [http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators](http://www.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators).

**United Nations Office on Drugs and Crime (UNODC)**

The United Nations Office on Drugs and Crime (UNODC) is a global leader in the fight against illicit drugs and international crime. UNODC is involved in HIV/AIDS programming in regions, such as South-East Asia, where injecting drug use is known to drive the HIV/AIDS epidemic.


**United States Department of Commerce, U.S. Census Bureau’s International Programs Center**

The International Programs Centre, part of the Population Division of the U.S. Bureau of the Census, conducts demographic and socio-economic studies and strengthens statistical development around the world through technical assistance, training, and software products. The IPS maintains an HIV/AIDS Surveillance database, the Monitoring the AIDS Pandemic (MAP) Network, and a series of HIV/AIDS country profiles. The Programmes Centre provides various country profiles that examine the patterns and trends of the epidemic, as well as maps and tables that serve to summarize the statistics for each region in a streamlined format.

[www.census.gov/ipc/www/hivaidsn.html](http://www.census.gov/ipc/www/hivaidsn.html).
Answers are provided in italics for each unit’s warm-up questions.

Answers to the small group discussion questions are not included. Small group discussion questions are designed to stimulate small group discussion among participants in the workshop or class.

Unit 1 Answers

Warm-up questions

1. True or false? A high risk group is at increased risk of HIV infection because of higher risk behaviours. True. Members of high risk groups are at increased risk of contracting HIV and passing the virus on to others due to high risk behaviours, such as, having unprotected sex with multiple partners, having a high number of new partners, and injecting drugs with shared needles.

2. Which of the following groups are at high risk for HIV infection in the South-East Asia region?
   a. sex workers
   b. injection drug users
   c. men who have sex with men
   d. all of the above
   In the South-East Asia regions, groups at high risk for HIV infection include, but are not limited to: sex workers, injection drug users, men who have sex with men, mobile populations, out-of-school youth, prisoners and uniformed personnel.

3. True or false? In low-level epidemics, surveillance of high risk groups can serve as an early indicator of the presence of HIV in a country. True. At the beginning of an epidemic, the first infections often appear in high risk groups because they have higher risk behaviours than the general populations.

6. List the two sampling methods that are commonly used in HIV surveillance of populations at high risk for HIV transmission. Respondent-driven sampling (RDS) and time-location sampling (TLS) are ideally suited for surveys of high risk groups, especially those that are harder to find.

4. An example of a potential legal harm to members of high risk groups because of HIV surveillance activities is arrest (and prosecution). Arrest and prosecution are both potential legal harms that members of high risk groups may experience due to HIV and behavioural surveillance in high risk populations.

Unit 2 Answers

Warm-up questions

1. True or false? SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners. True. Because their clients
can infect others in the general population; sex workers contribute greatly to sexual HIV transmission.

2. List two places where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found. Direct sex workers can be based in brothels, streets, hotels and bars, and work exclusively in sex work.

3. Indirect SWs do not engage in sex work full time, and may have another source of income. They are also called casual SWs or clandestine sex workers. Indirect sex workers sell sex to supplement their primary income, and are also known as ‘casual’ or ‘clandestine’ sex workers. Indirect sex workers can be found in bars or massage parlours.

4. True or false? Surveillance co-ordinators should meet with SWs to use their expertise in designing the behavioural surveillance approach and questionnaires. True. Sex workers often have inside information that could help you design a more effective approach to surveillance.

5. SWs and their clients are often a bridge to other high risk populations. For example, male clients of FSWs may transmit HIV to their wives and non-commercial sex partners. The infected clients of sex workers can serve as a bridge for spreading infection to the general heterosexual population. A bridge population is a group that serves to encourage the spread of HIV from a high risk group to the general population.

6. Name a sampling method that could be used among highly mobile sex workers, such as those who do not work in fixed brothels. Respondent-driven sampling can be used to sample highly mobile sex workers.

Unit 3 Answers

Warm-up questions

1. List two examples of blood-to-blood (or parenteral) transmission of HIV. Examples include transfusions, needle-stick injuries, needle re-use in medical settings, injection of illegal drugs, etc.

