



International
Network of People
who Use Drugs

INPUD Summary Report: WHO Key Populations' Values & Preferences for HIV, Hepatitis and STIs services

INPUD Summary Report: WHO Key Populations' Values & Preferences for HIV, Hepatitis and STIs Services

Introduction

Over the last several months INPUD has collaborated with the World Health Organization (WHO) Department for Global HIV, Hepatitis and STI Programmes on a global qualitative study examining the values and preferences of key populations, including people who inject drugs, for HIV, Hepatitis and STIs services. The findings of this study will inform the update of the WHO 2016 Consolidated Guidelines for HIV prevention, diagnosis, treatment and care for key populations. These Guidelines will be used to inform countries on the design and implementation of health packages for key populations, making it extremely important that they take into account the specific values and preferences of each key population included in the study (people who inject drugs, gay and bisexual men and other men who have sex with men, female, male and trans sex workers and trans people).

Across the globe, people who inject drugs continue to be at increased risk of HIV, viral hepatitis (HCV, viral hepatitis B (HBV) and tuberculosis (TB). In order to reduce HIV, HCV and HBV transmissions along with overdose deaths, a comprehensive package of harm reduction interventions must be made available to people who inject drugs. Although such interventions are considered by the WHO and other UN agencies as essential to achieve global targets, access to harm reduction is still limited or non-existent in many countries, with less than 1% of people who inject drugs having sufficient access to services. Structural barriers caused by the criminalisation of drugs and the

accompanying stigma and discrimination directed towards people who inject drugs are among the biggest contributors to this problem.

As one of the four key population networks included in the study, INPUD conducted eight regional focus group discussions and ten semi-structured interviews with people who use drugs from 27 total countries. This report is a summary of our key findings that will be used to update the Consolidated Guidelines with the values and preferences of people who inject drugs.

Summary of Participant Recruitment & Data Collection Methodology

In total, fifty-four (n=54) individuals from the key population of people who inject drugs participated in the study. A total of eight (8) focus group discussions (FGD) with 44 participants and ten (10) semi-structured interviews (SSIs) were conducted with participants from twenty-seven (27) different countries across four (4) WHO regions. FGDs and SSIs were conducted in English (12), French (2) and Russian (4) – although no FGDs or SSIs were conducted in Spanish, there were bi-lingual Spanish/English speaking participants in FGDs. The FGDs and SSIs were conducted via online communication platforms (i.e., Zoom, Teams, WhatsApp). All groups followed the SSI and FGD interview guides. All participants were recruited via INPUD's global network and the Regional Focal Points (RFPs) for the study. Data was collected by either one of the Principal Investigators (AM & JC), one of the

five (5) Regional Focal Points (RFPs) or by one of two (2) sub-regional community consultants/researchers engaged by one of the RFPs. All data was then checked for consistency, collated and analysed by one of the principal investigators (AM).

Detailed Participant Demographic Characteristics Breakdown

Total participants: 54 (17 (31%) cis-female, 30 (56%) cis-male, 6 (11%) non-binary, 1 (2%) other gender non-conforming identity)

Total interviews/focus groups: 8 focus groups and 10 interviews

Total countries: 27

Africa region: 13 (Burundi, Cameroon, Cote d'Ivoire, Kenya, Malawi, Mali, Mauritius, Nigeria, Rwanda, Senegal, South Africa, Tanzania, Uganda) - 12 participants total from Africa region

Americas region: 2 (Canada, United States) - 14 participants total from the Americas region

European region (also includes Central Asia): 11 (Italy, Georgia, Greece, Kazakhstan, Kyrgyzstan, Moldova, Portugal, Russia, Spain, Ukraine, United Kingdom) - 20 participants total from European region

Eastern Mediterranean region: 0 countries, 0 participants

Southeast Asia region: 0 countries, 0 participants

Western Pacific region: 2 (Australia, New Zealand /Aotearoa) - 8 participants total from Western Pacific region

Languages to conduct interviews & focus groups: (English (12), French (2), Russian (4) Spanish (0) – note this does not reflect bilingual Spanish/English speaking participants in FGDs)

Age breakdown:

18 - 25: 2 (4%)
26 - 35: 11(20%)
36 - 45: 20 (37%)
46 - 55: 17 (31%)
56 - 65: 3 (6%)
Over 65: 1 (2%)

