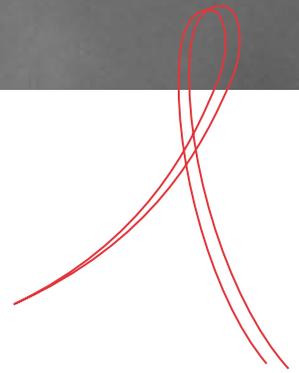


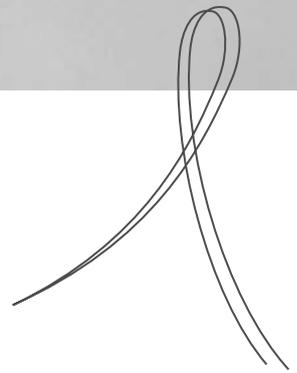


AIDS discrimination in ASIA





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APN+ 2004

Copies of this report can be downloaded from:
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ISBN 0 646 43388 1

Five project team leaders passed away before this project was completed.

APN+ continues to be greatly saddened by the loss of Jeramie Diaz, Archie Rivera and Mar Liwang (the Philippines), Ashok Pillai (India) and Suzana Murni (Indonesia), all of whose lives could have been extended if they had received timely and appropriate treatment and care.

This report is dedicated to them. They each contributed enormously to driving the project forward in their respective countries and to ensuring that it progressed from a firm base. Their keen dedication and commitment is reflected in the quality of this research. They were each esteemed activists and are sorely missed.

APN+ Human Rights Team

This project drew on the support of a considerable number of individuals, including scores of positive data collectors and several academics from various countries.

The Asia Pacific Network of People living with HIV/AIDS (APN+) wishes to thank everybody who has been involved in this project.

At the end of the project, the research team comprised the following persons:

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Mr Greg Gray (APN+ Co-ordinator)

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APN+ gratefully acknowledges the financial contribution of UNAIDS towards this project.



Outline	1
Project description	3
Objectives	3
Major project activities	4
History	5
Process	7
Development of questionnaire	7
Ethical protocol	8
Confidentiality	
Informed consent	
Referrals	
National advisory boards	9
Study sample	9
Training	10
Data collection	11
Data analysis	12
Findings	13
Discrimination in the health sector	15
Context of testing	
Right to privacy	
Right to health	
Reproductive rights	
Clinical trials	
Discrimination within the family	22
Discrimination in the community	23
Discrimination in the employment sector	26

Discrimination in the education sector	28
Right to self-determination and association	28

Conclusions 29

National actions	30
Project recommendations	31

Appendices 33

Appendix 1: Ethical code of conduct	33
Appendix 2: Information sheet	36
Appendix 3: Informed consent form	38
Appendix 4: APN+ human rights initiative questionnaire	39

Tables

Table 1: Sample according to country and sex	13
Table 2: Marital status and education level	14
Table 3: State of health and types of medication	15
Table 4: Context of HIV testing	16
Table 5: Discrimination in the health sector	20
Table 6: Violations of reproductive rights – women	21
Table 7: Violations committed during clinical trials	21
Table 8: Discrimination within the family	23
Table 9: Discrimination in the community	25
Table 10: Discrimination in the employment sector	27

Outline

From July 2001 to November 2002, the Asia Pacific Network of People Living with HIV/AIDS (APN+) conducted the first regional documentation of AIDS-related discrimination in Asia. The project is an action-based, peer-led study that aimed to develop an understanding of the nature, pattern and extent of AIDS-related discrimination in several Asian countries. The project was designed and implemented by people living with HIV (positive people) and received ethical approval and funding from UNAIDS.

This study generated quantitative and qualitative data. Trained positive people interviewed 764 of their positive peers in four countries (India 302; Thailand 338; the Philippines 82; Indonesia 42).

Findings indicate that AIDS-related discrimination is prevalent in every sector of society. Overall, 80% of respondents reported experiencing some form of discrimination, including 54% within the health sector, 31% in the community, 18% within the family and 18% in the workplace.

In all countries, the majority of people did not receive pre-test counselling before being tested for HIV and one in eight respondents said they were coerced into testing, particularly people who tested during pregnancy or because of employment. Many respondents were refused treatment after being diagnosed with HIV and many, including a high percentage of women who tested during pregnancy, experienced delayed provision of treatment or health services. Breaches of confidentiality by health workers were common.

Age and educational background do not influence the level of discrimination faced by positive people but sex, state of health, marital status and the level of choice one has in testing do. Those who said they were coerced into testing were significantly more likely to face subsequent discrimination than people who were prepared for their HIV test.

Women are significantly more likely than men to experience discrimination within the family and the community because of their HIV status, including ridicule, harassment and physical assault and being forced to change their place of residence.

Interviewers described the process of training and data collection as empowering; it equipped them to respond to future human rights violations, provided them with skills and self-confidence in carrying out research and helped to strengthen their networks.

This model of peer-based research may be easily adapted for other countries.

Project description

Widespread AIDS-related discrimination throughout Asia affects the quality of people's lives, their ability to access care and support and to contribute productively to society. Human rights violations of people living with HIV ultimately thwart efforts to prevent further HIV transmission.

Asia Pacific Network of People Living with HIV (APN+) decided that in order to respond to the human rights violations faced by positive people, it is important to map out the extent and complex nature of discrimination that positive people in the region experience. APN+ designed an initiative that would train positive people to interview other positive people in the field about the discrimination they face after their diagnosis.

The APN+ Human Rights Initiative is a community-based, action-research project. It provides data on the types and amount of discrimination that people living with HIV experience and identifies who is most vulnerable to discrimination. It is the first time that AIDS-related discrimination and human rights violations against positive people have been systematically documented in the region.

A unique aspect of the project is that it was initiated and driven by positive people. It aimed to build positive people's capacity to advance a rights-based response to HIV/AIDS and address future human rights abuse in a self-reliant manner. The consultative and participatory nature of the research was an important aspect of the study and was designed to increase the interviewees' awareness of their rights.

The goals of the project were to increase the capacity of positive people to promote the adoption of national policies and programs that protect their rights and reduce stigma and discrimination.

Objectives

- i To collect data on the context, pattern, nature and extent of perceived and actual AIDS-related stigma and discrimination experienced by people living with HIV in Asia

- ii To identify issues that need to be addressed and programs that can be implemented at country level to counter discrimination highlighted in the research results
- iii To increase the capacity of positive people to respond to future human rights violations

Major project activities

- 1 Development of survey tool
- 2 Development of ethical protocol
- 3 Establishment of national advisory boards
- 4 Development of human rights training module
- 5 National training in human rights documentation
- 6 Data collection
- 7 Data analysis
- 8 National reports
- 9 Regional consultation

History

In 1997, at an APN+ Strategic Planning Meeting, three APN+ Board Members (from Australia, Hong Kong and Taiwan), designed a peer-led initiative to increase the capacity of positive people to respond to AIDS-related discrimination and human rights violations. APN+ conducted basic human rights training for over 40 positive people at the GNP+ Conference, Chiang Mai, Thailand in November 1997. In May the following year, APN+ developed a questionnaire to be used in the study and applied to UNAIDS for ethical approval to carry out the project in four Asian countries: India, Indonesia, the Philippines, Thailand.

In August 1998, UNAIDS requested that APN+ also obtain ethics approval in each country in which the project was to be carried out. This was a challenge for country representatives, many of whom had never previously worked with academics. Identifying sympathetic academics and waiting for ethics approval took considerable time. During 1999, Research Ethics Committees of Pune University (India), University of Udayana (Indonesia), HAIN (the Philippines) and Mahidol University (Thailand) all approved the research protocol. UNAIDS also requested that APN+ develop the ethical protocol based on consultations with key stakeholders. In August 1999, APN+ carried out 82 interviews with positive people, lawyers, academics, ethicists, and staff of government, non-government and AIDS service organisations and UNAIDS in the each of the four countries.

In May 2000, UNAIDS gave ethical approval for the project to proceed. Unfortunately, by then all but two of the positive people from the original working group were unavailable for the project, mostly due to ill health. Therefore, APN+ had to train several new team members and reignite passion for the project within each country. In 2001 UNAIDS provided funding to commence the documentation.

Indonesia was the first country to start data collection, in July 2001, thanks to additional assistance from AusAID. The Philippines followed in August 2001, India in February 2002 and Thailand in August 2002. All data was collected by the end of 2002.

A regional workshop was held in Bangkok in May 2003, to report back on the preliminary project findings. The workshop was attended by APN+ Board Members and over thirty positive people from seventeen Asian countries, as well as representatives from various United Nations agencies and international non-government organisations (NGOs).

