

Values and preferences of people who inject drugs, and views of experts, activists and service providers: HIV prevention, harm reduction and related issues

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Summary

A values and preferences study of people who inject drugs explored the experiences and views of 32 people around HIV prevention, HIV testing modalities, ART for treatment and prevention, harm reduction and community distribution of naloxone. The key findings reveal some common views across regions as well as some experiences and views that are specific to a community, country or region. The study was conducted from January–March 2014 and included 25 members of the PWID community and 7 experts or service providers who work closely with this community. Nineteen individuals participated in in-depth interviews, 2 participants responded by email due to language restrictions and 11 individuals participated in a group discussion of the same issues covered in the interviews.

The main findings regarding PWID community preferences on key issues are summarized in the box below.

Needle and syringe programmes are considered the single most important HIV prevention strategy for people who inject drugs.

Opioid substitution therapy is considered a vital intervention for its direct benefits and for the access to a range of other HIV prevention and harm reduction services.

For HIV-positive PWID, viral suppression through ART—with condom use—is understood as beneficial for prevention of transmission.

HIV testing is delivered most effectively for PWID when it is offered alongside other harm reduction services.

PWID will seek testing only at safe, confidential sites staffed by knowledgeable, non-judgmental providers.

Rapid testing can reduce late diagnosis and loss to follow-up of PWID.

Self-testing is an acceptable option for PWID only in settings where there is no access to safe, confidential HIV testing. However, there are significant reservations about self-testing due to the lack of critical support from counsellors and other health providers.

PrEP is considered unacceptable, unnecessary or unfeasible by most respondents for ethical and practical reasons.

PEP is considered a useful prevention intervention by most respondents, but most PWID are not aware of it or can not access it, and 6 of those in favour felt that most PWID would be reluctant to ask for it.

Early initiation of ART is considered a good option for PWID by 14 of 19 respondents, as long as it is a fully informed and individual choice, not a coerced or punitive measure enforced by the state or others only for the public health benefit.

Criminalization of drug possession and use is the most important issue facing PWID: without drug law reform harm reduction will not have the impact needed to protect PWID and to prevent the spread of disease.

The larger issues that influence the potential impact of harm reduction interventions are poverty, homelessness, mental illness, social exclusion and joblessness.

Key interventions (NSP, OST, HTC, ART) should be prioritized to support advocacy and accountability.

Community distribution of naloxone should be added to the list of harm reduction interventions.

Naloxone is a cheap, safe, easy-to-use, life-saving drug. It should be available for community distribution to people who inject drugs, their peers and their families.

Pre-loaded syringes or nasal spray are preferred.

The importance of rescue breathing must be emphasized along with distribution of naloxone.

1. Introduction

The global response to HIV has been strengthened by an understanding of the importance of reducing new infections among the key populations at greatest risk of HIV acquisition and transmission and improving their access to vital treatment and care services. In an effort to accelerate this work, WHO is consolidating existing guidance on separate key population groups and incorporating additional information based on new insights and evidence. This guidance will consider a range of HIV prevention, treatment and care issues that affect all key populations, and it will highlight specific concerns and recommendations that reflect the unique needs of individual groups.

People who inject drugs (PWID) are one of the key population groups requiring more focused attention. Countries that have implemented a comprehensive harm reduction approach have seen significant declines in new injecting drug-related HIV infections;ⁱ however, outside of sub-Saharan Africa, 33% of all new HIV infections are among PWID, and in countries where HIV incidence is increasing, 70–80% of HIV cases are among PWID.ⁱⁱ Other data confirm that the target set for 2015 in the 2011 UN Political Declaration on HIV/AIDS for reducing HIV transmission in this community is not yet in sight:

The world is not on track to reduce HIV transmission among people who inject drugs by 50%, as recent evidence suggests little change in the HIV burden in this population. HIV prevalence among people who inject drugs remains high – up to 28% in Asia. HIV prevention coverage for people who inject drugs remains low, with only two of 32 reporting countries providing the recommended minimum of at least 200 sterile syringes per year for each person who injects drugs. Among 35 countries providing data in 2013, all but four reached less than 10% of opiate users with substitution therapy. In addition to exceptionally low coverage, an effective AIDS response among people who inject drugs is undermined by punitive policy frameworks and law enforcement practices, which discourage individuals from seeking the health and social services they need.ⁱⁱⁱ

One aspect of the WHO guidance development process involves engaging with communities to understand their values and preferences regarding elements of potential recommendations that will have a direct impact on their lives; their views and experience are considered along with systematically reviewed evidence and expert opinion. In this way, guidance can be more responsive to the needs of individuals who are confronting the challenges being addressed by new recommendations and guidance.

This report summarizes the findings of a qualitative study that explored the perspectives and experiences of active drug injectors and former PWID regarding HIV prevention and harm reduction services, and the ways they can be supported to protect themselves from HIV infection and to reduce transmission of HIV to others. Other key issues of concern to the PWID community were also discussed, including the need for greater attention to prevention and

treatment of hepatitis C and the need for community distribution of naloxone. It also takes note of the views of technical experts, NGO-based service providers and activists, several of whom identify themselves as members of the active injecting drug community or advocates for the rights and well being of this community.

2. Methods

An independent consultant conducted the study to ensure impartiality in the interviews and in the analysis of findings. Thirty-five prospective participants—members of the PWID community, experts, activists and service providers—were identified through international and regional networks and invited to participate in semi-structured, in-depth interviews regarding their personal experiences with and perspectives on:

- HIV prevention strategies;
- HIV testing modalities;
- The use of antiretrovirals for prevention of HIV;
- The comprehensive harm reduction package;
- Community distribution of naloxone.

Twenty-six people agreed to participate, and 19 people were actually able to participate in interviews, while 2 respondents provided written answers due to language constraints. In addition, 11 young injecting drug users (ages 16–25) participated in a group discussion of the interview topics led by one of the study participants who works with an organization serving the needs of young homeless people in San Francisco, USA. Those findings are also included in this report, comprising the views of 32 individuals (ages 16–57 years).