INPUD Summary Responses to PICO Questions for Consolidated Network Report

Chemsex

Perceptions about the relevance of Chemsex varied among the study participants ranging from: “not really relevant” to “has relevance but it’s not the most important thing” with a high degree of relevance for many gay and bisexual male participants. Participants noted that for some regions including Sub-Saharan Africa and Asia, although Chemsex is widely practised, it has not been a high priority for people who inject drugs, largely due to focusing on more pressing human rights violations. Some participants raised that Chemsex is too often discussed as only relevant for gay and bisexual communities but actually takes in a broad range of practices not only among LGBTQIA+ communities but heterosexual populations as well - even if the term ‘Chemsex’ is not specifically used.

A number of participants stressed the importance of not only focusing on ‘risks’ and ‘harms’. The term “sexualised drug use” was suggested as an alternative to the ‘Chemsex’ terminology to encourage more focus on “pleasure and fun”, “fluidity”, “creating cultures

of care" and "being a good host" that have the benefit of resonating well beyond gay, queer and bi-sexual men including for trans men, trans women and cis-gendered heterosexuals who engage in using drugs to enhance sexual experiences.

Participants also drew attention to the complexities surrounding 'Chemsex' including that it involves a variety of drugs being used by people from many age groups, identities, cultures, backgrounds and knowledge levels in a wide array of contexts and settings. There was a general consensus that interventions and services in relation to Chemsex need to be peer-led and tailored but also flexible to meet the specific and evolving needs of different communities:

"...so, it seems to be that there's kind of like a suite of offerings that work because it recognises that not every type of thing works for every person and people are at a different place in their own journey or in terms of how they reflect upon their own use, as well."
Gender non-binary drug user, Western Pacific region

Specific interventions suggested included:

- Adopting gender-affirming health care and broader cultures of care to support inclusive, non-stigmatising behavioural interventions and approaches;
- Tailored and flexible peer-led interventions for specific groups and communities, different contexts and settings, and various practices and drugs used;
- Access to "hosting packs" or "safety kits" that are harm reduction focused and encourage people to "plan to be safe" including sterile injection equipment, male and female condoms, lubricants, drug testing strips, naloxone, HIV, STI, hepatitis prevention and harm reduction information, and other materials as identified by communities.

Finally, many participants also stressed the critical importance of drug law reform to remove structural barriers, reduce stigma and discrimination and improve access to peer-based harm reduction.

Behavioural Interventions (Impacts on Reducing Risk)

Participants stressed the importance of behavioural interventions and counselling for HIV, STI and hepatitis prevention among people who inject drugs being focused on peer-led harm reduction approaches and outreach with a focus on safer injecting drug use practices. This included the importance of acknowledging different levels of access, knowledge and literacy:

"I mean, like having the information is essential. If you don't have the information, what can you do? Right? I think that's like, number one, like before anything before counselling, before anything else. If I don't have the information, then I can't protect myself anyway." Female drug user, the Americas region

"...street outreach is very important: available testing for these diseases, peer-to-peer consultations and web-outreach in social networks and messengers. It is necessary that drug users, especially young people, have maximum access to information on harm reduction." Female drug user, European region

"Continuous education where this will be repeated many times and not just giving people pamphlets but explaining to people as some are illiterate." Gender non-binary drug user, Africa region

Participants also noted that while access to information/education is critical, so too is adequate access to evidence-based harm reduction approaches such as NSP and OAT to put education into practice. Access to NSP &

OAT continues to be a problem in many countries and regions.

Other (Behavioural Interventions and their Impacts)

Participants raised the need to be clear about the definitions and approaches being used as well as the skills, training and attitudes of those delivering education and/or counselling in relation to HIV, STIs and viral hepatitis among people who inject drugs.

Several participants highlighted that counselling must be based on harm reduction rather than promoting abstinence from drug use per se. Participants from different regions recounted experiences of being denied access to HIV counselling (and other services) due to not being seen as sufficiently motivated towards abstinence from drug use including being on OAT:

“When I was diagnosed with HIV, I was refused counselling because I was on methadone. So, I mean, that’s not just for counselling, but like that’s for a range of healthcare, and especially if you are an opioid user.” Male drug user, European region.