By the end of 2003, national workshops had been conducted in each country to develop strategies and interventions to counter AIDS-related discrimination. Recommendations were developed based on the findings highlighted in the national reports.

An extensive survey was conducted among 764 positive people in four countries (India, Thailand, the Philippines, Indonesia). Case studies were also collected to illustrate the nature of AIDS-related discrimination. Selection of participating countries was based on the availability, strength and commitment of the positive leaders in each country at the time, and the support they could expect in carrying out the project.

Development of questionnaire

Positive people from eight countries in the Asia Pacific region developed the first draft of the data-collection instrument, an extensive questionnaire, which is designed to be completed by researchers during interviews, not self-administered by respondents.

Eight dimensions of discrimination, based on the human rights framework presented in the Universal Declaration of Human Rights and the APCASO Compact on Human Rights were used as the major sections of the questionnaire:

- ◆ Right to health
- ◆ Right to privacy
- ◆ Right to liberty and security of person
- ◆ Right to freedom from inhuman and degrading treatment or punishment
- ◆ Right to employment
- ◆ Right to marry, found a family and form significant relationships
- ◆ Right to education
- ◆ Right to self-determination and association

The questionnaire attempted to document all conceivable cases of discrimination that a person living with HIV might face, in the health sector, the family, the community, the workplace and within educational establishments.

Over 50 pilot interviews testing the questionnaire were carried out in the region and it was submitted to UNAIDS and selected researchers for preliminary review. Modifications were made to the questionnaire and it was translated into local languages before data collection began.

Ethical protocol

In order to develop the ethical protocol for data collection, the APN+ Human Rights Team conducted an extensive series of one-to-one consultations with key stakeholders in each country, including: positive people, lawyers, academics, ethicists, government officials, workers in non-governmental AIDS organisations and UNAIDS staff. The objective was to identify risks associated with the study, inclusion and exclusion criteria, criteria for discontinuation of the study, strategies for recruiting vulnerable populations, and to develop a referral network. In total, 82 people were formally consulted in four countries (India 23, Indonesia 25, the Philippines 14, Thailand 20). An Ethical Code of Conduct (see Appendix 1) was developed to guide the study. The research protocol was approved by ethics review committees in all collaborating countries and by UNAIDS.

Confidentiality

Maintenance of confidentiality was the key concern of the research team as it was recognised that a breach could lead to loss of employment, loss of health care facilities, ridicule, social ostracism or physical violence.

Using a small group of HIV-positive interviewers was a safeguard against breaches of confidentiality, as they understood the potential for discrimination, were particularly sensitive to the needs of the study participants and were therefore unlikely to disclose their status. As a further safeguard, no names, addresses or personal identification of respondents were recorded in the study.

Informed consent

An information sheet (Appendix 2) was provided to all respondents to inform them that they were free to refuse to participate or withdraw from the study at any time. This information sheet was translated into local languages. Oral informed consent (Appendix 3) was required from respondents; it was felt that written consent would be a real and unnecessary deterrent to potential interviewees in such a sensitive social research project. Participants were also informed of how to contact the person in charge of the study in the event that they had complaints.

Referrals

Legal, medical and social referrals were identified by the local investigators prior to data collection. At the end of the interview, respondents were offered referral services specific to each study location, if needed.

National advisory boards

A National Advisory Board (NAB) was set up in each country, consisting of members of AIDS service agencies, positive leaders, academics, National AIDS Program administrators, UNAIDS in-country advisers and community leaders. The role of the NAB was to advise the research team in all aspects of the project, including:

- ◆ to monitor that the study was conducted according to the ethical protocol;
- ◆ to advise and monitor the referral system;
- ◆ to advise the team on data analysis;
- ◆ to advise the team on follow-up activities based on the study findings;
- ◆ to resolve any complaints about the study;
- ◆ to advise the research team to abandon the project, partially or completely, if massive or systematic deviation occurred from the project protocol.

Within each country, an academic was appointed as the National Principal Investigator and a positive person as the National Team Leader. These two individuals worked collaboratively on the project.

National Team Leader's role was to:

- ◆ co-ordinate all in-country activities, including National Advisory Board meetings, recruitment and orientation of interviewers, overseeing data collection, organising National Workshop, writing National Report;
- ◆ liaise at regular intervals with the APN+ Human Rights Convenor;
- ◆ administer funding in-country.

National Principal Investigator's role was to:

- ◆ guide the team in carrying out the project in an ethically sound manner;
- ◆ analyse and manage data.

Study sample

The study sample contains a mix of positive people of different ages, sexuality and economic, social and educational backgrounds. The sample is not representative of the epidemiological profile of HIV infection in each country. Most people who are infected with HIV are not aware of it. People who are tested for HIV are a skewed sample of actual infections. They may represent, for example, higher numbers of migrant workers, women attending antenatal clinics or military personnel than in the general

population because certain groups of people are more likely to be tested for HIV than others, with or without their consent. Of the people who do test HIV-positive, most keep their status secret for fear of the stigma and discrimination they may face if they reveal their status. Many do not access medical care and/or do not reveal their status to anybody, even their family.

The sample size was determined by the maximum number of positive people that interviewers could reach in each country at the time the study was conducted. Interviewers cast their nets widely from peer support groups, testing sites, hospitals and AIDS service organisations to capture the experiences of as many positive people as possible. Within each country, respondents were recruited from several regions. The documentation, by necessity, utilised a convenience sample of positive people. The findings may not be representative. People interviewed may have suffered greater amounts of discrimination than others, or people who have no contact with AIDS organisations may have experienced more discrimination and been silenced to a greater extent and are harder to reach. Nevertheless, because of the large sample size, it can be assumed that the findings reflect the experiences of thousands of people living with HIV in the region.

The questionnaire did not ask respondents how they contracted HIV as this was seen to be intrusive. No data is therefore available to compare levels of discrimination experienced by people who contract HIV by different modes.

Training

Training was essential to strengthen the capacity of the positive people involved in data collection and was considered to be as important as the development of the data collection instrument. A three-day national training workshop was held for each data collection team. National Team Leaders, in consultation with Principal Investigators were responsible for co-ordinating the training and orientation of all data collectors.

Day 1 dealt with the concepts of stigma, discrimination and human rights; it was conducted by a person with a legal background, in conjunction with the APN+ National Team Leader. Day 2 focussed on training participants in interviewing techniques, particularly sensitising interviewers on how to deal with potentially difficult emotional situations; it was facilitated by an academic with experience in qualitative data collection. Day 3 was devoted to interview practice, developing a referral system and the logistics of

data collection. Training was rigorous in relation to the procedures and mechanisms to ensure confidentiality and was vital in ensuring the interviewers understood the ethical implications and psychological risks for the research participants.

In total, 46 HIV-positive interviewers (27 women, 19 men) were trained: India 14 (from Chennai, Calcutta, Goa, Manipur, Pune); Thailand 12 (Bangkok, Surat Thani, Chiang Mai, Chiang Rai); the Philippines 12 (all Manila-based); Indonesia 6 (Jakarta, Sulawesi, Bali). Data collectors gained increased confidence and self-respect by carrying out this project.

I am very happy with the training because usually we sit and listen and that is it but we are going to do something with what we learn. We are being trained to interview people. We are being trained as community-based researchers. It's very good.

Data collection

Each trained researcher was assigned to conduct approximately 20 interviews. Interviewers used the structured questionnaire (see Appendix 4) as a trigger to probe discrimination in greater detail, so as to build case studies. Administering the questionnaire via interview took approximately one hour. No monetary remuneration was given to study respondents.

In Indonesia and the Philippines, researchers travelled to outlying provinces to carry out interviews. In India and Thailand, researchers collected data within their own districts. During the data collection period, the research team met weekly, wherever possible.

The team members in each country developed pride and ownership of the project, resulting in strong team spirit. Interviewers were empowered by the process, from the data collection training to interviews with peers in the field. The strong motivation of the interviewers carried the project forward very efficiently and the study gained great momentum.

Some minor problems encountered in the data collection phase included:

- ◆ slow return of completed questionnaires;
- ◆ inability to reach targeted number of interviews;
- ◆ inaccurate or careless completion of the questionnaire;
- ◆ inability of interviewers to probe sufficient details of the discriminatory episode;
- ◆ difficulty in finding an appropriate private space in which to conduct interview.

The vast majority of people (over 95%) approached for an interview were keen to discuss their experiences. In Indonesia nobody refused to be interviewed; in the Philippines only one person refused. People who declined an interview said it was because they were unwell or had no time available.

Data analysis

Quantitative data was analysed using SPSS statistical package. Statistical comparisons including chi square tests were carried out; all significant differences reported have a probability of less than .05.

