Pre-Exposure Prophylaxis (PrEP) for People Who Inject Drugs:

Community Voices on Pros, Cons, and Concerns





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I. Introduction

Pre-Exposure Prophylaxis (PrEP), "the daily use of antiretrovirals in HIV-uninfected people to block the acquisition of HIV infection," is a new tool for preventing HIV transmission and has sparked considerable discussion and debate in many communities. In 2012, based on evidence that PrEP is safe and effective, the World Health Organisation (WHO) recommended that countries consider daily oral PrEP as an additional prevention strategy for HIV-negative partners

in serodiscordant couples, as well as men and transgender women who have sex with men.² The WHO did not recommend promoting PrEP among people who inject drugs in its 2014 Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, due in part to human rights and other concerns raised by community representatives, many of which are detailed below.

As this new tool begins to be used, it is essential that affected communities be meaningfully involved in related policymaking and in any subsequent programme implementation. The International Network of People who Use Drugs (INPUD) therefore researched the knowledge, beliefs. and opinions of people who "The WHO did not recommend promoting PrEP among IDUs...due in part to human rights and other concerns..."

inject drugs about potential pros, cons, and concerns related to PrEP. With this paper, INPUD aims to amplify the voices of people who inject drugs so that their unique knowledge and perspectives can be taken into account as policies related to PrEP are formulated. This is of vital importance, as many people who use drugs have grave concerns about the ethics, effectiveness, and safety of prioritising broad promotion of PrEP for people who inject drugs—especially in a global context of drug prohibition and limited access to harm reduction services and antiretroviral therapy for people who inject drugs living with HIV. For example, only 22 needles and syringes are distributed per year per person injecting drugs globally, and only 4% of people who inject drugs who live with HIV have access to antiretroviral therapy.³

¹ World Health Organisation. 2012. Guidance On Pre-Exposure Oral Prophylaxis (PrEP) For Serodiscordant Couples, Men And Transgender Women Who Have Sex With Men at High Risk Of HIV: Recommendations For Use In The Context Of Demonstration Projects. Accessed 8 September 2014. http://www.who.int/hiv/pub/guidance_prep/en/

² Ihid

³ Mathers, B.M. et al. 2010. "HIV prevention, treatment and care services for people who inject drugs: a systematic review of global, regional, and national coverage." Lancet 375: 1014-1028.

II. Methodology

In 2014, INPUD explored the values and beliefs of people who inject drugs in order to develop its official position on PrEP. It convened two international consultations with people who inject drugs, one in the Eastern European and Central Asian region (EECA), co-hosted by the Eurasian Network of People who Use Drugs (ENPUD) and the Eurasian Harm Reduction Network, and one in the Asian region, which was co-hosted by the Asian Network of People who Use Drugs (ANPUD). During the consultations, representatives of UNAIDS presented available knowledge on PrEP and answered questions, after which participants discussed their hopes, fears, and opinions. A third, briefer consultation was conducted in May 2015, with members of the European Network of People who Use Drugs (EuroNPUD). In addition to these face-to-face consultations, a series of interviews was conducted with INPUD members. Approximately 75 people from 33 different countries participated in the process. Approximately 30% of participants were women.

III. Findings

During the consultations and interviews, a number of themes emerged on which there was often, though not always, broad agreement. These themes include:

"Of course people who use drugs have a right to access it. That's just a question of fairness and equality."

—INPUD Member

- Recognition of PrEP as a new tool for HIV prevention and a belief in an equal right to choose it
- The idea that, while it may be desirable for preventing sexual transmission of HIV for some, it is probably not desirable as a means of preventing HIV transmission through injecting
- Misgivings about the ethics and feasibility of promoting the use of PrEP by people who inject drugs, given that access to antiretroviral therapy and harm reduction services are at such low levels
- Concerns about whether PrEP is feasible for people who use drugs in a context of criminalisation
- Concerns about side-effects and drug interactions
- Concerns about 'biomedicalising' the response to the HIV epidemic
- Support for the idea that PrEP may be a good option for some, but the scale-up of access to harm reduction should be prioritised
- · The idea that people who inject

drugs must be meaningfully involved in decision making when approaches to HIV prevention related to them are discussed

PrEP as a new tool

Participants in consultations and interviews recognised that PrEP will be an important means of HIV prevention for some people. All the interviewees agreed that people who use drugs have the same 'right' to access to PrEP as anyone else. "Of course people who use drugs have a right to access it. That's just a question of fairness and equality," said one INPUD member. "I think as a tool it's useful along with a whole group of other tools," said another. "PrEP could be a potential extra option if harm reduction services were sufficiently scaled up to be satisfactory, so that no one ever has to share a needle or syringe or other injecting equipment," they continued.