Participants stressed the need for education and training for health service providers and others who have contact with people who use/inject drugs such as law enforcement officials and social services workers to address stigma and discrimination towards people who use/inject drugs.

Modes of HIV/STI/HCV Service Delivery

Peer Navigators

There was a very high regard of peer navigators in the context of HIV, STI and hepatitis prevention treatment and care. Some participants were not familiar with the term “peer navigators” but once explained, were universally supportive of the concept and of the capacity of peer navigators (if properly supported and resourced) to “act as a bridge between two different worlds”:

“I think there has to be a kind of bonding figure, that immediately starts to care with you... being there with the person, organising calendars for exams and going to hospitals and this and that, because it’s hard, even for long term users to navigate the health system and social support systems.” Male drug user, European region

The specific characteristics that make for successful peer navigators, included: “having passion”, “being a good communicator”, “a supportive listener”, “trustworthy” and having “empathy” and “dedication”. While being an “active drug user” was viewed as essential, it was also recognised that being ‘out’ as a person who inject drugs is complex and even dangerous in many settings. Some participants believed that age, gender, cultural background and the drugs being used are also critical to being an effective peer navigator:

“Young people fear accessing these services due to maybe they will bump into their parent’s friend but knowing that their friends are doing an outreach they open and tell you all their issues... this will go a long way in treatment and prevention.” Female drug user, Africa region

“If I am an older person using opiates and come to advise a young consumer who uses

Mephedrone, then I won't be an authority for him. Young people need peer consultants of the same sex and age." Female drug user, European region

"It's like people aren't hard to reach. It's just that you don't have the right people to reach them." Male drug user, the Americas region

When asked about concerns regarding using peer navigators, most comments focused on the impact of being 'out' as a drug using peer and the potential negative implications for individuals including coming to the attention of police:

"The police sometimes come to disturb people who inject drugs and search you while you are offering services to the community thinking that you have drugs on you." Female drug user, Africa region

Participants highlighted that many factors could undermine the effectiveness and impact of peers including structural barriers such as criminalisation and stigma, inadequate funding, resourcing and support and peer workers not being valued and respected. Participants raised the need for structural reforms and stigma and discrimination training to support the effectiveness and impact of peer navigators.

Impacts of Online Services for Uptake

Overall participants were very supportive of online tools and platforms. Having said this, participants believed that people who inject drugs should have access to an appropriate mix of face-to-face/in-person services and online/digital tools and platforms. However, some participants said that because people who inject drugs are highly criminalised and stigmatised, it is important that face-to-face or in-person services and interventions continue to be prioritised due to concerns about online security (see more below), to facilitate

empowerment and to recognise issues related to lack of access to technologies and literacy levels:

"Face to face interventions are so important for PWUDs as they feel seen and heard. We can never do away with face-to-face interventions for this population." Male drug user, Africa region

"It would work well for PWUDs, however, not all of them as many do not own a smartphone and keeps it for long, or it is a second-hand or even stolen phone and can disappear at any time. If they do have these gadgets, they are always online and is a good way for them to access services for treatment." Female drug user, Africa region

"...most of the women that are coming, they are used to connecting with you on FB but not as a tool of information and treatment. We are really far away from this." Female drug user, European region

Participants highlighted that the advent of COVID had led to more online tools and access points for BBV and harm reduction services with both advantages and disadvantages for people who inject drugs. Examples included new online ordering systems combined with postal services for NSP/harm reduction supplies that are attracting younger and female drug users, as well as people who inject drugs from cultural backgrounds traditionally not well-reached by face-to-face services. Others however raised that in some settings, the shift to providing services online due to COVID has exacerbated existing structural inequities among highly marginalised people who inject drugs who are often living in poverty with less access to digital technologies. Participants also raised concerns about online security including digital footprints being used for surveillance and as evidence of illicit drug use to justify police

actions and support legal proceedings against people who inject drugs.

Ultimately, participants felt that online tools and platforms can work well but should be seen simply as another way of providing information and services that brings with it a variety of potential advantages and disadvantages depending on people's specific needs and circumstances.