2. Which of the following sampling methods can be used for surveillance in IDUs?
   a. time-location sampling
   b. multi-stage cluster sampling
   c. convenience sampling
   d. simple random sampling from a de-addiction clinic registry

   Along with respondent-driven sampling, time-location sampling is an ideal method for surveying hard-to-reach populations.

3. List two organisations with which you can form alliances as you develop your HIV surveillance system for IDUs. Examples include treatment clinics, needle-exchange programmes, prisons, social service organisations, etc.
4. List two interventions that can help reduce HIV transmission among IDUs. *Officials can help to reduce HIV transmission by promoting sterilisation of injection equipment, providing sterile needles, treating drug addiction, promoting condom use, etc.*

5. What are the ethical issues you must consider when conducting surveillance in IDUs?

*Ethical issues to consider when conducting surveillance in IDUs include:*

- The inability of IDUs to provide truly informed consent when under the influence of drugs or withdrawing from drug.
- Participation in surveillance activities may place IDUs at risk for harm and discrimination due to inadvertent identification as an IDU or as HIV-infected.

**Unit 4 Answers**

**Warm-up questions**

1. True or false? Because men who have sex with men are homosexual, there is little risk that HIV will spread to the rest of the population, including women. *False. MSM often have sex with both men and women, meaning that they are likely to transmit any infections they have to both their female and male partners.*

2. List two common points of access where MSM can be found.

   *Although MSM are often hidden because of discrimination, in some countries there are well defined gay communities who congregate at known locations. Examples of these include dance clubs, gyms, bath houses, parks, etc.*

3. Because MSM are often hard to reach because of discrimination and stigmatization, two successful sampling methods in this group are ________________ and ________________.

4. What are some of the ethical issues to consider when conducting HIV surveillance of MSM?

   *MSM are considered a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination, including: loss of confidentiality, inadvertent identification as an MSM, inadvertent disclosure of HIV status, negative reaction and backlash in response to publicized results, physical abuse and imprisonment.*

**Unit 5 Answers**

1. Which of the following terms is used to describe voluntary migrants, and which terms are used to describe involuntary migrants?

   a. refugees
   b. displaced persons
   c. mobile populations
   d. none of the above

   *Mobile populations’ is the term used to refer collectively to voluntary and involuntary migrants. The other two terms are types of involuntary migrants.*
2. True or false? Both biological and behavioural surveillance on migrant workers should be conducted regularly every year. True. This will ensure that in-depth information on this high risk group can be collected regularly.

3. Of the following, which is not a reason why migrants are especially vulnerable to HIV?
   a. Female migrants often sell 'survival sex' when they have no other source of income.
   b. Migrants usually only have one sexual partner.
   c. Migrants have limited access to healthcare.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.
   
   As they are often away from home for extended periods of time, migrants often have multiple sexual partners.

4. List two sub-groups that can be considered mobile populations. Examples of mobile persons are truck drivers, miners, factory workers, fishermen, sailors, etc.

5. Which type of migration occurs regularly in the South-East Asia region and usually involves young people who move from low-prevalence areas to high-prevalence areas and eventually return home?
   a. ‘circular’ or ‘oscillating migration’
   b. gross migration
   c. step migration

Unit 6 Answers

1. Out-of-school youth may include which sub-populations?
   a. street children
   b. child labourers
   c. adolescent sex workers
   d. married adolescents
   e. all of the above

   Out-of-school youth may have completed school, may have dropped out of school, or may never have started school. The experiences of OSY vary greatly—they may work in factories, hawk goods in markets, work on farms, stay at home to do housework or child-rearing, engage in prostitution, live on the streets or be unemployed.

2. True or false? By targeting youth through behaviour-change campaigns, several countries have successfully decreased national HIV prevalence rates. True. Several countries have successfully decreased national HIV prevalence rates by specifically targeting youth with behaviour-change interventions.

3. List three possible places where you would expect to find large numbers of out-of-school youth. Locations where OSY spend most of their time will differ by sub-group, and will depend on the particular sub-group of interest. To locate OSY, identify areas where young people tend to congregate. These include: beaches, parks, movie theatres, and sports clubs. Depending on the focus of the surveillance, other sub-
groups, such as OSY sex workers, intravenous drug users or factory workers may be included. In these cases, consider brothels/massage parlours, bars/discos, parks, beaches and other places where people gather to use drugs, truck stops, factories employing youth workers.