Findings

Major study findings are provided below; detailed National Reports are available from UNAIDS country offices. Although sample sizes are less than 100 in Indonesia and the Philippines, percentages are used in most tables for easy comparison only.

In total 764 interviews were conducted; after cleaning data there were 753 useable questionnaires.

Table 1: Sample according to country and sex

Country	Female	Male	Transgender	Not recorded	Total
India	126	159	2	4	291
Thailand	163	175	0	0	338
Philippines	39	40	3	0	82
Indonesia	20	20	1	1	42
Total	348	394	6	5	753

Overall, 46% of the sample was female and 52% male (1% transgender; 1% sex not recorded). Mean age was 32.1 years (females, 30.6; males 33.3; transgender 37.0). Ages ranged from 16 to 60 years. More than one in three respondents were married or living in a de facto relationship (females 32%; males 39%); 50% of females and 8% of males were widowed; 46% of males and 10% of females were single. Of the 55% of respondents who had children, the average number was 1.8 (maximum 7).

Women were less likely than men to have any secondary education (47% v 67%) and much less likely to have university education (12% v 24%). Indian respondents were most likely to have no formal education (13% v 2%). The Philippines cohort had the highest education level; 55% of respondents had a university education versus 11% from other countries. The Philippines also had the highest rate of unemployment (40%). There was no significant relationship between age, income or educational background, and the level of discrimination experienced.

Table 2: Marital status and education level

	Females (%) (n = 348)	Males (%) (n = 394)	Total (%) (n = 742)
Marital status			
Married/de facto	32	39	36
Widowed	50	8	27
Separated/divorced	5	6	5
Single	10	46	30
In a significant relationship	3	1	2
Total	100	100	100
Highest education level			
None	6	6	6
Primary	47	27	36
Secondary	28	34	33
Technical	7	9	8
University	12	24	17
Total	100	100	100

Respondents had been diagnosed as HIV-positive an average of 3.9 years; the range of time since diagnosis was 0–20 years. The vast majority of respondents were diagnosed within the past five years. Respondents in Thailand had been diagnosed, on average, for the longest period (mean 4.8 years) and Indonesian respondents for shortest period (mean 2.3 years).

Respondents were asked about their current state of health and to describe any medication they were taking. There were no appreciable differences between men and women. Less than half the respondents said they were in good health; 16% of men and 14% of women said they were ‘unwell’. Only in Thailand were 50% of people on prophylaxis to prevent opportunistic infections and 30% on antiretroviral medication. Overall, 21% of males and 15% of females were taking antiretrovirals.

People who described their health status as ‘unwell’ were more likely to experience discrimination than those who said they were in good health. People who were unwell faced more discrimination than other respondents, not only within the health sector (where they probably had more exposure of their status than well people did), but also in most other sectors including employment, family, friends and the general community.

Table 3: State of health and types of medication

	India (%) (n = 291)	Thailand (%) (n = 338)	Philippines (%) (n = 82)	Indonesia (%) (n = 42)	Total (%) (n = 753)
No. years since diagnosis	3.2 yrs	4.8 yrs	4.4 yrs	2.3 yrs	3.9 yrs
Current health status					
Good	41	44	39	50	43
Just okay	44	41	41	26	41
Unwell	15	15	20	24	16
Total	100	100	100	100	100
Currently taking medication	50	70	39	40	57
Type of medication*					
Antiretrovirals	8	30	22	2	22
Prophylaxis	15	50	4	14	31
Traditional medicine	5	6	9	10	6
Opportunistic infections	29	14	7	-	18
Other	8	4	12	14	7

* possibly more than one answer

Discrimination in the health sector

By far, the major area of discrimination in each country is within the health sector, probably because it is only within the health sector that most positive people are likely to disclose their HIV status. Over half of the sample (54%) experienced some form of discrimination within the health sector. This discrimination often commenced before the person knew they are HIV-positive, at the point of testing.

Context of HIV testing

The reasons why people go for HIV tests vary greatly. Men were much more likely than women to be referred for testing because they had HIV-related symptoms (37% v 10%), whilst women were much more likely than men to be tested because their partner had tested positive (42% v 11%).

In the Philippines, more than one in three respondents were tested for employment purposes, whilst in Thailand this only accounted for 4% of responses. Thais were more likely to test because they ‘just wanted to know’ than were respondents from any other country (33% v 16%). In Indonesia, many respondents were tested as a pre-requisite for enrolling in drug rehabilitation programs but this was not anticipated in the questionnaire. Sex workers who had undergone mandatory testing also fell into the ‘other’ category, as did people tested while donating blood (1% of Indian

respondents). Only in India and Thailand were respondents asked whether they were tested during pregnancy.

The majority of people (66%) were tested in a hospital. Most diagnoses, 56%, were given by a doctor; 21% by a nurse; 9% by a social worker; 3% by a counsellor and 11% by a person outside the health sector such as a family member or an employer.

Frequently, test results were given to respondents in front of a third person, usually a friend or family member. This happened more frequently with females than with males (44% v 39%). In Indonesia, if the respondent was admitted into a drug rehabilitation centre, the third persons present were parents, regardless of the client's age.

Table 4: Context of HIV testing

	Females (%) (n = 348)	Males (%) (n = 394)	Total (%) (n = 742)
Main reason for having test			
Employment	5	12	8
Pregnancy	25	5	14
STI clinic referral	3	5	4
Referral/HIV-related symptoms	7	32	20
Partner tested positive	42	11	26
Just wanted to know	7	24	17
Other	11	11	11
Total	100	100	100
Unprepared for test/reasons not explained	49	42	46
Coerced into taking the test	13	10	12
Received pre-test counselling	37	39	38
No information given pre-test	26	31	30
Received post-test counselling	55	51	53
No information given post-test	17	25	21
Result given in presence of someone else	44	39	41

Forty-five per cent of respondents said that they were not ready to be tested when the test was done and that nobody explained the reasons for the test beforehand. Only 22% of people who tested because of pregnancy said they were prepared for their blood test at the time, compared with 74% of people who tested because they 'just wanted to know' and 67% who tested because their partner was positive. In the Philippines and Thailand, the majority of people said they were unprepared to take the HIV-antibody test at the time it was done.

A doctor told me to take the blood test before having the operation but he did not tell me that the test was for HIV.

He did not give any information, only told me that he was unable to employ me due to my blood test.

One in every eight respondents said they were coerced into testing. Women were more likely than men to be coerced into an HIV test (14% v 10%). People most commonly cited coerced testing in relation to employment or pregnancy. Eighteen per cent of respondents who tested during pregnancy and 31% of those who tested due to employment said they were coerced into testing; only 29% who tested for pregnancy and 14% who tested for employment received pre-test counselling. The majority who tested due to employment, pregnancy or AIDS-related symptoms said nobody explained what the test was about before the test.

The majority of people in all countries received no pre-test counselling and only 53% of respondents received post-test counselling; 20% received no information whatsoever about HIV/AIDS at the time they were told of their positive diagnosis.

People who said they were prepared to take the test were less likely to experience subsequent discrimination from health workers. People who said they were coerced into testing subsequently faced significantly more discrimination than respondents who were not coerced, not only from health care workers (44% v 23%), but also from family (26% v 12%), neighbours (38% v 24%), landlords (21% v 8%) and employers (15% v 7%).

Right to privacy

Breaches of confidentiality by health care workers are common. One in three people (34% of the sample) said that somebody else had been told of their HIV status without their consent. Over 20% of the respondents said they had not disclosed their HIV test results to anybody else, but only 7% said that nobody else knew about their HIV status; two of every three people who wanted to keep their status secret were unsuccessful in doing so.

When Mike was hospitalised, doctors wanted to draw blood from him so they could do an HIV test. He already knew that he was HIV-positive, so he refused but the hospital staff managed to get a sample of his blood after telling him they were just going to take his blood pressure. Mike and his wife Anna endured humiliation when the entire hospital found out about his HIV status. The nurses suddenly refused to attend to him and non-medical personnel

such as hospital cleaners refused to enter his room. People in the hospital also avoided Anna's presence and would talk in whispers about her. The counsellor of the hospital told the owners of the house where Anna and Mike lived that they had AIDS. Anna was told over the phone that they had to move out. She sent a letter asking for a meeting because they had a lease on the house. The owner's son, who was a policeman, came and spoke to their house help. He shouted at her and told her, 'If you and your employer will not leave, I will shoot and kill all of you. You tell your employer to leave our house'.