Another INPUD member noted, "PrEP is going to have a role to play and [...] is going to be a good option for perhaps a lot of people. We should be educating people about it and we should be figuring out how to incorporate it into our programmes and our services." Most participants, however, were a bit more cautious. While recognising that PrEP would be a good option for some, they had misgivings and urged INPUD to take a cautious approach, as is discussed further below.

PrEP for preventing sexual transmission versus PrEP for preventing transmission through injecting

During the consultations, it was clear that PrEP was more desirable for preventing sexual transmission of HIV "PrEP could be a potential extra option if harm reduction were sufficiently scaled up to be satisfactory..."

—INPUD Member

than it would be for preventing transmission through the sharing of injecting equipment. "The argument with the men who have sex with men community is that sex is more pleasurable without a condom but it isn't more pleasurable using somebody else's equipment," said a EuroNPUD member. "Needles should never be reused, not even your own—it hurts!" said a participant in the ANPUD consultation.

Participants noted that PrEP would not prevent transmission of hepatitis C, abscesses, or endocarditis. "Even if we had PrEP, we would still need clean works," said one consultation participant from EECA. Moreover, while participants recognised that PrEP has been proven to be safe and effective for the prevention of sexual transmission of HIV, they were not convinced that there was adequate data to prove that PrEP programming could prevent transmission of HIV through sharing injecting equipment in real-world settings.

PrEP in the context of deficits of antiretroviral therapy and harm reduction services

During the consultations and interviews, many people expressed grave concerns that allocating scarce resources for PrEP for people who inject drugs might not be ethical, given the extreme deficit of antiretroviral medicines for people who inject drugs who

live with HIV and the extremely low levels of access to harm reduction services. They also questioned the degree to which it would be feasible to make PrEP accessible to people who inject drugs in contexts where the capacity to deliver HIV-related clinical services and community-based counselling and support services is already low or absent.

Concerns about ethics

Most of those participating in the consultations and interviews expressed awareness of the lack of access to antiretrovirals for people who inject drugs who live with HIV in most countries. A member of INWUD (International Network of Women who Use Drugs) noted, "When we consider that only 4% of people who use drugs who live with HIV have access to antivirals [sic], it seems crazy to start pumping in PrEP before antiretrovirals." A EuroNPUD member noted, "To provide these drugs for prevention when people don't get them for their treatment strikes me as being an extremely poor use of resources and entirely unethical. It's entirely inappropriate, given the exceptionally low levels of access for people who inject drugs who live with HIV," echoing a theme that came up in all of the consultations and most of the interviews. "It's like to say, for the people that have the virus already, forget them. Let's protect the next," said a participant in the EuroNPUD consultation. Some respondents from areas where there was better access to harm reduction services and antiretroviral therapy felt that PrEP could be added to the service options available. Many stressed that if other services were available, PrEP would be a good additional option.

"It's unrealistic!
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—European Activist

Concerns about feasibility

Participants questioned the feasibility of rolling out PrEP where harm reduction services and antiretroviral therapy provisions to people who inject drugs have not yet been rolled out. "It's unrealistic! If we can't get treatment for people living with HIV, how on earth would it be possible to get them to others?" said a European activist. Most consultation participants were well aware that antiretroviral therapy is effective for people who inject drugs who live with HIV and that with adequate support, good levels of adherence can be achieved. In all three consultations there were participants who spoke openly about their personal experience of living with HIV and taking antiretroviral drugs. There was broad recognition of the need to expand support services to enable people to decide to initiate treatment and achieve good levels of adherence. There was recognition that similar support would be needed to ensure adequate adherence for PrEP. Most participants expressed concern about prioritising

PrEP for people who inject drugs until other services were rolled out, as discussed below in the section on priorities (page 11).