4. What are two reasons why out-of-school youth may be considered a vulnerable population? Out-of-school youth may be more vulnerable to HIV infection for any of the following reasons: they do not receive reproductive health education and other school-based services, they are not exposed to the structure that the school environment would otherwise provide, they face stigma and discrimination that may prevent them from adopting risk-reduction behaviours, they are more likely to experiment with drugs and alcohol and they may be sexually exploited, trafficked, or involved in the sex industry.

Unit 7 Answers

1. Which of the following is a reason for high HIV prevalence among prisoners?
   a. the over-representation of injection drug users among prisoners
   b. male-to-male sex during long periods of incarceration
   c. sexual relations between prison staff and prisoners
   d. high concentration of female sex workers in some prisons
   e. sharing needles for drug use in prison
   f. all of the above
   Depending on whether prisoners are male or female, these reasons will differ.

2. True or false? The most practical way to collect information on HIV prevalence in prisons is to use the mandatory screening programmes when prisoners are admitted. True. If this option is not available, you will need to develop other sampling methods.

3. What is the simplest form of sampling that can be used if you are surveying prisoners who are already incarcerated?
   a. cluster sampling
   b. systematic random sampling
   c. snowball sampling
   d. time-location sampling
   A systematic random sample is the easiest and most appropriate method for this situation, since prisoners are not mobile or a hidden population.

4. True or false? High HIV prevalence among prisoners is a result of HIV infection both before and after entering prison. False. HIV infection during incarceration also contributes to HIV prevalence among prisoners.

5. Cohort studies provide the most exact measurements of incidence. However, they require the studied groups to be relatively stationary. Which of the following groups can be surveyed using cohort studies?
   a. street-based sex workers
   b. migrant workers
   c. prisoners
   d. refugees
Because prisoners are a relatively stationary group, calculating the incidence of HIV in prisons may be possible. Cohort studies provide the most exact measurements of incidence, but are only possible if correctional staffs allow public health workers access to prisoners for HIV testing during their incarceration.

6. Because of their inability to give true voluntary informed consent, prisoners are a vulnerable population and need special ethical protection. Prisoners are under unique constraints because of their incarceration, which affect their ability to make a truly voluntary and un-coerced decision about whether to participate as research subjects. For this reason, it is important to take special precautions when obtaining informed consent from prisoners.

Unit 8 Answers

1. List three reasons why uniformed personnel are at increased risk of HIV infection. Possible reasons include the following: personnel are usually young and sexually active; they are often away from home; they are surrounded by opportunities for casual sex; they are governed by peer pressure; they are likely to feel invincible and take risks, etc.

2. Access to uniformed personnel is usually restricted. Military officials, such as senior commanders and medical officers are important gatekeepers who can provide access to uniformed personnel. Prior to beginning surveillance activities, the surveillance team will need to form alliances at the highest levels, with the Ministry of Health and the Ministry of Defence for armed services, or with the Ministries of Interior or Justice for police. It will also be helpful to enlist the support of those operating the current medical care and public health intervention programmes that exist for these populations.

3. Informed consent is required when conducting HIV prevalence studies and other activities involving the non-routine collection of data. Informed consent is required when conducting HIV prevalence studies and other activities involving the non-routine collection of data. All data-collection activities, other than mandatory or clinical testing, usually require informed consent.

4. List two methods that may be used for sampling uniformed personnel. When uniformed personnel are not routinely tested for HIV, the following random sampling methods may be appropriate: systematic sampling, cluster sampling or stratified sampling.
## Antibody assays Performance characteristics Storage and processing Notes