Values & Preferences Surrounding Community-led, Online and Other Service Modalities

Participants expressed the strong view that drug user-led responses are critical to the health and human rights of people who inject drugs including in relation to HIV, STI and hepatitis prevention, testing and treatment. Further, participants stated that drug user-led responses are vital because they offer a comprehensive approach to drug user health and have a unique understanding of the specific health needs of people who inject drugs:

"It's not just a user's group, it's so much more. It's almost five services in itself, because you've got the blood borne viruses sorted, you've got the mental health sorted, or someone has had experience with the treatment system and will be able to guide and make others aware of what to expect..." Male drug user, European region

"Nowadays, the treatment of hepatitis C gets widely spread not by the state, but by the community. People with experience in using drugs have started their own NGOs dealing with hepatitis treatment and are now providing treatment for everyone in need all around the country." Female drug user, European region

Other participants spoke their preference for drug user-led responses and services because

they are flexible, non-judgmental and low barrier (including drop-in, mobile and outreach-based approaches) and therefore, have the capacity to reach and gain the trust of people who inject drugs from different backgrounds, identities and experiences:

"We have a drop in that is managed by peers. It's a super drop-in centre that mixes populations, you know, non-binary people and women and sex workers and migrants. [It's] already agreed with a hospital that a team with a doctor is going there with fibroscan and with everything to test and begin treatment. They managed to take the medicine out of the hospital to the community. So, it is a super great example." Male drug user, European region

Participants also stressed that drug user-led organisations are critical to protecting the rights of people who inject drugs through drug user-led advocacy to push back on harmful and repressive drug policies and laws and act as a much-needed watchdog for the community.

Values and Preferences Surrounding HCV Testing and Treatment

Treatment with pan-genotypic DAAs

When asked whether people who inject drugs should be offered DAA therapy immediately upon diagnosis, participants overwhelming answered "yes":

"Everyone deserves treatment as much as they need it! Hepatitis C elimination will never happen if we don't get it to the people who need it." Female drug user, the Americas region

Despite this overwhelming preference for immediate treatment, significant ongoing barriers to HCV DAA treatment remain in many

contexts. Although participants in a small number of countries have high levels of access to HCV DAA treatment, participants in many countries in all six WHO regions are still experiencing significant barriers including cost, delays, stigma and discrimination and lack of political will:

"We have treatment for HCV but it can take up to 3 months to get on the medication because they run a lot of tests and treat the other illnesses you might have first before you get the HCV medication. Therefore, many of my friends are discouraged from getting the treatment altogether." Female drug user, Africa region.

"If a patient does not have HIV status, then they need to pay for medications for HCV treatment. They can buy these medications at the pharmacy but this is only if they have the desire and financial ability." Female drug user, European region

Despite a large and growing literature showing high HCV DAA treatment adherence, SVR and completion rates among people who inject drugs and/or on OAT and that re-infection should not be used as a reason to withhold therapy from people who inject drugs, AOD clinicians in some contexts continue to use cessation of injecting drug use (and even cessation of OAT) as a treatment access criterion:

"We had a physician at a big hospital here, where people had to be off methadone in order to qualify for Hep C treatment." Male drug user, the Americas region

"They also want you to stop using for you to get treatment. They also say things like if you get re-infected, they will not treat you again."
Female drug user, Africa region

There was also strong support to open up HCV DAA treatment options and settings including at

NSPs, harm reduction services, health services, OAT clinics, drop-in centres, as well as GP and hospital settings to maximise access and uptake. Participants also highlighted the importance of drug user-led and peer-based service models for HCV testing, treatment and follow-up. Participants from the 'Global North' gave examples of peer-led Point of Care (PoC) Brief Intervention Approaches through NSP, peer-clinics, drop-in or outreach services for peer-supported testing, diagnosis and immediate treatment commencement with medications collected in-person or posted. Financial and other incentives are also being used to encourage testing, diagnosis, treatment and referring a peer. Participants from the 'Global South' however are struggling with many ongoing barriers to basic HCV information let alone HCV DAA access.

HCV testing frequency after negative test

Several participants expressed the view that regular HCV RNA re-testing following cure, should be made available and promoted in a similar way to HIV 'Test and Treat' approaches whereby regular monitoring of HIV status is publicly and positively promoted, widespread HIV testing is facilitated and immediate ART treatment for those diagnosed is encouraged and accessible.