Two interview guides were developed in a consultative process with WHO and other experts in the field, one for PWID community members (Annex A) and one for experts and service providers who did not identify themselves as PWID (Annex B). The different sets of questions reflect a distinction between the values and preferences of PWID community members—the primary focus of this study—and the views of those who work closely with the community but who may not have the same personal experience on the topics covered. Where views of the two groups differ, this is noted. Interviews were 1–1.5 hours in length, and they were recorded with participants' permission; recordings were used only by the interviewer to facilitate analysis and ensure accuracy of quotes. All participants gave their verbal consent to participate in the study.

Due to the limited number of participants in this study, the content of interviews was not categorized as majority or minority positions; findings were analysed by assessing the level of support for new interventions being proposed and highlighting areas where positive views were qualified by concerns around ethics, feasibility, acceptability or other issues. Unique views are also included in

the report as they contribute important perspectives to the analysis of findings and should be noted in the guidance development process. Findings are summarized in boxes at the opening of each topic section, and the narrative report reflects the analysis of findings as they emerged in interviews. Direct quotes are used to capture the detail and tone of participants' contributions. However, quotes are not identified by gender or country in order to maintain the anonymity of respondents; some views are identified by region where conditions and experiences appear to be significantly different from other regions. In general, references are not made to individual countries unless in relation to specific data.

3. Participant profiles

Table 1. Participant profiles by gender and WHO region¹

	AFR	PAH	SEAR	EUR	EMR	WPR
Women	2	7	--	2	2	2
Men	2	8	3	4	--	--

Age range of participants is 16–57 years.

Table 2. Participant profiles by self-identification and injecting drug use²

	Member of PWID community	Expert/Activist/Service provider
Current injecting drug use	16	(5)
Former injecting drug use	9	2 (7)
Never used or no answer	--	5

Numbers in parentheses indicate current or former injecting drug users who identify as members of the PWID community as well as experts, activists or service providers for the community

Contributors to this study live in urban areas; 18 people work in a wide range of settings: community-based services in capital cities and provincial towns, international, regional and national networks of PWID (or drug users more generally) based in urban areas in the North and South, street-based and mobile services in all regions. Eleven participants in a group discussion are homeless young people who inject drugs and 1 participant affiliated with a university focuses primarily on research. None of the participants were service providers in public health settings.

¹ One service provider from Europe works in Africa; 2 PWID and 1 expert from Europe work with international networks; 1 expert from Western Pacific works with an international network; 11 adolescents and young people who inject drugs (in the USA) contributed views during a group discussion facilitated by a study participant.

² Two respondents who self-identified as former injectors reported that they are likely to use injecting drugs again in the future; their inputs reflect an ongoing concern about their own access to harm reduction services.

4. Study findings

4.1 Current HIV prevention practices among PWID

Box 1. Key findings regarding HIV prevention and PWID

- 1) **Needle and syringe programmes** are considered the single most important HIV prevention strategy for people who inject drugs. Where NSP is not available, it is understood that not sharing injecting equipment is the most essential strategy.
- 2) **Opioid substitution therapy** is considered a vital intervention for its direct benefits and for the access to a range of other HIV prevention and harm reduction services.
- 3) For HIV-positive PWID, **viral suppression through ART**—with condom use—is understood as beneficial for prevention of transmission. However, in many countries, PWID are reluctant to seek testing and treatment services due to stigma, health provider attitudes and fear of prosecution; this often results in late diagnosis and poor adherence if treatment is initiated.

Almost all participants consider needle and syringe programmes (NSP) the most important HIV prevention strategy for PWID. A requirement of 'exchange' should not be a key feature of these programmes, especially in countries where possession of a syringe or drug residue are grounds for suspicion or prosecution. Safe disposal should be facilitated through distribution of bins and, where possible, outreach services for collection of used needles and syringes. Where NSP is not available, respondents recognize the importance of not sharing injecting equipment, but this is not always an option. In these cases, access to sterilization supplies is considered a good, though not optimal, strategy.

Opioid substitution therapy (OST) is considered nearly as important as NSP, not only for the reduction of needle use but also for the stabilizing effect of this intervention, which supports effective adherence to ART for HIV-positive PWID as well as access to a range of other prevention and harm reduction interventions. Less than half of participants mentioned condoms as a preferred preventive strategy, and 7 participants noted routine HIV testing as beneficial.

NSP and OST are generally available in western European countries, Canada, US and Australia, although access often depends on many structural and individual factors. In countries where these services have been relatively easy to access in the past, some respondents note that austerity measures and changing political climates, as well as increasing political and social pressure for recovery and rehabilitation over maintenance and harm reduction objectives, are prompting cutbacks in services, reducing access to and uptake of services, negatively impacting quality of services, undermining harm reduction programmes and potentially exacerbating HIV and hepatitis C epidemics. One respondent Europe described a government 'payment by results' approach, which incentivizes services for the number of clients who are moved out of programmes; in the case of OST services, this could have negative impacts on the PWID community when individuals are pushed to leave before they are clinically or

psychologically ready. Another European provider and member of the PWID community who works at a mobile needle distribution site has also noticed a greater focus on recovery among colleagues; this person is emphatic about the need to support people to stay healthy, regardless of their choices about injecting drug use.

In other regions, availability of these services has always been uneven, and NSP and/or OST services are usually located—when they are available—in more densely populated areas, restricting access to those who live outside of catchment areas.

In some countries of Southeast Asia, Africa and the Southern Cone region of Latin America, HIV prevention and treatment are prioritized over harm reduction services for PWID, which, when available, are generally limited to major cities. However, most respondents noted that “PWID are often the last in line” for ART; many injectors are reluctant to seek services due to the negative attitudes of providers, fear of prosecution and the stigmatization they experience in general, and providers are reluctant to prescribe ART for patients they consider unstable and unlikely to adhere to treatment. Three respondents who are also NGO service providers expressed it more starkly: some public service providers feel that medications are wasted on injecting drug users.