### Serum Assays

<table>
<thead>
<tr>
<th>HIV-1/2</th>
<th>EIA, rapid tests.</th>
<th>Excellent.</th>
<th>Transport at +4°C Store at -20°C.</th>
<th>Detect lifetime exposure. Serial testing can be used to determine incidence of infection in a cohort.</th>
</tr>
</thead>
<tbody>
<tr>
<td>BED capture EIA</td>
<td>EIA.</td>
<td>Excellent.</td>
<td>Transport at +4°C Store at -20°C.</td>
<td>Used to detect recent HIV infection, not dependent on HIV type.</td>
</tr>
<tr>
<td>Herpes simplex virus type 2</td>
<td>EIA.</td>
<td>Variable.</td>
<td>Transport at +4°C Store at -20°C.</td>
<td></td>
</tr>
<tr>
<td>Hepatitis A</td>
<td>EIA.</td>
<td>Good.</td>
<td>Transport at +4°C Store at -20°C.</td>
<td></td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>ALT, EIA, polymerase chain reaction (PCR) RPHA.</td>
<td>Good.</td>
<td>Poor, but inexpensive.</td>
<td></td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>EIA; recombinant immunoblot assay (RIBA); nucleic acid amplification tests (NAAT), including PCR, SDA and TMA.</td>
<td>Good.</td>
<td>Transport at +4°C Store at -20°C.</td>
<td></td>
</tr>
<tr>
<td>Other tests</td>
<td>Antibody assays</td>
<td>Performance characteristics</td>
<td>Storage and processing</td>
<td>Notes</td>
</tr>
<tr>
<td>-----------------------------------</td>
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<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Syphilis serology</strong></td>
<td>Non-treponemal antibody tests (VDRL, RPR)</td>
<td>Good</td>
<td>Transport at +4°C</td>
<td>Poorly predictive in early infection</td>
</tr>
<tr>
<td></td>
<td>treponemal antibody tests (TPPA, FTA)</td>
<td></td>
<td>Store at -20°C</td>
<td></td>
</tr>
<tr>
<td><strong>p24 antigen</strong></td>
<td>NAAT</td>
<td>Excellent</td>
<td>Varies by NAAT</td>
<td>Detects replicating HIV. Can be used to detect recent infection in persons who have not yet developed HIV antibody</td>
</tr>
<tr>
<td><strong>HIV RNA and DNA testing</strong></td>
<td>NAAT</td>
<td>Varies by HIV subtype</td>
<td></td>
<td>Used like p24 antigen test to detect early infection</td>
</tr>
<tr>
<td><strong>CD4 testing</strong></td>
<td>Flow cytometry and others</td>
<td>Choice of method depends on laboratory facilities available</td>
<td>Whole blood required. Transport at room temperature. Analyse within 48 h</td>
<td>Used to stage HIV infection and monitor effect of antiretroviral therapy</td>
</tr>
<tr>
<td><strong>Urine Assays</strong></td>
<td><strong>HIV-1</strong></td>
<td>High, but more sensitive then serum</td>
<td>Transport at +4°C. Addition of boric acid prevents bacterial overgrowth. Store at +4°C, test within 6 months</td>
<td>Detects lifetime exposure. Serial testing can be use to determine incidence of infection in a cohort</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct detection of organism</td>
<td>Antibody assays</td>
<td>Performance characteristics</td>
<td>Storage and processing</td>
<td>Notes</td>
</tr>
<tr>
<td>-----------------------------</td>
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</tr>
<tr>
<td><strong>Trichomonas vaginalis</strong></td>
<td>Microscopy and culture</td>
<td>High for culture</td>
<td>First void urine (15 ml), use spun deposit</td>
<td>Leukoesterase dipstick test (LE) may be used to determine who to screen in certain populations.</td>
</tr>
<tr>
<td><strong>Trichomonas vaginalis</strong></td>
<td>PCR</td>
<td>High</td>
<td>First void urine (15 ml)</td>
<td>Can pool specimens for PCR testing in low prevalence settings to reduce cost.</td>
</tr>
<tr>
<td><strong>Chlamydia trachomatis</strong></td>
<td>NAAT</td>
<td>High</td>
<td>Varies by NAAT</td>
<td></td>
</tr>
<tr>
<td><strong>Neisseria gonorrhoea</strong></td>
<td>NAAT</td>
<td>High</td>
<td>Varies by NAAT; may require RNA protectant or dilutant</td>
<td></td>
</tr>
<tr>
<td><strong>Neisseria gonorrhoea</strong></td>
<td>Microscopy and culture</td>
<td>Higher in men than in women</td>
<td>First void urine (15 ml)</td>
<td>Use spun deposit.</td>
</tr>
</tbody>
</table>