Consultation participants noted that adherence would be a challenge and that, as with antiretroviral therapy, friendly services catering to the specific needs of people who inject drugs

would need to be in place for it to be effective. Participants highlighted the need to address issues like homelessness and social exclusion. "It strikes me that the people that might most benefit from PrEP are probably potentially the most at risk, with the most difficult-to-manage lifestyles, for want of a better word. And people in those situations might have genuine adherence issues," said a member of INWUD. "And some people don't have houses! Where are they going to put the bloody pill?" said an INPUD member. "The people that would be most at risk don't have the infrastructure or the social supports that would allow them to use this drug in an efficient manner," said another INPUD member.

There were mixed opinions about where the best place for people to receive testing, counselling, and support for PrEP might be. Some participants stated that they would prefer that these services be provided in low-threshold harm reduction service settings. Some highlighted the importance of the

work of peers in counselling and adherence support. Others suggested that the clinical setting would be more trusted, and that they would prefer to speak with doctors and/or other health professionals. Concerns about confidentiality were noted and are discussed further below in the next section.

The impact of criminalisation and stigma on feasibility and safety

During the consultations, the results of available research on the safety and effectiveness of PrEP were presented by UNAIDS officials and discussed. Many participants expressed concerns that the results of the trials might not be replicable in the 'real world.' The Bangkok PrEP trial, which has been criticised for ethical and methodological shortcomings⁴, was felt by some participants not to sufficiently take into account many of the dynamics created by the criminalisation of people who use drugs, which include: fear of accessing health services; stigma and fear of stigma; fear of being identified and registered as

"It strikes me that the people that might most benefit from PrEP are probably potentially the most at risk..."

—INPUD Member

a person who uses drugs; fear of arrest; homelessness; and arrest and imprisonment. These, and other factors, would impact uptake and adherence to PrEP as a method of HIV prevention. One interviewee noted that the Bangkok study controlled for incarceration: "Those who were incarcerated during the course of the trial were continued on PrEP if they were on it, which again is not reflective of the real world." Others noted that the incentives provided for adherence may have skewed findings, since without incentives, motivation for uptake and adherence could be less. Many participants noted that it seemed there was not an adequate understanding of the risks and fears involved for people who inject drugs in accessing clinical services. One INPUD member noted that people who inject drugs "really don't want to engage with the general community because they

Wolfe, Daniel. 2013. "Beyond the Hype: PrEP for People Who Inject Drugs." The World Post, 14 June. Accessed 5 August 2015. http://www.huffingtonpost.com/daniel-wolfe/beyond-the-hype-prep-for-_b_3437910.html

⁵ Mathers, B.M. et al. 2010. "HIV prevention, treatment and care services for people who inject drugs: a systematic review of global, regional, and national coverage." Lancet 375: 1014-1028.

don't think it's got anything to offer them, and they think it's actively trying to eliminate them."

Concerns about confidentiality

"Being on PrEP could put you at risk to be identified as a person using drugs."

—Asia Pacific Consultation Participant

In the consultations and interviews, participants highlighted concerns about confidentiality. "You wouldn't be able to get it without giving your name, which would be a barrier for sure," said an INPUD member from North America. In order to be tested and prescribed PrEP, a person could be identified as someone who uses drugs. This thus puts them at risk of arrest or of inclusion in registries of people who use drugs. A consultation participant from Europe highlighted the concern: "As a mother there is fear of social services, fear of getting children removed, fear of losing one's job." Participants had little faith that confidentiality would be respected even if it were recommended. "And it needs to be with confidential records and no linking to drug user registration or anything like that. So that's where I'm scared. This is where we haven't seen methadone rolled out well—do we really expect to see PrEP rolled out well for people who use drugs?"

"As a mother there is fear of social services, fear of getting children removed, fear of losing one's job."

—Consultation participant

Concerns about mandatory or coerced PrEP

"I think people need to be concerned about the use of PrEP and treatment as prevention in coercive contexts with people who use drugs and how that can be used by authorities and prisons or other public health authorities."