Family members (20%), co-workers (8%), other health care workers (7%), government officials (3%) or media (1%) were told of people's HIV status without their consent, sometimes even before the person was told. Breaches of confidentiality can have far-reaching consequences. One Filipina respondent described facing extreme hostility from villagers after her HIV status was accidentally disclosed by the media; she was requested to leave and did so in the middle of the night dressed as a man.

Right to health

Overall, 26% of respondents (33% of those who said they were unwell) reported having been discriminated by a health care worker; 15% of respondents were refused treatment or care; 17% experienced a delay in the provision of health care services. Many positive people were turned away from health centres once their HIV status was known. Some respondents (9%) were persuaded or advised not to access health care services, often by health care workers; 9% said they were forced to pay additional charges for treatment or health services because of their HIV status.

Respondents who tested because of pregnancy or employment were most likely to experience a delay in treatment or health care (21%); those who tested during pregnancy were significantly more likely than other respondents to have been forcibly required to submit to a medical or health procedure (15% v 6%). Men were significantly more likely than women to have been denied medical treatment over the previous twelve months (17% v 9%).

Other people who came after me received treatment while I did not. My appointment was arranged again for the next day without any attention paid from the doctor.

I went to the hospital for treatment of another disease but as they knew I had HIV from the history file, the doctor refused to treat me. He said this disease would not be necessary for treatment.

When arriving at the hospital about to give birth, I was told, 'You're not fit to give birth here'.

In Indonesia, women were twice more likely than men to experience discrimination from health workers. In India, one respondent claimed his child had died due to neglect by health care workers. Most people who experienced discrimination within the health care sector said it was an isolated incident, rather than something that tended to happen often.

Respondents who said they were unprepared to take the test before it happened were significantly more likely to have ever been discriminated by a health care worker because of their HIV status (33% v 20%) or to have been denied medical treatment in the twelve months prior to the interview (16% v 9%) than respondents who had been prepared for their HIV test.

People coerced into HIV testing were significantly more likely to experience much more discrimination from health care workers (44% v 23%), be forced to pay more than other people pay for the same services (22% v 8%) and to have participated in clinical studies (32% v 17%).

Ratih found she had cancer and was admitted to hospital in a poor state of health. She was asked to have an HIV test and felt somewhat pressured into it. Ratih had to fetch the results from the hospital laboratory and read them herself, because there was no counselling. The result showed that she was HIV-positive, so Ratih did not want anyone else to know, but the results were leaked widely. Suddenly, Ratih was moved to a single ward and the catering staff refused to enter her room and instead passed her food through a window. Ratih was due to have lung and heart tests, but staff were unwilling for the test equipment to be used on her so the tests were cancelled and her oncologist refused further treatment.

Overall, 7% of respondents (females 10%, males 5%) were denied private insurance because of their HIV status. Thai respondents were most likely to report losing or being denied private insurance once their HIV status was known (15% v 2%); 33 of the 51 Thai respondents who reported discrimination in private insurance were women.

Table 5: Discrimination in the health sector

	India (%) (n = 291)	Thailand (%) (n = 338)	Philippines (%) (n = 82)	Indonesia (%) (n = 42)	Total (%) (n = 753)
Experienced AIDS-related discrimination from health care worker	30	17	49	31	26
Experienced breaches of confidentiality	29	40	36	29	34
Refused treatment due to HIV-positive status	20	11	11	14	15
Experienced delay in treatment due to HIV status	20	11	22	14	17
Denied medical treatment in past 12 months due to HIV	14	10	15	-	13
Persuaded or advised not to access health care services due to HIV status	11	6	5	10	9
Person who gave this advice					
Family members	3	1	5	2	2
Friends	2	4	1	5	3
Health care workers	7	2	2	2	4
AIDS service agencies	1	1	0	-	1
Other	1	-	7	-	1
Forced to pay additional charges for medical services/treatments	15	4	11	5	9
Forcibly required to submit to medical or health procedure	5	9	7	7	7
Denied private insurance due to HIV status	1	15	7	0	8

Reproductive rights

Of the women who tested during pregnancy, 79% said they were unprepared for the test, 35% said the test was ‘mandatory’, only 30% received pre-test counselling, and 20% said they were coerced into testing.

Over 15% of all the females in the study said they had undergone mandatory testing whilst they were pregnant or because of the illness of a child. Almost one third of the sample (45% of females, 18% of males) was advised not to have children after diagnosis, but only one in five respondents was given information about prevention of parent-to-child transmission. A majority of the women who tested whilst pregnant (69%) was advised not to have children and 31% of these said they were coerced into an abortion or sterilisation after diagnosis.

Table 6: Violations of reproductive rights – women

	India (%) (n = 126)	Thailand (%) (n = 163)	Philippines (%) (n = 39)	Indonesia (%) (n = 20)	Total (%) (n = 348)
Mandatory HIV testing during pregnancy or due to illness of child	18	15	5	15	15
Coerced into an abortion or sterilisation due to your HIV status	10	17	0	5	12
Advised not to have a child since HIV-positive diagnosis	23	62	46	60	45

Lakshmi was pregnant and about to give birth. When she arrived at the hospital that she had been visiting during her pregnancy, the workers on duty refused to admit her and referred her to another hospital saying they did not have the right staff on duty that night. She took a rickshaw to a second hospital. Here again staff refused to admit her. Although she did not know how it was possible, Lakshmi understood that the staff already knew of her HIV status. They backed away when she entered and avoided touching her. Again she was referred on to a third hospital. By now having heavy labour pains due to strong contractions, she took another rickshaw to the third hospital. Again the clerk refused to admit her. Nurses began to argue with her saying they could not deliver her baby because she was HIV-positive. By then Lakshmi was partly delirious and started to give birth. The hospital staff members were forced to help with the delivery but they did not touch the baby and Lakshmi was made to clean the floor after giving birth.

Clinical trials

In total, 143 people (one in five respondents) were involved in clinical trials (India 39, Indonesia 2, the Philippines 31, Thailand 21). The average length of time spent on a clinical trial was 16 months.

Table 7: Violations committed during clinical trials

	India (n = 39)	Thailand (n = 71)	Philippines (n = 31)	Indonesia (n = 2)	Total (n = 143)
Did not know drug/trial name	19	18	8	1	45 (31%)
Did not know purpose of trial	18	22	7	1	48 (34%)
Risks of trial not explained	24	14	8	1	47 (33%)
Average period on trial (months)	8	25	9	6	16
Requested to stop participation	6	9	7	1	23 (16%)
Request not honoured	2	2	2	1	7 (5%)
Offered treatment at end	4	24	11	0	39 (27%)

One in three trial participants was unaware of the purpose of or the risks associated with the trial before they agreed to participate. Respondents involved in clinical trials were significantly more likely to have been coerced into HIV testing than others. Five per cent of people involved in clinical trials asked to cease their participation but their request to stop was not honoured. Thai respondents were most likely to receive treatment at the end of the trial (34% v 21%).

Discrimination within the family

After diagnosis, 18% of the sample experienced some discrimination from their family; 14% were excluded from usual household activities such as cooking, sharing food or eating implements or sleeping in the same room as other family members. Women were significantly more likely to be excluded from usual household activities than men were (18% v 11%), often by in-laws. When people experienced discrimination from their family, it was not an isolated incident but tended to be a frequent or continuing occurrence. Respondents who reported coerced testing were significantly more likely to experience discrimination from family members than were respondents who did not report coerced testing (27% v 13%).

In India, women were twice as likely as men to be deserted by their spouse because of their HIV status (13% v 6%), whilst in Thailand, women were much less likely than men to have been deserted (5% v 9%). In each country, women were more likely than men were to have lost financial support from their spouse (35% v 12%) or from other family members (11% v 5%) due to their HIV status. Many women faced a greatly increased financial burden after the death of their spouse; several ended up in very destitute conditions with no money for food. Forty-two per cent of female respondents who tested during pregnancy are now widowed (including 73% of women who tested because their partner was found to be positive). These women often have dependant children and faced the greatest amounts of stigma in society. Eighteen respondents said their children were involuntarily taken away from them because of their HIV status.

Table 8: Discrimination within the family

	India (%) (n = 291)	Thailand (%) (n = 338)	Philippines (%) (n = 82)	Indonesia (%) (n = 42)	Total (%) (n = 753)
Excluded from usual activities by family members	20	10	15	7	14
Deserted by partner because of HIV status	10	6	4	21	8
Lost financial support from family members due to HIV	13	3	14	-	7
Child(ren) involuntarily taken away due to HIV status	2	2	4	5	3

Discrimination in the community

When people’s confidentiality about their HIV status is breached in the community, the response from ‘friends’ and neighbours can be extremely negative; 32% of respondents experienced some AIDS-related discrimination within the community.