Several other participants, however, raised concerns about coming forward for HCV RNA testing following treatment or viral clearance if they are currently on OAT due to concerns about having to admit to concurrent injecting drug use and/or the risk of being 'punished' such as losing take home doses or even being removed from the OAT program all together. Participants therefore highlighted the critical importance of peer-based and community-led PoC HCV RNA testing and DAA treatment services to reduce these barriers to access in the mainstream health system:

“Access to tests is needed that is not associated with visiting medical institutions, if a peer-to-peer counsellor and the drug user himself can do this on their own - it is much more convenient and effective.” Female drug user, European region

Participants also referred to being “treated like children”, seen as “irresponsible” and judged as “not caring about their health” if they acquire a new infection following treatment and how this can significantly deter people from coming forward due to fears about punitive requirements and responses. Participants were also clear that all HCV testing services must be fully voluntary and based on consent:

“You can’t impose testing and say to people you must be tested and force people to do things. It must be with information and consent.”

Female, European region

In relation to the issue of frequency HCV RNA testing following a negative result, participants offered a range of potential timeframes with most people suggesting every 3 months for the first year after successfully completing treatment/clearing the virus and then, either every 6 or 12 months after the first year depending on whether people are engaged in practices that can be associated with HCV transmission.

Other Values & Preferences for HCV Service Provision:

Major barriers to HCV prevention among people who inject drugs remain in many contexts primarily due to inadequate funding for and access to NSP, OAT, safe consumption rooms and lack of movement on addressing structural barriers including securing safe drug supply and drug law reform. Along with strong messages about the need to address these ongoing barriers to HCV prevention, a number of participants stressed the importance of always

needing to embed HCV treatment in a broader HCV prevention harm reduction approach which has also been found to be critical in preventing new infections post-treatment:

“Hepatitis C treatment and harm reduction services go hand-in-hand. People talk about access to [HCV] treatment and leave the prevention side out, or they expect that once someone gets [HCV] treatment they will remain abstinent and that’s not always the case. So, prevention always needs to be linked to treatment because health services and treatment don’t exist in a vacuum.” Female drug user, European region.

Although not a specific focus in this study, participants from several regions also emphasised the importance of offering HCV DAA treatment (and HCV prevention and harm reduction) for people in prisons given the overwhelming lack of access to sterile injecting equipment and harm reduction measures in most prisons coupled with the large number of people in prison for drug-related offences.

Other Values & Preferences Surrounding STI Services:

Although values and preferences in relation to STI services were not a major focus in the research with people who inject drugs, where access to STI services were specifically raised, participants generally expressed similar views to access to HIV and HCV services. That is, that people who inject drugs prefer “peer-based and community-led STI services” that are “non-judgemental”, “low barrier” and provided as part of a “comprehensive service model” that understands the priorities and needs of people who inject drugs. Female participants also identified the need for confidential, trusted and sensitive STI services with staff who are “trained in relation to trauma-informed care and eliminating stigma towards people who inject drugs”.

Values and Preferences Surrounding HIV Prevention (including PrEP)

Preferences surrounding different HIV prevention methods/technologies

Participants overwhelmingly supported the free availability of core, evidence-based HIV prevention approaches and technologies among people who inject drugs in the form of NSP, OAT, male and female condoms and lubricants and other harm reduction supplies that support the engagement of people who inject drugs with services:

"Harm reduction must be the first HIV prevention technology made available." Male drug user, Africa region

"I don't really see anything really, as more useful and cost effective as needle and syringe programs, naloxone and overdose prevention responses. They are easy to access and easy to explain... they should be developed." Male drug user, the Americas region

In addition to this broad consensus, a small number of participants also raised the importance of HIV prevention services remaining up-to-date and relevant. Specifically, participants from different regions spoke about problems associated with HIV prevention service providers not offering the services people need, not listening to service users or not regularly reviewing the services they provide:

"How many times do we say this: we receive 10 ml syringes, but a person who uses salts needs insulin syringes, but still providers cannot hear us. No prophylaxis is possible as long as the patient uses one syringe for 30-40 injections."
Female drug user, European region

"I know women who simply will not use the NSP because they are worried about their children being removed. So, they re-use needles and syringes all the time. They need to provide services that are confidential and accessible like more vending machines for example."
Female drug user, Western Pacific region

A number of other participants also highlighted problems with police creating barriers to people who inject drugs accessing HIV prevention services due to “police harassment near to NSPs”, “people being stopped and searched after leaving the NSP” and “being strip searched in public and having new injecting equipment confiscated”. Participants stressed that these practices by police in many different contexts, are undermining the effectiveness of HIV prevention approaches and creating barriers to services even where they exist.