—INPUD member from North America

"Recommendations are interpreted and manipulated as governments see fit."
—People Who Inject
Drugs Activist from EECA

In both interviews and consultations, numerous participants expressed concern that PrEP could be made mandatory in societies that systemically violate the human rights of people who use drugs. Participants highlighted that governments often violate these rights, notably the right to informed consent, and that this could impact the way they would implement PrEP for people who inject drugs. "I think that it's a risk that is real for sex workers, and I think it's a risk that is real for people who inject drugs. It's because of the human rights situation. We know of very widespread mandatory testing for sex workers, and I don't think

it far-fetched to imagine that, added on to that, would be mandatory PrEP," said a European activist. Activists also highlighted the risk of mandatory PrEP in prisons, one saying, "the possibility of mandatory PrEP in incarcerated environments where people were identified as drug users or drug offenders is terrifying," and another emphasised,

"a lot of countries have mandatory rehabilitation lock-ups – and they might find it [mandatory PrEP] quite attractive – with a controlled audience, if you like." Another respondent stressed the extent to which rights can be violated in prisons: "I heard a story where women in prison were tested for HIV – mandatory tested – so that the prison guards could determine who to rape. If that can happen, it's not hard to imagine that

PrEP could be made mandatory." many participants expressed that mandatory or coercive PrEP was a risk in countries traditionally thought to be more authoritarian, highlighted that it could also be a risk in contexts perceived to be more liberal. such as Canada. "PrEP is being widely promoted at the same time as people living with HIV who have detectable viral loads are being incarcerated for not disclosing their HIV status to people. So there's this big shift and I can see them happening

"PrEP is being widely promoted at the same time as people living with HIV...are being incarcerated for not disclosing their HIV status to people."

—INPUD Member

together. People haven't been talking about how the two can be intertwined but I think ... people could be put in a situation where they are forced to take PrEP or forced to take antivirals [sic] by state authorities," said an INPUD member during an interview.

Concerns about side-effects and drug interactions

"We don't know the effect the drug is going to have on drug users—interactions with heroin, ice, all those sorts of things. We don't know ... it hasn't been studied enough in our community for us to have any real faith that, even though it's stopping HIV, what else is it doing or not doing?"—INPUD Member

Many participants in all three consultations expressed concern with regard to potential side-effects of PrEP and asked numerous questions related to them. Most concerns in the first two consultations were allayed by the UNAIDS representatives, though some remained. Participants raised concerns about the impact of PrEP on the health of people living with hepatitis C. Participants also expressed concerns about drug interactions with both substitution drugs, such as methadone and buprenorphine and other drugs. Knowing that some antiretroviral medicines impact the way the body metabolises other drugs, especially opioids, there was concern. Respondents also expressed frustration that people who use drugs are often left out of clinical trials: "We're never on any of the Hep C drug trials because they don't know what we're using, so drug users are always left out of those sort of trials," said one INPUD member.

The dangers of 'biomedicalising' HIV prevention among people who inject drugs

"I think globally we are seeing an increasingly triumphalist biomedical rhetoric suggesting that we can resolve a problem as complex and driven by social determinants as HIV, with a pill—with simple biomedical intervention—and I find that pernicious and dangerous."
—INPUD Member

During consultations and interviews, many participants expressed concern over what they saw as the 'biomedicalisation' of the response to HIV: "The 'end of AIDS' rhetoric ... is very much predicated on biomedical solutions. I find it alarming, because I think it's diverting attention away from the larger determinants of the risk environments and the reasons why particular groups have become key affected populations," said one respondent from Europe. The same respondent pointed out that "what makes the risk in injecting drug use is criminalisation and the discrimination and human rights violations that come with it. "Another, a respondent from EECA, pointed out, "One pill cannot stop the stigma we face," with an INPUD member noting, "It's just like it's a chemical pharma response to a human behaviour that really can't be dealt with by a pill."

Many participants voiced concern that PrEP would not address the determinants of risk, with one participant observing that "a community-driven approach to the epidemic is one that addresses the things that make people so disproportionately at risk of contracting HIV. The biomedical response doesn't address the determinants. So it's a very reductive response." Many feared that an approach like PrEP might overshadow the work needed to address such determinants of risk: "Biomedical responses are all about individualising responsibility for HIV transmission

"One pill cannot stop the stigma we face"

—EECA Respondent

... the responsibility is loaded on to the person to prevent transmission, as opposed to governments or communities or organisations or funders," said a North American respondent.