Three of the 6 HIV-positive respondents have been on ART for many years and are virally suppressed; 2 of them are in stable relationships and usually use condoms, while 1 of them is not in a relationship. Three respondents living with HIV are active injectors, and they all rely on needle and syringe programmes to prevent transmission and to protect themselves from acquiring other blood-borne viruses.

One HIV-positive PWID (who has been on ART for 6 years) feels that ART in general is not an option in some south Asian countries given the reality of most injectors' lives.

“ART is not a priority. PWID know about ART, but their drug use is their #1 priority and there is no time for other things, including seeking treatment. But the basic conditions of life do not even allow PWID to keep a pill box with ART meds in a safe place”.

When this respondent encouraged a homeless peer to seek and adhere to treatment, the person replied:

“Yes, we can be on treatment, but [gesturing to a pill box] where would I put this pill box for the next 30 days?”

Poverty, homelessness, stigma and lack of basic services are the most significant barriers to HIV prevention for people who inject drugs. Criminalization of drug use and HIV transmission in many countries also serves as a powerful deterrent to

PWID when deciding whether or not to seek testing or other preventive and treatment services.

4.2 HIV testing modalities

Box 2. Key findings regarding HIV testing modalities

- 1) HIV testing is delivered most effectively for PWID when it is **offered alongside other harm reduction** services.
- 2) PWID will seek testing only at **safe, confidential sites** staffed by **knowledgeable, non-judgmental providers**.
- 3) **Rapid testing** can reduce late diagnosis and loss to follow-up of PWID.
- 4) **Self-testing** is an acceptable option for PWID only in settings where there is no access to safe, confidential HIV testing. However, there are **significant reservations** about self-testing due to the lack of critical support from counsellors and other health providers.

Most respondents feel that regular HIV testing is important for the PWID community, but they report that PWID are very reluctant to seek testing unless it is available through other services that they use and trust. When they do get tested at a public facility, they often do not return for results due to negative experiences with health providers, stigma and fear. In some settings they are apprehensive about getting another lecture about quitting their injecting practices. In some settings the risks are greater where young injectors are apprehended and forced into rehabilitation against their will. Consequently, late diagnosis and late initiation on ART is a common concern among service providers.

Access to HIV testing for people who inject drugs is facilitated when they feel safe and supported to learn their HIV status and to take the follow-up measures that may be necessary. Several respondents mentioned 'low threshold centers'³ as a particularly good environment for HIV testing for the PWID community because of the holistic and no-judgmental approach to serving the injecting community's needs.

Self-testing is viewed in a positive light in terms of increasing opportunities for knowing one's HIV status as long as there are clear instructions for how to do it, what the results mean and where to go after taking a test. However, almost every respondent expressed reservations about an injector with a chaotic life and little support using a self-testing kit and having to deal with a positive

³ Low threshold centers offer a space where marginalized people who use drugs can cope with difficult life situations and reduce the harms associated with their drug use. These centers generally provide health services and referrals on a walk-in basis; food, showers and peer support; and safe injecting spaces.

diagnosis alone, with possibly little information about next steps for counselling, confirmatory testing and care.

4.3 Antiretrovirals for prevention

Box 3. Key findings regarding the use of antiretrovirals for prevention

1) **PrEP** is considered **unacceptable, unnecessary or unfeasible** by approximately 24 of 32 respondents for ethical and practical reasons. There were 8 positive views of PrEP, but 4 of those were qualified by concerns about feasibility in many settings, significant barriers to ART for PLHIV in the general population who are eligible, stigma that discourages PWID from using services and the far more urgent challenges facing PWID in many countries: poverty, homelessness, hunger, illness and criminalization.

2) **PEP** is considered **a useful prevention** intervention by 14 of 21 respondents, but **most PWID are not aware of it or can't access it**, and 6 of those in favour felt that most PWID would be reluctant to ask for it. More advocacy is required to inform the community about this intervention, to develop policies that focus on the importance of PEP for PWID and to work with law enforcement where PWID risk prosecution when seeking health services at public facilities.

3) **Early initiation of ART** is considered **a good option for PWID** by 14 of 19 respondents, as long as it is a fully informed and individual choice, not a coerced or punitive measure enforced by the state or others only for the public health benefit. However, 7 of those respondents did not think it was feasible in their settings.

Pre-exposure prophylaxis (PrEP)

Ten of 32 respondents had not heard of PrEP or were not sure of what it involved. Eight respondents expressed positive views about PrEP as an HIV preventive option, although 4 of them acknowledged that they did not know very much about it. Four respondents' views were positive but with reservations. Fourteen respondents were unequivocally opposed to PrEP, while only 1 of a group of 11 young injectors spoke favourably about the intervention, the others expressing concerns or ambivalence.

In general, respondents were uncomfortable with an intervention that is imposed on individuals for the public's health.

"The possibly negative effect on the individual's health and wellbeing is not being considered as having the same value as the public health benefit. There is the old narrative about drug users as disease transmitters, and there's not enough attention to the needs of drug users as individual human beings and whether this intervention has real benefits for the individual who injects drugs."

"[Many PWID] understand PrEP as a way to put the responsibility on drug users (with all of the implications they have to face in terms of toxicity, side

effects, daily meds) rather than a collective, societal effort [to promote harm reduction]."

"In the EECA region [eastern Europe and central Asia], people are deeply alarmed by the possibility of their governments picking up on PrEP. [It] raises a whole series of human rights threats and risks: registries that could be shared with the police, compulsory attendance, a whole range of potential human rights infringements . . ."

"What are the side effects, what is the potential toxicity and what are the alternatives? An individual should have all the information to weigh the pros and cons, the toxicity, side effects, daily burden of meds as well as the benefits (which are more for the public's health than for the individual's)."