Over one in four people faced ridicule, insult or harassment because of their HIV status. Women who were not married or in a de facto relationship were significantly more likely to experience AIDS-related ridicule, insult or harassment than married women (36% v 22%). For women who tested during pregnancy, the likelihood of being subjected to harassment and/or ridicule increased; respondents who tested because they ‘just wanted to know’ their status were least likely to be ridiculed or harassed (13% v 28%).

I felt that everyone was looking at me. I was very angry because they were disgusted. When they passed by me, they would walk sideways. They didn’t want to be touched by me. They would pretend as if they were walking towards another direction. I saw that clearly and I would cry and cry.

Some people laughed at me when I walked past them. When I looked at them, they stopped quietly.

People refused to sit nearby. Some ran away from me.

He told me not to come to his shop again to buy a soft drink. He was afraid of no customers coming to his shop.

I went swimming in the stream but someone admonished me not to swim because I have AIDS and all the fish would die. Although I was sleeping in my own field, people still complained about me.

My sister went to the temple and the monk told her that if she is HIV-positive, she would be refused entry.

The neighbours did not want their children to play with my child. Previously, they used to play together but since they knew my status, they stopped.

They always said to be careful of mosquitoes from my house.

I was blamed that I have HIV from selling sex in Bangkok. 'Having HIV means having bad behaviour', they said in front of me.

Seventeen per cent of women and 13% of men said they had been denied benefits, privileges or services given to others because of their HIV status. Fifteen per cent of respondents (19% of those who said they were unwell) experienced AIDS-related discrimination from friends and 12% (women 16%, men 9%) said they were excluded from social functions at some time. Of the respondents who were tested because of pregnancy, one in four was subsequently excluded from social functions; of respondents who tested because they 'just wanted to know', only 8% experienced exclusion from social functions. Thai respondents were most likely to be excluded from social functions because of their HIV status (18% v 7%).

One in ten people was forced to change their place of residence because of their HIV status; some people moved residence more than once (up to nine times in one instance). Women were twice more likely than men to have changed their place of residence due to their HIV status (12% v 6%). For many, finding an alternative place to live was a difficult challenge. One Indian woman said her in-laws chased her out of her home and she had to sleep in the graveyard.

One day an officer from the Social Welfare Department visited Dina's workplace. Without any explanation as to why, a sample of her blood was taken. Several months later, Dina married her partner. Dina was amazed at the attention paid to her marriage by the officials concerned. Several days after the wedding, she felt that she was receiving abusive treatment from her new neighbours. Dina learned that her wedding photograph had been published in a newspaper, together with her name and details of her village. The newspaper presented it as news of the marriage of a person with HIV. Dina was very surprised, because this was the first she knew that she was HIV-positive. The neighbours asked Dina to move immediately, and if she didn't they threatened to report her to the owner of the house. The next day, the owner came and evicted Dina and her husband. They moved to another village, but a policeman demanded that they not live in that village. Similar situations happened six times.

In total, 30 women, 11 men and one transgender person had been refused entry to, asked to leave or removed from a public establishment due to their HIV status; this includes some people who were refused entry to places of religious workshop. Physical violence and segregation or quarantine are violations to people's liberty and security of person. Of the total study sample, 5% have been assaulted because they are HIV-positive. Women were more than twice more likely than men to have been physically assaulted because of their status. In Indonesia, 12% of respondents have been detained, isolated or quarantined because of their HIV status.

Whilst attempting to enter another country, 5% of respondents (19 men, 17 women and 2 transgender persons) were forced to disclose their HIV status. Overall, 2% of respondents were charged, sued or brought to court in relation to HIV.

Women were significantly more likely to be ridiculed, insulted or harassed, excluded from social functions, forced to change residence, refused entry into a public place, and physically threatened and assaulted because of their status than men were.

Table 9: Discrimination in the community

	Females (%) (n = 348)	Males (%) (n = 394)	Total (%) (n = 742)
Ridiculed, insulted or harassed because of HIV status	31*	20	26
Experienced discrimination from friends because of HIV status	16	15	15
Excluded from social functions because of HIV status	16*	9	12
Forced to change residence because of HIV status	12*	6	9
Refused entry to, removed from, asked to leave public establishment due to HIV	9*	3	6
Threatened by physical violence due to HIV status	8*	3	6
Physically assaulted because of HIV status	7*	3	5
Had to disclose status in order to enter another country	5	5	5
Quarantined, segregated, detained, isolated due to HIV	4	3	4

* indicates significant difference in proportions between female and male respondents ($\leq .05$)

Discrimination in the employment sector

One of every six people in the sample (18% of respondents; 63 women, 69 men) experienced some form of discrimination within the workplace setting. However, only in Thailand and India were respondents asked whether they had worked for an employer since their diagnosis; 48% of Thais and 70% of Indian respondents said they had.

Of the 63 people who were tested for HIV because of potential employment, 43 (68%) said that the reasons for the test were not explained beforehand and 15 said they were coerced into testing; only 9 respondents received pre-test counselling and 17 received post-test counselling.

In total, 16 women and 48 men had been tested for HIV because of employment yet 23 women and 29 men lost their jobs because of their HIV status. Of those who said they worked for an employer at the time of or since their diagnosis, one in five said they had lost their job because of their HIV status.

Pramod, a police constable who worked in a jail, came to know about his HIV-positive status when he went to the government doctor with a complaint of Herpes Zoster. In good faith he told his senior officer. After some days he got a letter of transfer to another district jail; he was told that it was a routine transfer. When Pramod reported for duty at this jail, he learnt that everyone there knew his status. He was then given a letter stating that since he is positive, he and his wife must look for other accommodation instead of the government premises allocated to him. He was also told that he would not be allowed to use the facilities available to other employees for washing clothes, bathing, or shaving, due to his status. Pramod was very disturbed but when he argued with his superior about this, he was badly beaten by the jailer and his subordinates and they told him that he should leave the premises immediately. Pramod fell to the ground unconscious and was taken to the government hospital for treatment.

Table 10: Discrimination in the employment sector

	India (%) (n = 291)	Thailand (%) (n = 338)	Philippines (%) (n = 82)	Indonesia (%) (n = 42)	Total (%) (n = 753)
Worked for an employer since diagnosis	70	48	-	-	-
Experienced AIDS-related workplace discrimination	12	7	21	15	10
Discrimination by employer because of HIV status	8	6	33	14	10
Discriminated by colleagues due to HIV status	8	11	-	-	10
Lost job because of HIV status	6	2	33	2	7
Job description or duties changed due to HIV status	3	7	44	5	9
Offered early retirement due to HIV status	1	1	16	0	2
Lost prospect for promotion because of HIV status	2	2	21	0	4
Experienced harassment or discomfort on job due to HIV	6	6	13	5	7

In the Philippines, a much higher proportion of respondents experienced workplace discrimination than respondents in other countries. Although only 21% said they had faced discrimination in the workplace, in fact the incidence of violations was much higher. People lost their job (33%), their job description or duties changed (44%) or they lost prospects for promotion (21%) because of their HIV status. In many instances, the respondent did not immediately identify this as a form of discrimination or violation of their right to employment.

Most people who experienced AIDS-related discrimination in the workplace said it was not an infrequent event but tended to happen 'quite often'. The vast majority (97%) had no recourse for action. Twenty per cent of respondents, including half of the respondents from the Philippines, said that their earning capacity had decreased because of their HIV diagnosis.

Discrimination in the education sector

There were fewer violations within the sphere of education than in other areas. On the other hand it is probable that educational institutions are not aware of most students' status. Overall, 12 women and three men (2% of sample) said that they or their child(ren) had been denied admission into an educational establishment because of their HIV status; most were from Thailand.

Right to self-determination and association

A small proportion of respondents (5%) was excluded from associations, societies or clubs due to their status. Over 40% of the respondents had participated in some form of decision-making committee and in the vast majority of instances (97%) respondents found their participation useful. Unfortunately, over 20% of respondents were not referred to any self-help group for people living with HIV, 27% did not know of any local groups and 4% were restricted in their ability to meet with other positive people. Family members were usually responsible for discouraging meetings with peers.

Over half of the sample needed referrals after the interview, mostly for counselling; one in ten needed legal advice.

Conclusions

These findings provide a broad sweep of the nature, pattern and extent of AIDS-related discrimination in Asia. Serious and harmful discrimination against positive people prevails, even in countries with progressive anti-discrimination legislation in relation to AIDS, such as the Philippines, and in countries with well-established epidemics and 'model' responses, such as Thailand.