A threat to scarce harm reduction funding

"The risk is that some governments would favour the idea of medicalising HIV prevention with a pill, rather than grappling with the broader social issues that harm reduction services acknowledge and work with. It is very narrow and straightjacketing as an approach, potentially"—INWUD Member

"One of the concerns is that...we've given people PrEP so we don't need to give them access to any other harm reduction support."

—ENPUD Member from North America

Harm reduction interventions, like needle and syringe programmes and opioid substitution therapy, are often politically unpopular. In this context, many respondents perceived a biomedical approach as a threat to current funding of harm reduction, which is already considerably lacking in many regions. "PrEP could give them an excuse to close harm reduction programmes," said one consultation participant from the EECA region. This respondent pointed out that Dr Onishenko, Russia's former Chief Sanitary and Epidemiological Physician, stated publicly that PrEP could be a good alternative to substitution therapy in Russia. ⁶

There was broad consensus among participants that harm reduction aims not only to address HIV prevention, but also a broad spectrum of health and rights vulnerabilities faced by people who use drugs. Yet there is awareness that funding for harm reduction has historically come in response to HIV. One INPUD member highlighted, "the only reason we ever got anything is

because we were vectors of the disease...Remember, we were going to be the third wave of HIV that infected the rest of the community. And then when that went away we could barely exist, until they realised hepatitis C was going to be an enormous financial burden on governments—so then we got funding there. Once they take away those incentives to do anything with our community, we're in real trouble."

Argument in favour of expanding practices known to be cost-effective

"We know that it is cost-effective to have harm reduction programmes and they are effective in preventing HIV and plus, plus, plus ... so much more! And that's what we know works already. We should get that right first, if we can." —INWUD Member

In all three consultations, and in the interviews, participants raised questions about the cost-effectiveness of PrEP in contrast with other harm reduction interventions that are proven to be cost-effective, such as needle and syringe programmes and opioid substitution therapy. "I mean, we have other things we know work remarkably well and are totally cost effective – like needle and syringe programmes and methadone,"

said a member of INWUD. There were concerns voiced about the cost of PrEP. "We are talking about a really expensive pill that is inaccessible to a large majority of people already. What would help people who use drugs is not access to expensive patented medicines but more resources to support people in ways they need and want to be supported," said one INPUD member, continuing, "I am happy that we can use HIV medications as a prevention initiative and it's great that that works and it's great that the science is behind it. But, ensuring that people where I'm from had a minimum standard income would reduce HIV infections probably more than PrEP."

"We are talking about a really expensive pill that is inaccessible to a large majority of people already..."

Suspicion of pharmaceutical industry profiteering

"This is clearly in the interests of Big Pharma"
—Consultation Participant from Asia Pacific

—INPUD Member

Mistrust of the pharmaceutical industry was frequently expressed in the interviews and during the consultations. Investment in PrEP for people who inject drugs, while harm reduction and antiretroviral services for them are not yet scaled up or comprehensive, was perceived as diverting money away from services that are well-proven to be effective. It was seen as diverting funds away from communities and to the pharmaceutical industry. The emotions expressed by many may be linked to the fact that many activists from communities of people who use drugs are engaged in work to campaign against the extremely high pricing policies of Gilead on its hepatitis C drug, Sofosbuvir, which is harming the health of millions of people who use drugs who live with hepatitis C, especially, but not only, in middle-income countries. The fact that Gilead holds the patent for Truvada (the main drug used for PrEP) appears to inform this sentiment. "It's

interesting when you see something like PrEP become such a big issue. And why is this the big issue? That's the question to ask, and to keep asking. Because Gilead is the company that owns the patent for PrEP, for Truvada," said an INPUD member, who went on to note, "Gilead continues to promote the patents of their drugs and reduce access ... the prices are ridiculous. So, as people who use drugs and [as] a network of people who use drugs, we should be really cautious about how we talk about and engage with a company that is promoting a drug that is really inaccessible

"Until we have other interventions scaled up, I think PrEP is a step too far"

—EECA Respondent

to large parts of the world." Many participants expressed questions about why there was so much discussion about PrEP for people who use drugs when there were many high-priority topics that pressingly need attention. "I query that, of the two new recommendations that came out—the one on PrEP [referring to Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations (WHO 2014)] and the recommendation that community naloxone distribution should go ahead ... Those recommendations came out at the same time, and there is this surge of meetings around PrEP, and I haven't heard of one subsequent meeting about naloxone and helping countries roll that out," said a member of INWUD.