Three individuals expressed unqualified support for PrEP. One person lives in a setting where HIV prevention and harm reduction services are easily accessible, acceptable and affordable. While acknowledging that access to ART for those who are eligible is still inadequate, this person felt that any opportunity for protection against acquiring HIV would be desirable (this respondent is living with HIV). At the same time, this person believes that the acceptability of PrEP would depend on an individual's comfort in society – a person who is vulnerable due to homelessness or social isolation might be less willing to engage with health services in order to access PrEP. One person who lives in a setting where criminalisation is a significant barrier to health services for PWID, and harm reduction is not easily accessible, had not heard much about it, but he felt that *"the more degrees of protection the better"*. One member of a group of young injectors felt that it would be a good thing *"if I felt that I was continually putting myself at risk"*.

Four respondents who support the idea of PrEP live or work in countries where criminalisation of drug use creates a context of persistent and acute fear, and where harm reduction is largely unavailable or difficult to access; however, they emphatically qualified their views in terms of:

- Uncertain feasibility in contexts where PWID are reluctant to access health services in general;
- Unlikelihood in contexts where there are major barriers to ART and significant shortfalls in coverage, even for those who are currently eligible;
- Current lack of awareness and information about this option; there would need to be full information about how PrEP works, the implications for adherence and resistance and costs to individuals;
- The chaotic quality of most injectors' lives, which creates challenges for engagement with health care in general and adherence to ART or any other medical protocol even when it is needed as treatment for HIV or other health issues;
- The aversion to being associated with the HIV-positive community, which could add more stigma to already highly marginalized lives;

- Other more pressing needs for human rights shelter, food, health care, HIV treatment for PLHIV.

“If some doctors would prescribe PrEP for PWID, it would be really useful to prevent new infection. But in many EECA countries, to get PrEP a person would need to go to a doctor at the AIDS center, which is a horrible place, and to get there takes so much effort and is so connected to stigma and discrimination. And these doctors do not see drug users as clients, they see them as drug users, people who will not take these medications, will just sell it or whatever . . .”

“PWID are not even aware [of PrEP] in eastern Europe. The situation is catastrophic. HIV-positive people cannot get ART, nobody discusses PrEP or PEP . . . not even service providers. In eastern Europe, [PWID are not an issue] until people are dying of overdose. There is not basic health for this community, so it's too early to talk about PrEP. Some doctors and experts are discussing it, but people are hungry and they are homeless and they are just dying in the streets, so PrEP would not even be an option for them. It's not a priority.

“It may be an option for some people but not for all. It has to be people who are going to take the treatment responsibly and look after their health. It sounds like a good idea, but the reality is in order to take medication, you need food, water, shelter, etc. Maybe PrEP is not a good idea unless people have the other conditions of life.”

“The challenge is that the people who could most benefit from PrEP are the [the people with the] most chaotic [lives], which in many cases are the people who would be least likely to comply with the programme—that's the contradiction.”

Among the young PWID who participated in a group discussion, most⁴ were averse to the idea of a protocol that required daily medication, although some suggested that they might take it if there were an ‘incentive’.⁵

Fourteen other respondents were opposed to the idea of PrEP as an intervention for the PWID community at this time. Their views ranged from unequivocal rejection of the notion that ARVs should be used as a preventive intervention in light of continued shortfalls in access to ART for eligible PLHIV, to opposition to what is seen as a ‘medicalization’ of harm reduction, to a concern that HIV-negative PWID in some settings where awareness and understanding are very low would suffer additional stigma and harassment if they were to start taking an HIV-related drug regimen.

“Until we have the other interventions scaled up, I think PrEP is a step too far.”

⁴ Exact number not reported.

⁵ Young PWID in this community have been receiving cash incentives for HIV testing through the UCSF/CAPS UFO study since 1997. See <http://caps.ucsf.edu/ufo-study/>

"I am completely and utterly opposed to the use of PrEP for injecting drug users . . . supporting the use of PrEP for non-positive injecting drug users is . . . obscene. Until we have 100% treatment access for HIV-positive injecting drug users, [we should not have] discussions about the use of PrEP for non-positive injecting drug users."

"It's not ethical or acceptable as long as most people do not have access to the basic conditions of life and as long as diagnostics are not adequate to providing a true picture or where epidemics are and the magnitude—HIV as well as Hep C, TB, etc—to determine what drugs and what quantities are actually needed."

"The introduction of and backing of PrEP is part of a much larger agenda to medicalize the HIV response, which poses a very serious threat to community-based preventive responses—across all communities. In the context of PWID, the bio-medical magic bullet promise of PrEP, [especially for] governments who are resistant to harm reduction, will be seen as an excuse not to scale up or introduce [proven] harm reduction programming."

"As a health issue it might be good, but from a social perspective [in India] I don't think it would be a good idea . . . the stigma and discrimination would be worse for [PWID who started taking ARVs even though they are HIV-negative]."

"If IDUs take drugs for prevention this way, it would be hard to make them understand that they are not HIV-positive and it would be hard for the rest of the community and their families to understand. There is not enough information and understanding about this. As a health issue it might be good, but from a social perspective I don't think it would be a good idea."

Three experts speculated that pharma companies might have a lot to gain from a PrEP rollout.

"In Russia, with 1.8 million injecting drug users and a government adamantly opposed to harm reduction, they're looking at a very large captive market."

Many respondents noted that adherence to a daily protocol would be challenging for people who often have chaotic lives, and that poor adherence would increase the possibility of resistance to an important class of drugs, which an injector might eventually need for their own health.

"There are quite a lot of people who inject who are HIV-positive and who do not follow treatment; it could be a challenge to get people who are not positive on treatment like that, especially people who don't take care of their general health on a regular basis."

One respondent who is strongly opposed at this time can see how PrEP might be useful when many other conditions are met (e.g. harm reduction to scale and universal access to ART), but most of his peers see it as a distraction from better access to harm reduction which is needed immediately. Others expressed concerns that the availability of PrEP in some countries would undermine the critical message that NSP, OSP, HTC and ART are vital harm reduction interventions, and that services themselves might be cut back or closed if PrEP were rolled out. This is a particular threat with regard to hepatitis C prevention (a far greater problem than HIV for the PWID community), as PrEP does nothing to address this; in effect, PrEP could pose a double risk, undercutting proven options and undermining hepatitis C prevention. In general, PrEP is seen as unnecessary and a poor investment when proven, low-cost harm reduction interventions are already available, and which some countries are still not providing.