Preferences surrounding PrEP and its different dosing regimens/modalities

Some participants did not feel sufficiently informed on PrEP to offer a view in relation to values and preferences. Indeed, even among the majority of participants who did feel able to comment, there was still evidence of gaps in participants’ knowledge, particularly in relation to new developments in PrEP modalities:

"The PrEP has advantage to cure people who had risk behaviour. But community members need more trainings and explications for a better use." Male drug user, Africa region

A number of participants raised questions and concerns about ongoing gaps in the evidence-base in relation to both the efficacy and suitability of PrEP for people who inject drugs. These questions highlight the need for greater discussion, education and training within drug user-led networks about the available evidence in relation to PrEP and people who inject drugs, to identify what is known, where further

research is needed and what constitutes best practice in relation to PrEP and people who inject drugs:

"Some of these modalities are quite new to me but even so, I don't think they've done studies anyway with people who inject drugs. I think it's fair to say across, probably really all of the modalities, that the research is limited in relation to people who inject drugs, right?"
Female drug user, European region.

Participants raised the fact that although oral PrEP is already available in some contexts, other forms of PrEP such as injectable, long-acting modalities are either not available or people are unaware of how to access it despite preferences for such modalities due to greater perceived efficacy, tolerability and convenience when compared to daily oral PrEP. Female participants in some regions also raised issues related to new PrEP modalities including vaginal rings, but once again highlighted that despite interest in these options, they are either not available or women are unsure about their availability.

Although most participants viewed PrEP as a potentially helpful HIV prevention intervention, they stressed that the availability of PrEP should not distract from the urgent need to address inadequate access to existing, cost-effective and evidence-based HIV prevention interventions among people who inject drugs globally such as NSP and OAT:

"PrEP should be part of the picture but it's not a 'silver bullet' and I worry that we could end up with all the funding going into one bio-medical response at the expense of everything else that we know works and is very cost-effective but seen as politically difficult – like NSP." Gender non-binary drug user, Western Pacific region.

"Safe, sterile syringes first, then PrEP, if they want it!" Female drug user, the Americas region

Health Priorities

With reference to a diagram that included a framework for prioritising health interventions, all participants were asked to identify key health priorities for people who inject drugs:

1. Harm Reduction: participants noted that harm reduction was like an umbrella priority that would take in a wide range of issues, interventions and approaches including preventing hepatitis C, preventing HIV, overdose prevention and OAT. One participant noted that *"all these things are linked to harm reduction and I think whatever can be provided through harm reduction services should be because that's usually a first contact point to health services for people who inject drugs"*. It was also noted that globally harm reduction services are not scaled up and not widely available and are becoming even less available as funding is retracting for harm reduction which is a major concern given that harm reduction is a key health intervention for people who inject drugs.

2. Drug Law Reform: this was identified as a core priority by a majority of participants due to its critical role in addressing the *"significant and pervasive harms associated with criminalisation and associated stigma and discrimination"*. It was felt that without comprehensive drug law reform people who inject drugs will continue *"to experience barriers to HIV and hepatitis C prevention, testing and treatment"* and will also continue to experience *"police violence, high level of incarceration and all the associated harms and trauma that comes with being criminalised"*.

3. Community Empowerment: was identified as a priority by several participants due to being viewed as a critical facilitator of harm reduction and peer-based and drug user-led

services and also because of its role in “stimulating and encouraging health seeking behaviours”.

4. Violence Prevention: was identified by participants due to the role of violence at a social and structural level and how it acts as an impediment and major barrier to people being able to access services or even prioritise their health. Participants also noted that “*experiencing violence is very common amongst the drug user community whether it's intimate partner violence, or community mob violence in Sub Saharan Africa or whether it's law enforcement violence*”. Participants felt that violence prevention approaches need to view health as much more than “*simply a set of interventions*” and instead to focus more on “*what might bring people in and what might make people feel more empowered to think about and address their health*”.

5. Sexual Reproductive Health: was identified by participants as a priority for women who inject drugs due to “*a real lack of access or lack of uptake of sexual reproductive health, and part of that is linked to avoiding health services because of criminalisation, stigma and discrimination*”.