The level of unemployment of positive people overall is disconcerting considering that most positive people have the responsibilities of parenthood and many are single or widowed. In the Philippines, the very high proportions of people tested for employment and of people refused entry into another country reflect the Philippines' high proportion of migrant workers. This country sample has the highest levels of education, workplace discrimination and unemployment. Many people were tested for overseas contract work and subsequently lost prospects of employment. Regional organisations need to place greater international pressure on receiver countries to overturn policies requiring HIV tests for employment or educational purposes.

The extent of coerced testing and the number of people tested without pre- or post-test counselling is disturbing. Most diagnoses are given by a doctor; but busy doctors may not be the most able persons to provide appropriate counselling and support to somebody who has just received the news that they have a highly-stigmatised, life-threatening condition. Positive people can be trained and employed widely to provide this necessary post-test counselling. Most people coerced into testing go on to experience discrimination within the very sector that tested them. This is particularly worrying considering the increasing trend in many countries to test all pregnant women. These women are tested during a very vulnerable period of their lives and may then be subjected to refusal of treatment, abuse and breaches of confidentiality that may have severe consequences on their mental and physical health; these women may also experience extreme violations of their right to security of person by their family.

Many instances of discrimination by family, work colleagues or community members are triggered by breaches of confidentiality by health care staff.

Concerted, extensive and comprehensive HIV awareness raising, by positive people, needs to be carried out amongst health sector workers. Counsellors, nurses and doctors can be the vanguards of change, and are significant players in the fight against discrimination.

The findings in relation to clinical trials are of concern. An investigation into the quality of informed consent given to trial participants should be undertaken.

There are remarkable similarities in the extent of discrimination between countries, particularly in the lack of information provided to people before and after they are tested for HIV and the extent of discrimination against women. The most significant factor influencing whether people experience AIDS-related discrimination within the family and the community is not age or country, but the sex of respondents. Women consistently face significantly more discrimination than men do, including being forced to move residence, being harassed, ridiculed, threatened and physically assaulted. This reflects the judgemental and blameful attitudes to HIV/AIDS, women's low social status and the different expectations of men and women in society. A strong focus is needed to educate women about their rights; positive women are uniquely placed to carry out this education.

A lasting outcome of the project is the enhanced capability of positive people's organisations to conduct research and carry out human rights advocacy. In training positive people to go out and interview others, all parties became more aware of AIDS-related stigma and discrimination and began to realise that many of their experiences violated their rights. The process educated those most vulnerable to discrimination and mobilised them to take action to challenge and change the status quo and to become more involved in policy development at a national level.

The project strengthened the resolve of people to fight discrimination in each country and provided an informed and strategic direction. The participatory, action-based nature of the project proved to be invaluable. This model of AIDS-related human rights documentation can easily be adapted for other regions.

National actions

National reports of the country-specific findings and stakeholder's consultations (with human rights institutions, labour organisations, legal support networks, health care system, media) are being used

to develop policy and program guidelines to counter AIDS-related discrimination. Positive people's organisations have responded to the study findings by developing national action plans to address the critical human rights issues highlighted in the study, including strategies to lobby governments, NGOs and other target groups to effect attitudinal, legislative and policy change.

Interventions include advocacy campaigns in relation to:

- ◆ addressing violence towards women and children;
- ◆ addressing discrimination in the workplace;
- ◆ protecting migrant workers' rights;
- ◆ monitoring whether anti-discrimination laws are upheld;
- ◆ examining how the legal system can deal with perpetrators of discrimination and launching legal challenges to specific discrimination;
- ◆ improving the standard of health care delivery;
- ◆ providing adequate information about and access to antiretroviral drugs;
- ◆ assessing the information given to and follow up of clinical trial participants;
- ◆ developing media awareness campaigns.

Project recommendations

Protecting the rights of positive people enables individual members of society to examine their vulnerability to HIV infection. This is the most effective way to improve public health outcomes for all people.

APN+ recommendations arising from this study:

- ◆ All HIV-testing should be accompanied by voluntary, informed consent and the provision of appropriate counselling by a trained counsellor who can supply medical, social and peer referrals; advocacy is needed to eliminate policies of mandatory testing in relation to employment and pregnancy;
- ◆ Further research is needed into the violations committed against positive people during clinical trials;
- ◆ Legal sanctions must be invoked against people or organisations that breach the confidentiality of people living with HIV; positive people must be able to retain their anonymity when pursuing confidentiality breaches through legal channels;
- ◆ The APN+ Human Rights Team should mentor other positive people's groups to replicate this project in other countries and transfer the skills they have acquired;

- ◆ In-country development of policies and strategies is needed to counter AIDS-related discrimination in government, non-government and private sectors and to change attitudes, particularly within the health sector;
- ◆ Training and employment of positive people as counsellors and as AIDS educators;
- ◆ Education of positive people about their fundamental, non-negotiable rights and available redress when rights are violated;
- ◆ Education of the wider community about AIDS-related discrimination and its consequences.

Appendices

Appendix 1: Ethical code of conduct

1 Introduction

- 1.1 The principles given below are intended to apply to data collection on the study 'Living with AIDS in Asia: A multi-city participatory action research on AIDS and Human Rights in Asia Pacific region'. All those who are associated with the study are expected to uphold these principles while carrying out this study.
- 1.2 These principles will not replace the ethical requirements applicable to each country but will complement such principles.
- 1.3 All the associates of this study are expected to approach the participants of the study with mutual respect and confidentiality.
- 1.4 All the associates of this project must recognise the possibility of legal action if they infringe the rights and dignity of participants of this research.

2 General

- 2.1 In all circumstances the associates of this study must consider the ethical implications and psychological consequences for the participants in this research. The essential principle is that the data collection for this study should be considered from the standpoint of participants of this study. All efforts must be taken to identify foreseeable threats to their psychological wellbeing, health, values or dignity and to eliminate these. All associates of this study should recognise that, in our multi-cultural and multi-ethnic society and where investigation involves individuals of different ages, gender and social background, we may not have sufficient knowledge of the implications of our study for the participants. It should be borne in mind that the best judge of whether an investigation will cause offence may be a member of the population from which the participants in the research are to be drawn.

3 Informed consent

- 3.1 Whenever data is being collected for this study the investigators should inform all participants of the objectives of the investigation.
- 3.2 Data collection from children or from those who have impairments that will limit understanding or communication such that they are unable to give their real consent requires special safeguarding procedures. In addition, when data is collected from persons under sixteen years of age, consent should be obtained from parents or from those 'in loco parents'.
- 3.3 An informed consent form should be administered. Before beginning the interview, the researcher should read out this form.
- 3.4 If data is collected from a detained person (for instance in drug rehabilitation centres) particular care should be taken over informed consent, paying attention to the special circumstances which may affect the person's ability to give free informed consent.
- 3.5 No participants should be pressurised to participate in this study.

4 Debriefing

- 4.1 When data is being collected for this study, the investigators of this study will be provided with sufficient information to complete their understanding of the nature of the research. If any unforeseen negative effects or misconceptions arise from this research it should be informed to the concerned parties.
- 4.2 All associates of this study have a responsibility to ensure that the participants receive any necessary debriefing in the form of active intervention or referral before they leave the data collection setting.

5 Withdrawal from the investigation

- 5.1 At the onset of this study the data collectors should make plain to participants their right to withdraw from the research at any time.
- 5.2 The participant has the right to withdraw retrospectively any consent given, and to require that their data, including recordings, be destroyed.

6 Confidentiality

- 6.1 Subject to the local legal requirements, including the Data Protection Act, data collected through this study should be kept confidential.

7 Protection of study participants

- 7.1 All the associates of this study have a primary responsibility to protect participants from physical and mental harm during the investigation. Participants should not be exposed to emotional risk greater than in ordinary life. All the associates of this study should be aware of the possibility of mental conditions that could trigger off emotional stress during the data collection.
- 7.2 Participants should be informed of procedures for contacting the person in charge of this study.

8 Giving advice and referrals

- 8.1 During the data collection, the data collectors may observe psychological or physical need for social support (such as counselling) or legal problems of which a participant is, apparently, unaware. In such a case, the investigator has a responsibility to inform the participants, if the data collectors believe that by not doing so the participant's future wellbeing may be endangered.
- 8.2 During the normal course of data collection, if a participant solicits advice concerning educational, health or social support, caution should be exercised. The research associates are expected to offer appropriate sources of professional advice. (A list of such resources is presented separately.)

9 Collective responsibility

- 9.1 All the associates of this study share responsibility for ethical treatment of research participants.

Appendix 2: Information sheet

This information sheet briefly introduces a research study on AIDS and human rights being carried out by the Asia Pacific Network of People living with HIV/AIDS (APN+), with the financial support of UNAIDS.