"Wouldn't it make more sense to have clean injecting equipment?"

"For people who are concerned about high exposure to sexual transmission (e.g. MSM, SWs, TG), PrEP might be a good option, but for the injecting community it is more important to promote cheap and effective harm reduction, especially needle and syringe programmes. The priority should be availability of clean needles."

"It's a very expensive way to reduce the risk of HIV transmission, when we know that NSP and handing out harm reduction supplies is such an effective way to reduce HIV, and a lot cheaper. I would rather see a focus on the 15 million people who can't get access to ARVs, rather than trying to get injecting drug users on PrEP."

"It might be a good thing, but it's not necessary. The priority is to work on harm reduction [referring to the current comprehensive package]."

Post-exposure prophylaxis (PEP)

Most respondents believe that PEP is an important intervention that PWID have a right to know about and to access, but that the community is generally not aware of PEP as an option. Some people feel that the availability of clean needles helps to remove a need for PEP among PWID (as long as they engage in protected sex), and for most people this would be preferable to seeking PEP in a public health facility. In some settings PWID would be reluctant to ask for PEP due to laws that would require providers to report drug users seeking services to the authorities; fear of prosecution would be more compelling than fear of HIV for most people in those settings.

"We need to start by decriminalizing drug users, then spread awareness about interventions like PEP."

Two service providers felt that in some countries PWID would be unlikely to be given PEP due to stigma and marginalization of drug users as well as the cost of the drugs.

“PEP should be available to drug users but it's not. Drug users are considered as taking a known risk and so perhaps don't 'deserve' to get it.”

Furthermore, in many settings where active injecting drug users can't go to health care facilities to ask for ART if they are HIV-positive, they are even less likely to be able to go to an ER and ask for PEP because they used a possibly contaminated syringe; stigma is a powerful deterrent to seeking services, as is the fear of having one's drug-using history become part of a permanent electronic health record.

“It should be available for all. But [in Tanzania] they don't have access to clean syringes, so 100% have been exposed. So all PWID should get it, but we can't even get them to clinics in the first place—it's about stigma, it's about money, it's about lack of trust, so it's difficult to imagine PEP as an option [in this setting].”

“There is a value judgment element. There's more empathy toward a person who has been raped or a service provider [who has had a needle stick injury] than there is for a person who injects drugs, and this is excluding community members from a vital intervention.”

“When a person who injects drugs asks for PEP, it is because s/he is very sure that s/he's been exposed to HIV by a needle. When someone is that sure that they've been exposed, they should absolutely be given PEP regardless of the reason for the exposure.”

Several respondents, PWID community members and experts, two of whom had personal experience with PEP, felt that this was a good intervention as long as the individual had an understanding about the process and some level of stability in terms of housing and a support network to help the person cope with the process and the side effects. Some providers might be reluctant to provide PEP for young injectors because of consent issues.

One participant, a member of the PWID community as well as a technical expert, shares a more nuanced view of PEP for PWID: investment in PEP would be a diversion from the real issue. His position is that people who inject drugs should not be in a situation where they need to re-use needles. While unprotected sex might be more pleasurable than protected sex, and some people might choose to take that risk, there is nothing pleasurable about sharing needles, and it is not a choice that people would make voluntarily. He feels that UN guidance on targets for harm reduction is part of the problem; e.g. 200 syringes/year is not an adequate supply for a daily user, and the recommendation should be as many needles and syringes as any individual needs.

“We don't expect people to re-use condoms, we shouldn't be expecting people to re-use syringes. And that is effectively what we're being expected to do. Harm reduction programming is nowhere near the scale at which it needs to be, and that, for me, is a greater imperative than PEP. If we're choosing where to put resources, we should be putting them into pro-preventive measures.”

When asked about limiting an individual to a certain number of courses over a period of 12 months, 2 service providers felt that there should be no limits, but that prescribing PEP required considerable counselling, support and follow-up, along with information for more effective prevention strategies.

Early initiation of ART

Early initiation is viewed favourably by 14 of the 19 people who responded to the question, but 7 respondents felt that it was not at all feasible in their settings due to criminalization, stigma, and general lack of ART for PLHIV who are currently eligible. Most of those in support of early initiation would be opposed if this were a mandatory measure imposed on the HIV-positive injectors.

One expert expressed concern that the way that some ART recommendations are worded facilitates imposition of treatment without the real consent of the patient.

“Even when the recommendation says that ART should be offered, in some countries, saying 'no' to a physician is not really an option, so those patients are effectively being forced into treatment. And you can be blamed and marginalized further if you refuse this treatment.”

Another member of the community and a technical expert pointed out the view that there is an important omission in the Consolidated ARV guidelines in that early treatment is not recommended for people with hepatitis C, as it is for people with hepatitis B; several respondents assert that hepatitis C is actually a much larger concern to PWID than HIV.

A more widely held view among respondents is that the health of the individual must be the first concern, and that early treatment must be an individual choice. Most respondents rejected the notion of the public health benefit as more important than the individual's wellbeing.

“There is a concern that in some countries this will be used to identify possible 'vectors' of transmission, especially among key populations and to force them into treatment to prevent transmission to others.”

“This notion that a given population is disproportionately contributing to transmission is stigmatizing; it's about others being more comfortable with the idea of starting around CD4 500, not the individual.”

However, in many places, there is a more urgent need for other support services for HIV-positive PWID, better treatment literacy, and universal access to HIV treatment for those who are eligible before early initiation of ART is a viable or acceptable option.

“Service delivery would be problematic, there are already long lines and overcrowded clinics. There would have to be more clinics just to serve the current population [who are eligible for ART].”