Finally, some participants noted that what was missing from the health priorities diagram were drop-in centres, run by peers. Participants again emphasised that peers are central, and community empowerment needs investment. They felt that generally, “*experts cannot understand that it starts with community and are resistant to allocating more value and resources towards peer-led responses and peer workers*”. Mental health issues particularly associated with COVID were also identified due to isolation, uncertainty and increased vulnerability as a criminalised population.

Structural Barriers and Enabling Interventions

Impacts of stigma, discrimination and criminalisation on access to services

The overwhelming response from most participants was that the ongoing criminalisation of drug use in most countries and regions across the world, is the factor that has the greatest impact on the health, rights and dignity of people who inject drugs and this includes (but is not limited to) the devastating impact on people’s capacity to prevent and treat blood-borne viruses such as HIV and hepatitis C, as well as STIs and TB:

“If you want to see somebody's life go from decent to chaos, get the police involved. I mean, criminalisation is the worst thing you can do to a person and one good way of just destroying someone's life.” Female drug user, the Americas region

“Criminalization is the main barrier in access to services and treatment for HIV, STIs and hepatitis, since it immediately portrays the drug user as a criminal, to whom the society, including health workers, have an appropriate attitude.” Female drug user, European region

“Change the law and PWUDs will access easily to harm reduction services” Male drug user, Africa region

For the majority of participants, issues related to stigma and discrimination for people who inject drugs are so inextricably linked to criminalisation that one participant described it in this way: “*The point of criminalisation is to stigmatise.*” Male drug user, North America region. In this context, it is hardly surprising participants routinely described stigma and discrimination as being at the heart of the barriers and problems experienced by people

who inject drugs in relation to accessing services and being able to stay in treatment:

“Stigma and discrimination are like the lynchpin. I mean, that’s what’s killing us. It’s the stigma and discrimination that keeps services from being offered in a way that useful, keeps us from actually being able to access treatment. I mean, stigma and discrimination is at the core of every negative problem. We’ve got to erase stigma and discrimination.” Female drug user, the Americas region

“There are the barriers to service access, if you take away the stigma, then I will not be ashamed to present myself.” Female drug user, Africa region

“It makes people default and makes them not associated with people who inject drugs causing them to use alone and in secret, putting them at risk of overdosing and using the same needle repeatedly because you do not want to be seen in the queue of people taking NSPs.” Male drug user, Africa Region

Participants viewed the need to address stigma, discrimination and criminalisation through comprehensive drug law reform and full decriminalisation as being urgently required and as the only way to truly realise the health and human rights of people who use drugs:

“With drug law reform, there has been some progress, but not a lot. You know we’re just replacing one faulty system with a lesser evil, but it still comes with similar harms and punishments. So, we need complete decriminalisation of drugs as the only pathway to make sure that people who use and inject drugs have their right to health realised. As long as drug use is criminalised there’s not going to be enough funding or attention towards either the introduction or the scale up of services such as HIV, hepatitis C and harm reduction services.” Female drug user, European region

Enabling interventions

Once again, in relation enabling interventions most participants stressed the need for decriminalisation to address the many barriers and inequities already outlined above. Although some participants noted the so-called ‘decriminalisation’ measures that have been much celebrated in various countries undertaking such reforms, participants felt that the majority of these efforts have not gone far enough and continue to rely on stigmatising, controlling, punitive and judgmental approaches that do little to address the fundamental concerns at the heart of criminalisation:

“Depenalisation does not mean that people are not criminalised. They are talking about decriminalisation and it’s not a real thing. We have been de-penalising drugs for the past 30 years, but 80 percent of the people in jail is because of crimes related with drug use.”
Female drug user, European region

In the context of decriminalisation and enabling interventions, several participants stressed the critical need to secure a safe drug supply as the first step in creating an enabling environment for people who inject drugs and their access to health services for HIV, STIs and hepatitis. For these participants, securing a safe drug supply and stopping the current levels of overdose deaths through the addition of overdose prevention sites, safe consumption rooms and on-demand OAT treatment must be prioritised if we are serious about improving the health of people who inject drugs including in relation to BBVs:

“I think that if we have safe supply of drugs that should be number one – everything else follows from there...” Male drug user, the Americas region