Purpose of the study

The study intends to collect information on AIDS-related discrimination and stigma experienced by people living with HIV/AIDS in selected Asian countries. The study will contribute towards a greater understanding of the nature of AIDS-related discrimination, and in particular, the extent, pattern, and context of such discrimination. This is the first time such information has been systematically documented in your country.

Procedures of the study

APN+ would like to interview you as part of the study. All information collected is to be voluntary, anonymous, and confidential. No record will be made of your name, or other identifying details. If you agree to take part in the study, you have the right to withdraw at any time, and to request that any data the project has gathered from you be destroyed.

During the interview you will be asked about your experiences, as a person living with HIV, in areas such as health, employment, education, privacy, security, freedom from inhuman treatment, family life, and self-determination, via a detailed questionnaire. The final report of the project will include the overall national context, statistical results from all the interviews with people living with HIV/AIDS, and specific case studies to illustrate the nature of discrimination. This report will be used as a tool for change, for example in challenging health or workplace policy, community attitudes, or for legal reform.

Risks

Although we are taking all the necessary steps to identify and reduce any psychosocial risk in participating in this study, there is a low risk of breaches of your confidentiality. In certain circumstances a breach of confidentiality could lead to stigmatisation, such as losing social status, deprivation of services, loss of job, media exposure, losing family and community support, being targeted by the authorities, or pressured by authorities to disclose the status of other participants.

All interviewers are HIV-positive and are trained in human rights documentation, and have signed agreements to protect the confidentiality of the participants. All data collected during this study will be kept

confidential and stored in a locked filing cabinet in the office of the Principal Investigator (name and contact details of PI in each country) until six months after the completion of the project, when all data will be destroyed.

Discomfort

There is the possibility that you may experience some emotional distress during the interview. You may decide to pause or stop the interview at any time, if necessary. All the associates of this study have a primary responsibility to protect participants from physical and mental harm. In the event that you do need psychological or physical support (such as counselling or legal assistance), or advice concerning educational, health, or social support, a list of referrals to appropriate professional support services is available to you. A copy of the ethical principles guiding this project is also available on request. The interview process takes approximately 45 minutes to one hour.

Benefits to participants and others

APN+ hopes that the data collected in this study will contribute towards a greater understanding of the nature of AIDS-related discrimination experienced by people living with HIV, the range of discriminatory attitudes and actions, and the pathways of AIDS-related discrimination and stigma. We believe that such data is essential in developing appropriate legal, social, cultural, and institutional responses to combat discrimination and human rights violations faced by people living with HIV.

Alternatives to participation

If you prefer not to participate could you recommend somebody else who might want to participate in the study?

Appendix 3: Informed consent form

(Before beginning the interview, the researcher will read out this form, and leave one copy of the form with the respondent.)

My name is _____.

I am collecting data for the APN+ Human Rights Initiative, described in the accompanying information sheet.

This study is being conducted by _____ (name and contact telephone number). If you have any questions about any aspects of the study, please feel free to contact them.

Before you answer any questions I would like you to know that:

- a Your participation in this study is entirely voluntary;
- b You are free to refuse to answer any questions;
- c You are free to terminate this interview at any time.

The data collected in this interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from individual interviews may form part of the final research report, but under no circumstances will your name or any identifying characteristics be included in the report.

May I seek your consent to interview?

(If the respondent declines to be interviewed, please thank the respondent and discontinue the interview.)

Thank you for agreeing to take part in this study. I will now declare that oral consent for the interview has been given by you.

Has oral consent been obtained? Yes/No

Name of interviewer:

Signature of interviewer:

Date of interview:

Appendix 4: APN+ human rights initiative questionnaire

Data for this study should be collected from people living with HIV/AIDS, who are sixteen years or older. In selecting the respondents, have a good mix of people of different age, sex, social background and mode of infection. They could be selected through local positive people's groups, hospitals, and AIDS service organisations/non-governmental organisations.

It may be necessary to translate the questionnaire into the local language. The translation should be done in two stages. As a first step you (or a translator) translate the questionnaire into the local language and ask another independent translator to translate the local language version back into English. Finally, you along with the other person try to clarify the discrepancies in translation.

Instructions for interviewer

Please do not attempt to administer this instrument to other respondents without first familiarising yourself with the attached interview guide and completing the questionnaire once by yourself.

When you interview respondents, remember to ensure their privacy. Conduct the interview in a private place, preferably alone with the respondent.

Begin by administering the information sheet and consent form. Please make sure you read out this section and get the respondent's oral consent to participate in this study. You must get the informed consent before the interview. If the respondent refuses consent for the interview, please thank him/her and terminate the interview.

Boldly mark the number corresponding to the correct answer to each question in the third column. Some questions will not be applicable to everybody or a respondent may not want to respond. If the answer is 'other' please provide a description. The timeframe of the questions is since the respondent has known his or her HIV status.

During an interview, if you feel that some follow-up questions are important, please note them down promptly in the space available besides each question for notes. You may remark on any significant observations about issues that arise in the interview and suggest modification of any questions, additional questions and difficulties in canvassing responses to the survey. If respondents have experienced instances of severe

discrimination and are willing to discuss this in detail, you can probe the questions at the time of the survey or make a time to return for an in-depth interview later. Before case studies can be audiotaped, respondents must give further consent to this.

Sometimes while interviewing respondents you may face adverse reactions such as emotional outbursts, anger or hostility to the interviewer. If you feel you cannot continue, you should stop the interview.

Familiarise yourself with the list of local resources and contacts, which you have already prepared. If you need additional support or need to make referrals for medical, emotional or legal support, the local resource list would be helpful.

At the end of the entire interview, check each questionnaire for completeness and accuracy and note down all the questions and concerns expressed by the respondent.

APN+ Human Rights Team

Section 1: Location/country specific information

- 1.1 Interview schedule no. []
- 1.2 Country []
- 1.3 Interviewer code no. []
- 1.4 Date of interview
- 1.5 Where is the interview being carried out?
 - [1] Hospital
 - [2] Residence
 - [3] Public place
 - [4] Private room
 - [5] Other

Section 2: Demographic information

Q	Question and filters	Coding	Notes
2.1	How old are you?	Years:	
2.2	What sex?	[1] Male [2] Female [3] Transgender	
2.3	What is your current marital status?	[1] Married/de facto [2] Widowed [3] Separated/divorced [4] Single [5] Significant relationship	
2.4	What is your highest level of education?	[1] None formal [2] Primary [3] Secondary [4] Technical [5] University	
2.5	How many children do you have?		

Section 3: Right to health

3.1	How would you describe your health status?	[1] Very good [2] Moderately good [3] Unwell	
3.2	Are you currently taking antiretroviral medication for HIV infection?	[1] Yes [2] No [3] Don't know	
3.3	Are you currently taking any prophylaxis or HIV medication for opportunistic infections?	[1] Yes [2] No [3] Don't know	
3.4	Are you currently taking any traditional or complementary medication for HIV infection?	[1] Yes [2] No [3] Don't know	

3.5	Have you ever experienced discrimination by any health care worker(s) due to your HIV status?	[1] Yes (please give details) [2] No [3] Don't know	
3.6	If yes, how often has this happened to you?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
3.7	Has a health care worker ever refused to treat you/denied access to medical treatment or care because of your HIV status?	[1] Yes [2] No [3] Don't know	
3.8	If yes, has this happened within the past year?	[1] Yes [2] No	
3.9	Have you ever experienced a delay in the provision of health services/treatment due to your HIV status?	[1] Yes (please expand) [2] No [9] Not applicable	
3.10	Have you ever been stopped from accessing health care services due to HIV status?	[1] Yes (please expand) [2] No [9] Not applicable	
3.11	Who stopped you accessing health care services?	[1] Family members [2] Friends [3] Health care workers [4] AIDS service agencies [5] Other	
3.12	Have you ever been forced to pay <i>additional</i> charges for medical services (e.g. dental care, surgery) because you are HIV-positive?	[1] Yes [2] No [9] Not applicable	
3.13	Since your HIV diagnosis, did you apply for private health insurance?	[1] Yes [2] No	
3.14	Have you ever lost or been denied private insurance once your HIV status was known?	[1] Yes [2] No [9] Not applicable	
3.15	Have you ever participated in any AIDS-related medical studies or clinical trials?	[1] Yes [2] No [3] Don't know	
If NO, skip to Section 4. If YES, were the following aspects of the study explained to you?			
3.16	The name of the drug or the study/trial	[1] Yes [2] No	
3.17	The purpose of the study/trial	[1] Yes [2] No	
3.18	The risks and consequences of the study/trial	[1] Yes [2] No	