“Most people are just not ready to make a decision about treatment at that point, there are so many implications to consider (including that you have to take charge, carry the meds with you everywhere and deal with those issues as well) and so many other things to deal with.”

“Pills make you feel sick. If you are feeling well and you are not convinced you need this, adherence will be difficult.”

One member of the community who is also a service provider felt that in EECA countries, especially in Russia, doctors would never offer drug injectors early initiation on ART because of the low value placed on their lives.

“PWID are pretty much outside of society in Russia, and nobody in the MoH will ever think that drug users have families and friends, they simply can't conceive of this. They think that PWID are people who live on the street, have no friends or family, and of course they can infect only each other, which [in the view of the MoH] is good.”

A similar view is held by a respondent in Asia who first noted that he liked the new ARV guidelines on treatment initiation, because he thinks starting earlier is good for all PLHIV. However he sees other, more fundamental issues as needing more urgent attention.

“CD4 count is not the issue for PWID. Just to get them to the ART center is difficult, they are dirty and public transport doesn't even want to take them. There are no mobile services, and ART is only available through the government hospital, it is very unrealistic to [think about getting] PWID on ART early. People do not care about them, and they need so many other things: food, clean water, they sleep in the streets, they have nothing. So ARVs are not really important.”

Another member of the community and a service provider in a country where HIV transmission is illegal notes that early initiation can be an excellent strategy for PLHIV to achieve viral suppression and avoid criminal prosecution, especially when there are aggressive efforts to find and arrest people who are suspected of 'criminal' behaviour.

“Protection from prosecution is a huge individual benefit; there have been witch hunts of people who are [suspected of being] HIV-positive. “

A member of the PWID community in a setting where very few eligible people have access to ART notes that many service providers are not even aware of the new guidance on ARVs (recommending initiation at a higher CD4 level). He feels that early initiation might be a good idea in theory but a long way from reality in his setting where most PWID are reluctant to get an HIV test.

4.4 Comprehensive harm reduction package

Box 4. Key findings regarding the comprehensive harm reduction package

- 1) **Criminalization** of drug possession and use is the most important issue facing PWID: without drug law reform harm reduction will not have the impact needed to protect PWID and to prevent the spread of disease.
- 2) The larger issues that influence the potential impact of harm reduction interventions are poverty, homelessness, mental illness, social exclusion and joblessness. WHO must take a stronger position on the **social determinants of health** in order to ensure the effectiveness of the comprehensive harm reduction package.
- 3) **Key interventions (NSP, OST, HTC, ART)** should be prioritized to support advocacy and accountability.
- 4) **Community distribution of naloxone** should be added to the list of harm reduction interventions.

Of the 21 adult participants who responded to questions about the comprehensive harm reduction package⁶ 18 felt that the package was good in terms of its usefulness as reference points for advocacy. However, availability is uneven within countries and across regions. Respondents point out that access to OST in eastern European and central Asian countries is extremely limited, and it is prohibited in Russia, Turkmenistan and Uzbekistan. Poverty, homelessness, criminalization and disregard for human rights in other regions such as the Southern Cone countries of Latin America and in South Asia place harm reduction low on a list of priorities for governments and for PWID themselves. In some Eastern Mediterranean countries, there are high rates of hepatitis B, hepatitis C and TB affecting PWID, but there is little attention paid to harm reduction related to those diseases. Governments in North America and Europe are cutting back on services in order to push recovery.

⁶ The comprehensive harm reduction package is considered by WHO, UNAIDS and UNODC to include needle and syringe programmes, opioid substitution therapy, HIV testing and counselling, ART, condoms, targeted information and education and screening and treatment for STI, and screening and management of HBV, HCV and TB.

Respondents highlighted a number of weaknesses in terms of the way the package was developed, the way it is presented, and in terms of missing elements.

“Very dry and technical set of recommendations . . . and it has not been prepared on the basis of any consultation with the community.”

Some participants feel that it would be helpful to view harm reduction as a process as well as a set of interventions. This would allow for a less limiting approach to harm reduction that also recognizes issues such as drug consumption limits, crack pipe distribution

One person felt that the only 3 that matter are NSP, OST and ART, but he added that getting PWID enrolled in ART was a huge challenge. Six other respondents believed that the package would be more useful if WHO would take a stronger position on the necessity of NSP and OST, two interventions that are critical to both HIV and hepatitis C prevention, but which are less available in many countries for social, political and financial reasons. The WHO, UNODC, UNAIDS Technical Guide for setting targets related to access to HIV prevention, treatment and care for PWID emphasizes the importance of a comprehensive approach, with high levels of coverage, to significantly reduce HIV transmission and other harms.^{iv} However, most countries are not doing this.

“With a list like this, countries can ignore the ones they don't like and choose to implement the easier ones, and still say they are doing harm reduction. WHO should make a clear emphasis on NSP and OST. It is not possible to deliver good harm reduction programmes without appropriate coverage of OST. A WHO recommendation is a powerful tool for advocates, especially in countries like Russia. It provides more ammunition for advocates and sends a clearer message to governments. As it stands now, with the 9 interventions, each one seems to have the same importance, and this is not the case. ”

Others would prefer that NSP, OST, HTC and ART be presented as the core, non-negotiable interventions.

“There has been a sense that if you do some on the list (condoms etc, things that a bit more marginal for PWID), then you're doing something at least . . . if you aren't doing these top 4, and you aren't doing all of them, then you're not going to be hitting the 50% reduction rates that we can achieve in HIV epidemics among PWID.”

In terms of pieces that are missing from the harm reduction package, and number of additional elements were suggested:

- More explicit and non-moralistic information and education (life skills education for young PWID, safe injecting practices, vein and mouth care, overdose prevention);

- More explicit reference to the need for harm reduction services for prisoners, or a prison-specific harm reduction package;
- Attention to the specific needs of women at service delivery sites;
- The importance of safe injecting spaces as part of harm reduction service delivery sites;
- Psychological follow-up;
- Community distribution of naloxone.