**Oral Fluid Assays**

<table>
<thead>
<tr>
<th>HIV 1/2</th>
<th>ELISA, Particle agglutination assays, western blot</th>
<th>High, but more sensitive than serum</th>
<th>Use saliva collection device with preservative.</th>
<th>Detects lifetime exposure. Serial testing can be used to determine incidence of infection.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibody assays</td>
<td>Performance characteristics</td>
<td>Storage and processing</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------</td>
<td>------------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td><strong>Genital Swabs (Vaginal/Urethral)</strong></td>
<td><strong>Direct detection of organism</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trichomonas vaginalis</td>
<td>Microscopy and culture EIA</td>
<td>High for culture, variable for EIA</td>
<td>Wet preparation for microscopy. TV culture medium or TV In Pouch.</td>
<td></td>
</tr>
<tr>
<td>Trichomonas vaginalis</td>
<td>PCR</td>
<td>High</td>
<td>Transport at +4°C Store at -80°C</td>
<td></td>
</tr>
<tr>
<td>Chlamydia trachomatis</td>
<td>NAAT</td>
<td>High</td>
<td>Transport at +4°C Store at -80°C</td>
<td>Can pool specimens in low prevalence settings to reduce costs</td>
</tr>
<tr>
<td>Chlamydia trachomatis</td>
<td>Direct fluorescent antigen, EIA</td>
<td>Less sensitive than NAAT</td>
<td>Non wooden swabs, sample must include host cells, transport at 2-8°C</td>
<td></td>
</tr>
<tr>
<td>Neisseria gonorrhoea</td>
<td>LCR/PCR</td>
<td>High</td>
<td>Transport at +4°C Store at -80°C</td>
<td></td>
</tr>
<tr>
<td>Neisseria gonorrhoea</td>
<td>Culture</td>
<td>Less sensitive than NAAT</td>
<td>Selective transport media, incubate at 35-37º C in CO₂ enriched atmosphere</td>
<td></td>
</tr>
<tr>
<td>HSV-2</td>
<td>PCR</td>
<td>High</td>
<td>Transport at +4°C Store at -80°C</td>
<td></td>
</tr>
<tr>
<td>HSV-2</td>
<td>Culture</td>
<td>High-less sensitive than PCR</td>
<td>Transport at +4°C Store at -80C</td>
<td></td>
</tr>
<tr>
<td>HIV RNA</td>
<td>Dependent on specimen collection technique</td>
<td></td>
<td>Cervico-vaginal lavage/swabs in women</td>
<td>Quantification requires exact quantity of specimen to be standardized</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Semen in men</td>
<td></td>
</tr>
</tbody>
</table>

References

5. UNGASS National Report: Nepal 2005
6. MMWR August 11, 2006. 55(31);844-848
11. Reducing HIV Vulnerability from Drug Use by Padmohedojo, UNODC, 2004
12. 2006 UNAIDS Epidemic Update
14. “As India tops with world’s largest number of HIV cases, new strategy targets drug users”, 11/29/2006, International Herald Tribune,
15. HIV/STD Prevalence and Risk Factors among Migrant and Non-Migrant Males of Achham District in Far-Western Nepal, 2002, Family Health International
17. Adolescent and Youth Reproductive Health in Nepal, POLICY, January 2003
18. Sarkar et al, Young Age is a Risk factor for HIV among female sex workers - An experience from India, *Journal of Infection*, November 2005
22. Indonesia Fact Sheet, WHO 2006
Module 6 introduces HIV surveillance among high-risk populations. Eight high-risk populations are described in-depth with recommended surveillance techniques. Detailed case studies are provided for each population to help participants think through implementation. After completing this course, participants should:

- be able to discuss the importance of surveillance in high-risk populations
- understand the purpose of pre-surveillance assessments and the role of qualitative and quantitative research in these assessments
- be able to discuss the advantages and disadvantages of various sampling approaches
- be able to discuss how to choose the most effective biological and behavioural measures in surveys of high-risk groups
- understand the special ethical consideration of conducting behavioural and biological surveillance among high-risk groups.

This course is meant primarily for state/national-level surveillance officers. This module can also be used for self-study.

Module 5 is a prerequisite for this module.