Priorities

"We don't want to deny anyone access to PrEP ... but it cannot be at the expense of expanding harm reduction approaches." —INWUD Member

Most participants did not see PrEP as a priority given the low levels of access to harm reduction globally. "Sustainability and expansion of harm reduction services is a much bigger priority," said a respondent from Asia Pacific. "Until we have the other interventions scaled up, I think PrEP is a step too far," said one respondent from EECA. "I don't see why it can't be part of a truly comprehensive, universally accessible package of services. But that is not the reality. So given that, it is simply not a priority and it's not just not a priority for people who inject drugs," said an activist from Europe. There was generally broad consensus that it should not be prioritised ahead of well-proven harm reduction interventions. "It is good that the answers are coming bottom-up, and I am glad that we agreed that this is not a priority," said a respondent during the Asia Pacific consultation. "PrEP is not ready for our community, and our community is not ready for PrEP," said another INPUD member.

One interviewee suggested that PrEP shouldn't be thought of in terms of priorities: "You don't have to trade one for the other ... I think that's a false dichotomy," said an INPUD member from North America. He continued, "Now you might say we have other priorities, we have other things that may be as important, or may be more important. I think that's okay, but if it comes across as a kind of anti-PrEP thing it's going to be a problem, because people should have their options ... And like anything else, if you're not at the table, but you're just being a naysayer, you're going to be left out of how these things actually get rolled out."

IV. Conclusions and key Messages

Overall, there was agreement that in a context where other key harm reduction services were in place, PrEP would be a desirable option for some people who inject drugs. It was felt, however, that there was considerable work to be done to build that context.

Key messages highlighted in the consultation process include:

- Ethical concerns are raised concerning or about making antiretroviral medicines available
 to people who do not have HIV when there are deficits of these medicines for people
 living with HIV.
- For some people who inject drugs, PrEP might be a desirable option for preventing sexual transmission of HIV.
- Access to clean needles and syringes and other safer injection equipment is preferable to taking a daily pill for preventing HIV transmission through injection. While sex without a condom may be desirable for some, reusing injecting equipment is not.
- Scale-up of access to harm reduction services would be necessary to make access to PrEP
 feasible for people who inject drugs who might want to choose it. Community-based
 services would be the desired setting for initial and supportive counselling services for
 many. Scaled-up access to clinical services would also be necessary.
- In a context of criminalisation, stigma, and discrimination, wide-scale application of PrEP for people who inject drugs is not feasible.
- Promotion of a biomedical response to the HIV epidemic is dangerous as it would neglect work to change the factors and structural barriers that contribute to the risk environments that make some populations particularly vulnerable.
- A shift in funding towrds PrEP for people who inject drugs could take already scarce resources away from more important activities like work to build harm reduction services and to change drug policy.
- There is suspicion of pharmaceutical industry interest in shifting resources towards a biomedical solution.
- Scaling up access to harm reduction services is a higher priority than accessing PrEP.
- There should be meaningful participation of people who inject drugs when it comes to discussing PrEP globally, nationally, and locally.

V. About INPUD

The International Network of People who Use Drugs (INPUD) is a global peer-based organisation that seeks to promote the health and defend the rights of people who use drugs. INPUD will expose and challenge stigma, discrimination, and the criminalisation of people who use drugs and its impact on our community's health and rights. INPUD will achieve this through processes of empowerment and international advocacy.



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This report was produced on the basis of three face to face consultations with communities of people who use drugs, one in the Eastern European and Central Asian region (EECA), cohosted by the Eurasian Network of People who Use Drugs (ENPUD) and the Eurasian Harm Reduction Network; one in the Asian region, co-hosted by the Asian Network of People who Use Drugs (ANPUD); and third with members of the European Network of People who Use Drugs (EuroNPUD). The consultations and report form part of INPUD' work in Bridging the Gaps—health and rights for key populations. This unique programme addresses the common challenges faced by sex workers, people who use drugs and lesbian, gay, bisexual and transgender people in terms of human right violations and accessing much needed HIV and health services. Go to www.hivgaps.org for more information.

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Unit 2C05, South Bank Technopark 90 London Road London SE1 6LN

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