Several respondents commented on the importance of peer-led services and outreach, deeper partnerships with civil society and a more community-centered approach to delivering harm reduction services.

“Sex workers have blazed the trail on community-led services. It’s now accepted that services should be provided by and for sex workers, and the same applies to the IDU community. What has tended to happen has been quite the opposite; we are excluded from working in services that are aimed at our community.”

Many respondents see the issue of harm reduction as something that extends beyond a list of 9 interventions. Some spoke at length about the need to address the social determinants of health before harm reduction can have a real impact on HIV and other epidemics. Issues such as poverty, shelter, hunger, mental health, joblessness and social and economic exclusion are all barriers to effective harm reduction. In some countries, racism and loss of cultural identity of entire groups of people, e.g. the aboriginal community in Canada, have a profound effect on the HIV epidemic within sub-groups of the PWID community. Some of these issues are systemic and need to be addressed by governments, but WHO and other international bodies are in the best position to engage on these issues at the highest levels.

Critical enablers such as the legal environment, access to justice and human rights must be addressed before harm reduction objectives can be achieved. Ten respondents mentioned the lack of access to harm reduction in prisons as a major concern. Almost every respondent called for decriminalization of injecting drug possession and use; this is considered the key that will unlock the response to HIV. Currently, penalties for possession and use send PWID to prisons, where they are often denied protection and harm reduction services; create climates of stigmatization and fear, which discourage PWID from seeking vital services; and fuel the distrust and exclusion that PWID experience as marginalized members of society.

“We can’t talk about HIV and the injecting drug community without looking at global drug prohibition. And we certainly can’t talk about getting to the ‘3 zeros’⁷ without really comprehensive drug law reform.”

⁷ Zero new infections, zero AIDS-related deaths, zero discrimination

The UNAIDS strategy for 2011–2015 echoes this view:

Social and legal environments that fail to protect against stigma and discrimination or to facilitate access to HIV programmes continue to block universal access. Countries must make greater efforts: to realize and protect HIV-related human rights, including the rights of women and girls; to implement protective legal environments for people living with HIV and populations at higher risk of HIV infection; and to ensure HIV coverage for the most underserved and vulnerable communities.^v

4.5 Community distribution of naloxone

Box 5. Key findings regarding community distribution of naloxone

- 1) **Naloxone is a cheap, safe, easy-to-use, life-saving drug.** It should be available for community distribution to people who inject drugs, their peers and their families.
- 2) Community distribution of **naloxone should be added as an element of the comprehensive harm reduction package.**
- 3) **Pre-loaded syringes or nasal spray** are preferred.
- 4) The importance of **rescue breathing** must be emphasized along with distribution of naloxone.

"Naloxone saves lives."

"We deserve to live, to be okay, to have more chances. We have lives of value, we are people, too."

"People are dying every day in Russia. The quality of drugs is changing every day because heroin is often not available and so people have to take whatever they can find, and it's very difficult to find the right doses, and so overdose happens all the time. Naloxone used to be more available with Global Fund money and it was so successful, and service providers distributed naloxone in the communities, and it helped a lot and saved a lot of lives. But GF has not been operating since 2013, now there is [not enough] naloxone."

The discussions of community distribution of naloxone were brief and the views were clear. Thirty-one respondents (one is based in a country where injecting drug use is limited to stimulants, and naloxone was not discussed) expressed unqualified support for making naloxone widely available without prescription and without burdensome conditions. Three respondents acknowledged that overdose is not a significant problem in their settings, however they felt that naloxone should be available to every person who injects opiates.

“Availability with prescription (as is the case in many countries) is not enough—it needs to be in the hands of peers, families etc, so that it is easily available.”

Many respondents feel that resistance to making naloxone more widely available to the PWID community and their families and friends can have a dramatic effect in terms of further marginalization of members of the community, reinforcing a sense of alienation from society, which only makes injecting drug users more reluctant to seek and use vital harm reduction and other health services. In many countries, continued criminalization of PWID also deters peers from getting emergency assistance when someone has overdosed.

“There's something so symbolic about naloxone. It's a life-saving intervention. If you say community distribution is not worth [doing], it's a value judgment on our lives.”

“What does that say about us if you're willing to let us die when there's such a preventative option in place? [Even if] you oppose harm reduction fundamentally, not being willing to save our lives feels so alien and says so much about what you think about us, and then that affects how we want to engage in services.”

In general, availability of naloxone is variable across regions. In Europe and North America, availability is becoming more widespread but there is not universal access, and it can still be difficult to get naloxone for peer distribution. In most countries where naloxone is legal and available for community use, there are usually conditions that require a prescription and training. In almost all of those cases, only a small amount is given to each person, generally a 2ml vial, which may be sufficient for 1 or 2 doses, depending on the situation. Respondents who mentioned the doses all felt that it would be better to have larger quantities available for community distribution.

Ideally, a sufficient and consistent supply of naloxone for peer workers to distribute along with basic training could create a cascade out to all members of the community. Training must continue to emphasize the importance of rescue breathing; one respondent worries that widespread availability of naloxone could overshadow the critical importance of this overdose management strategy. Another respondent feels that rescue breathing must be designated as preferable to chest compressions which are advised in her setting, but which result in additional trauma (e.g. cracked ribs).

In sub-Saharan Africa and South Asia, availability is much more limited. In most cases, only health professionals are allowed to administer it; in some cases, health providers themselves are not aware of it. In many Eastern Mediterranean countries, naloxone is available only at government health facilities, and only some first responders have access to it; however, administration of naloxone requires a doctor's permission, which in turn triggers a report to the police.

"Often people will be thrown on the street to die because they are afraid of trouble with the police."

One respondent in sub-Saharan Africa raised the issue of health information systems as an issue to be addressed when advocating for naloxone.

"Current death registration masks the real extent of the problem; death caused by OD is called 'pulmonary embolism', so we don't have the real numbers to use when we advocate for wider distribution of naloxone."

Arguments against community distribution of naloxone are considered to be baseless.