3.19	What type of study/trial was it?	[1] Antiretroviral medication [2] Herbal medicine [3] Other (please specify)	
3.20	How long were you on a trial?	Months:	
3.21	Did you ever make a request to stop being a participant?	[1] Yes [2] No	
3.22	If yes, was your request honoured?	[1] Yes [2] No [9] Not applicable	
3.23	Were you offered treatment at the end of the trial?	[1] Yes [2] No [9] Not applicable	

Section 4: Privacy

4.1	In what year did you find out your HIV status?	Year:	
4.2	Why was the test taken?	[1] Employment [2] Pregnancy [3] STI clinic referral [4] Referred due to suspected HIV-related symptoms [5] Partner tested positive [6] I just wanted to know [7] Other (please specify)	
4.3	Did you ask to be tested for HIV?	[1] Yes [2] No	
4.4	Did you feel you were prepared to take the test at the time it was done?	[1] Yes [2] No	
4.5	Were you coerced into having the test?	[1] Yes [2] No	
4.6	Was it explained to you what the test was for before you were tested?	[1] Yes [2] No	
4.7	Did you receive any counselling before the test was taken?	[1] Yes [2] No	
4.8	Did you receive any other information before the test?	[1] Yes [2] No	
4.9	Where were you tested?	[1] Government hospital [2] Other government facility [3] Private hospital/lab [4] Private doctor [5] Other (specify)	

4.10	Who informed you of the results?	[1] Doctor [2] Nurse [3] Social/health care worker [4] Counsellor [5] Other (specify)	
4.11	Was someone else with you when you got your result?	[1] Yes [2] No	
4.12	If yes, who was it?	[1] Friend [2] Family member(s) [3] Co-worker [4] Spouse [5] Other (specify)	
4.13	Did you want the other person to be with you at the time?	[1] Yes [2] No	
4.14	Did you receive any counselling when you received your test result?	[1] Yes [2] No	
4.15	Did you get any other information when you received your test result?	[1] Yes [2] No	
4.16	Has a <i>health care worker</i> ever told other people about your HIV status without you wanting them to know?	[1] Yes [2] No [3] Don't know	
4.17	Who has been told about your HIV status without your consent?	[0] Nobody [1] Health care worker(s) [2] Family member(s) [3] Employer/co-worker(s) [4] Spouse [5] Sex partner(s) [6] Media [7] Government officials [8] NGOs [9] Members of community [10] Other (specify)	
4.18	Have you told anyone about your HIV status?	[1] Yes [2] No	
4.19	If yes, whom did you tell first?	[1] Friend [2] Spouse/partner [3] Immediate relative [3] Colleague [4] Other (specify)	

4.20	How widely is your HIV status known to others?	[1] Nobody else knows [2] Only immediate family [3] Family members and a few friends [4] Only a few friends [5] Widely known in the community [6] Not known in the community but open elsewhere	
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Section 5: Liberty and security of person

5.1	Have you ever been refused entry to, removed from or asked to leave a public establishment due to HIV?	[1] Yes (please give details) [2] No	
5.2	Have you been forced to change your place of residence because you are known to be HIV-positive?	[1] Yes [2] No [9] Not applicable	
5.3	If yes, how many times have you changed your place of residence?		
5.4	Have you ever been ridiculed, insulted or harassed because of your status?	[1] Yes [2] No	
5.5	Have you ever been threatened by physical violence because of your HIV status?	[1] Yes [2] No	
5.6	Have you ever been physically assaulted because of your HIV status?	[1] Yes [2] No	
5.7	If yes, who assaulted you?	[1] Spouse/partner [2] In-laws [3] Other family member [4] Community [5] Other (please explain)	
5.8	Have you ever had to disclose your HIV status in order to enter another country?	[1] Yes [2] No [9] Not applicable	
5.9	Have you ever been quarantined, detained, isolated or segregated because of your HIV status?	[1] Yes (please expand) [2] No	

Section 6: Inhuman and degrading treatment or punishment

6.1	Have any benefits, privileges or services given to others been denied to you because of your HIV status?	[1] Yes (please explain) [2] No [9] Don't know	
6.2	Have you been excluded from any social functions due to your HIV?	[1] Yes [2] No	
6.3	Have friends ever discriminated against you because of your HIV status?	[1] Yes [2] No [9] Not applicable	
6.4	Have you ever been forcibly required to submit to any medical or health procedure because of HIV?	[1] Yes (please explain) [2] No [3] Don't know	
6.5	Have you ever been charged, sued or brought to court on an offence or an act related to your HIV status?	[1] Yes (please expand) [2] No	

Section 7: Right to employment

7.1	Has your earning capacity decreased due to your HIV status?	[1] Yes [2] No	
7.2	Were you in paid employment at the time of your HIV diagnosis?	[1] Yes [2] No	
7.3	Have you ever been in paid employment since your diagnosis?	[1] Yes [2] No	
If NO to both Q.7.2 & Q.7.3, go to Section 8			
7.4	Have you ever experienced any AIDS-related discrimination in your work environment?	[1] Yes [2] No [3] Don't know	
7.5	Has your employer ever discriminated against you because of your HIV status?	[1] Yes (please expand) [2] No [9] Not applicable	
7.6	Have you ever felt discriminated against by your colleagues because of your HIV status?	[1] Yes [2] No [9] Not applicable	
7.7	Have you ever lost your job because of your HIV status?	[1] Yes [2] No [9] Not applicable	
7.8	Has your job description or duties changed because of your HIV status?	[1] Yes [2] No [9] Not applicable	
7.9	Have you been offered early retirement due to your HIV status?	[1] Yes [2] No [9] Not applicable	

7.10	Have you ever lost your prospect for a promotion because of your HIV status?	[1] Yes [2] No [9] Not applicable	
7.11	Have you ever experienced harassment or discomfort on the job because of HIV?	[1] Yes [2] No	
7.12	Did you have any way to address the abuse/any recourse for action?	[1] Yes [2] No [9] Not applicable	
7.13	If yes, were you satisfied with the recourse of the action taken?	[1] Yes [2] No	

**Section 8: Right to marry, found a family
and form significant relationships**

8.1	Have you ever undergone mandatory HIV testing because of pregnancy or illness of your child (women only)?	[1] Yes [2] No [9] Not applicable	
8.2	Since your diagnosis, have family members excluded you from usual family activities?	[1] Yes (expand) [2] No [9] Not applicable	
8.3	Has your partner deserted you because of your HIV status?	[1] Yes [2] No [9] Not applicable	
8.4	Have you ever lost financial support from family members due to your HIV status?	[1] Yes [2] No [9] Not applicable	
8.5	What were the repercussions?		
8.6	Has your child (or children) ever been involuntarily taken away from you because of your HIV status?	[1] Yes [2] No [9] Not applicable	
8.7	Has a health care worker ever advised you not to have a child since you were diagnosed as HIV-positive?	[1] Yes [2] No [9] Not applicable	
8.8	Were you given information about preventing parent-to-child HIV transmission?	[1] Yes [2] No [9] Not applicable	
8.9	Have you been coerced into an abortion or sterilisation due to your HIV status (women only)?	[1] Yes [2] No [9] Not applicable	

Section 9: Right to education

9.1	Have you or your child(ren) ever been made to experience discomfort due to your HIV status whilst attending an educational institution?	[1] Yes (expand) [2] No [9] Not applicable	
9.2	Have you or your child(ren) ever been dismissed, suspended, prevented from continuing with your/their education or denied admission into any educational institution because of your HIV status?	[1] Yes (expand) [2] No [9] Not applicable	

Section 10: Right to self-determination and association

10.1	Have you ever been excluded from any associations/societies/clubs/self-help groups due to your HIV status?	[1] Yes [2] No [9] Not applicable	
10.2	Have you ever been restricted in your ability to meet with other people living with HIV?	[1] Yes [2] No [9] Not applicable	
10.3	Has your family ever restricted your ability to join associations or groups of people living with HIV?	[1] Yes [2] No [9] Not applicable	
10.4	Have you ever been referred to any self-help group for people living with HIV by an AIDS/health care worker or other person?	[1] Yes [2] No	
10.5	Have you ever participated in any AIDS-related decision-making committee(s)?	[1] Yes [2] No [9] Not applicable	
10.6	Do you know of any local self-help group for people living with HIV?	[1] Yes [2] No	
10.7	Do you intend to join a peer self-help group in the near future?	[1] Yes [2] No	
10.8	If not, why not?		

Thank you very much for your participation. You have now completed the survey.

Are there any further issues you want to talk about? If you are willing to permit a detailed interview about your specific experiences of discrimination we request your informed consent to tape it.