Other participants stressed the need for enabling interventions including community

empowerment that allow people who inject drugs to build self-esteem and confidence in the general health system and as members of the community. In particular, they stressed the need for sensitisation training with the police and the wider criminal justice system, religious leaders and in a broader cultural and community context by educating people about issues related to drug use, criminalisation, stigma and discrimination. They also emphasised the importance of adequate gender-based violence (GBV) structures and training:

"If you have a structure where I can report the violence and if the community is inspired, then we have a group of people motivating one another to say I am on ARVs I feel better and the other person will go too." Female drug user, Africa region

Conclusion

The findings of this research emphasise the critical importance of listening to the values and preferences of people who inject drugs to guide services and interventions and ensure there is a primary focus on delivering genuine person-centred care. From INPUD's perspective this is inextricably linked to peer-based and drug user-led approaches as they are fundamental to ensuring that the design, development and delivery of interventions align with community and individual needs. Participant responses in this study reflected what INPUD consistently hears: that peer navigators are too often being asked to be part of programmes that are hostile to their very presence, and where people who inject drugs are not welcome. This fundamentally needs to change.

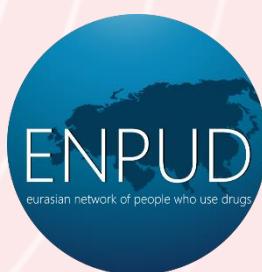
Furthermore, participants in this study highlighted the profoundly negative impacts of structural barriers such as criminalisation, stigma, discrimination and violence on the

health, rights and dignity of people who inject drugs. These experiences are not rare or infrequent, but rather a pervasive, routine, and relentless aspect of their everyday realities constantly reinforced through harmful, punitive and repressive laws and policies. For too long we have allowed these injustices to continue despite longstanding evidence of how they diminish the capacity of people who inject drugs to access vital services. Recent developments at the international level, such as the "10-10-10 Social Enabler Targets" included in the UN *"Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030"* and the *Global AIDS Strategy 2021-2026*, specifically call on member states to end all inequalities faced by people living with HIV, key and other priority populations by 2025. This builds on other commitments such as the "80-60-30 Targets" which commit to increasing the proportion of HIV services that are led and delivered by communities.

There is much talk about enabling interventions such as peer-led responses, community mobilisation, decriminalisation and reducing and/or eliminating stigma and discrimination. INPUD fully welcomes these discussions and commitments, but the there is still a question of how such change will be realised when comprehensive access to evidenced-based HIV and HCV interventions is still yet to be seen in many contexts. Realising the right to health for people who inject drugs will require not only the removal of harmful and punitive laws, policies and practices, but also the appropriate funding and scale-up of community-led interventions and services that properly recognise the value of peer-led interventions among people who inject drugs. Until we properly value the expertise of peer navigators and the values and preferences of people who inject drugs, criminalisation, stigma and discrimination will continue to fundamentally erode the health, rights and dignity of people who inject drugs globally.

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 their impact on the drug-using community's health and rights. INPUD will achieve this through processes of empowerment and advocacy at the international level, while supporting empowerment and advocacy at community, national and regional levels.

INPUD is very grateful for financial support from the World Health Organization and for contributions by the regional and national drug user networks who helped facilitate this research: the African Network of People who Use Drugs, Canadian Network of People who Use Drugs, Eurasian Network of People who Use Drugs, South African Network of People who Use Drugs and the Urban Survivors Union



Publisher: International Network of People who Use Drugs (INPUD)

Principal Investigators: Annie Madden and Judy Chang

Written by: Annie Madden

With Contributions from: Judy Chang and Jake Agliata

Regional Focal Points: Olga Belyaeva, Matthew Bonn, Angela McBride, Charity Monareng, Richard Nininahazwe, Kassim Kyuni, Louise Vincent

Designed by: Mike Stonelake

This work is licensed under a Creative Commons Attribution-Non Commercial-No Derivs 3.0 Unported License

INPUD Summary Report: WHO Key Populations' Values & Preferences for HIV, Hepatitis and STIs Services

First published in 2021 by

INPUD Secretariat Unit

2B15, South Bank Technopark

90 London Road, London SE1 6LN

For the latest news, publications and to access related information, go to:

www.inpud.net



International
Network of People
who Use Drugs