"The main resistance is based on a belief that people will feel safer and engage in more high risk behaviour and try to get as close to OD as possible, because we have naloxone sitting there. It's a ridiculous argument. It's true, for some users this is part of the game, getting as close as possible without overdosing. But if you know what it's like to go over and then get brought out with naloxone, which is not a pleasant experience, then actually getting your 'stone' right makes much more sense than being reckless, you can enjoy it without being interrupted. The arguments against naloxone just don't add up.

And there are complexities to the situation that don't fit with this simplistic assumption that people will act more recklessly (e.g. there may be other substances such as alcohol that are changing the way the body is processing the drug, or a health condition that makes the drug act differently)."

"Dealing with overdose is scary. There are no downsides to having naloxone. We could be saving people's lives! When you work with this community, you lose so many people. People's lives could be saved so easily, it's so easy to administer, it's so logical. The reality is that people hate drug users . . . and some people feel it's a waste of money if you're using it for drug users."

When asked if there are any downsides to community distribution of naloxone, one respondent summed up the views of all participants:

"None. What kind of question is that?"

4.6 Adolescent and young people who inject drugs

While the issues of young injectors were not a main focus of this study, respondents in all regions signalled the urgent need to develop more youth-specific services for young PWID, including clinic-based, mobile and outreach services. Some service providers noted their lack of expertise for addressing the needs of young people who use injecting drugs, and they understand that young people are not comfortable seeking services in places where older injectors congregate. Another problem is that young people do not have the same type of peer support that older injectors have when services are staffed by

current or former injectors.⁸ Peer counsellors who share lived experience with young injectors can provide opportunities for building relationships and supportive networks that promote good HIV prevention and harm reduction practices. Service providers also noted that most young injectors do not self-identify as members of the PWID community; they are injecting on an occasional, recreational basis, they are generally healthy, and they do not feel a need to seek HIV prevention or harm reduction services.

Regarding PrEP and early initiation of ART, most respondents feel that initiation of a daily, lifelong regimen would be unacceptable for young PWID as the decision is complex and adherence would be extremely challenging. Furthermore, there is not enough evidence about the long-term effects of either of these interventions in adults, much less young people. One expert who works with a global youth-led network for reducing drug-related harm noted that it was already very difficult for HIV-positive young PWID to access ART— due to chaotic lives, exclusion from OST which has a stabilizing effect that can facilitate ART initiation and adherence and stigmatization which discourages young PWID from seeking services—and that early initiation of ART is not a feasible option for young members of the PWID community.

Consent is an issue that concerns providers with regard to young clients. However, service providers who participated in the study said that they would provide a young injector the prevention and harm reduction services requested. Some providers would encourage the individual to involve a parent or guardian, but many young injectors live on the street or apart from family, and they would be unlikely or unable to do this. The most important thing for providers is that a young person understands the implication of the service or intervention being offered.

Most respondents who have some interaction with young injectors said that they would not support the use ARVs for prevention by young PWID due to concerns about adherence, side effects, resistance and other potential complications related to their age and lack of supportive services for adolescents and young people who inject drugs.

⁸ Several respondents feel that there should be more members of the community involved in service delivery as the shared experience promotes greater trust in service providers, stronger peer support and more effective advocacy.

5. Conclusion

Four issues were the main focus of this values and preferences study:

The introduction of PrEP as a harm reduction intervention for people who inject drugs. *This was not supported by a majority of the participants in this study.*

The comprehensive harm reduction package. *Participants felt that prioritization and additional components could make the package a more effective tool for advocacy and for strengthening the response to HIV and hepatitis C.*

Community distribution of naloxone. *Participants assert, with no reservations, that this life-saving intervention is absolutely necessary and should be made available immediately to injecting drug users, their peers and their families.*

Experience and preferences around HIV testing modalities. *Introduction of more peer outreach and mobile services and as well as broader availability of rapid testing are seen as starting points for addressing low uptake of HIV testing by members of the PWID community. Self-testing is not viewed favourably due the lack of counselling, support and referrals for follow-up services.*

Participants in this study emphasized the need for more attention to critical enablers that fundamentally determine the accessibility and effectiveness of harm reduction for injecting drug users:

- Human rights including empowerment of the PWID community for advocacy and equity
- Poverty, homelessness and hunger
- Stigma and discrimination
- Equitable access to HIV prevention, treatment and care, and harm reduction services as well as basic health care
- Legal environment and criminalization of drug use and HIV
- Social and economic inclusion and re-integration
- Psychological support

Participants also drew attention to four key messages that address fundamental gaps or weaknesses in current responses to HIV among the injecting community:

1. Hepatitis C is a bigger problem than HIV for PWID.
2. Youth-specific services are urgently needed.
3. Policies and services for prisoners are urgently needed.
4. Decriminalization of injecting drug use is the key to effective harm reduction.

Study participants represented a diversity of social and economic backgrounds. Their experiences as injecting drug users, service providers or researchers contributed important insights on the challenges facing the PWID community as they seek protection of their fundamental rights to health, decent conditions of life, a place in society and a voice at the table. While the study was limited in terms of the number of participants, the consensus was loud and clear: marginalization of people who inject drugs—through criminalization and lack of protection, violence and abuse, denial of medical and harm reduction services, poverty, homelessness, stigma, intolerance, fear and moralistic societal norms—will continue to force the community to live in secrecy and fear, to support transmission of HIV and other blood-borne viruses, and to undermine efforts to achieve the ‘3 zeros’.

Endnotes

ⁱ UNAIDS 2012 Global report.

ⁱⁱ Altice, F, 2013. *Why pills alone are not the silver bullet*. Presented at the TasP PrEP Evidence Summit, Controlling the HIV Epidemic with Antiretrovirals: From Consensus to Implementation. IAPAC, London, September 2013.

ⁱⁱⁱ UNAIDS 2013 Global report.

^{iv} WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users – 2012 revision.

^v UNAIDS, 2010. *Getting to Zero: 2011–2015 Strategy*.