Key Populations’ Values and Preferences for HIV, Hepatitis and STI services: A Qualitative Study

INPUD
International Network of People who Use Drugs
## CONTENTS

<table>
<thead>
<tr>
<th>SECTION</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0 BACKGOUND &amp; RATIONALE</td>
<td>04</td>
</tr>
<tr>
<td>1.1 Who is INPUD?</td>
<td>04</td>
</tr>
<tr>
<td>1.2 Study Purpose &amp; Aims</td>
<td>04</td>
</tr>
<tr>
<td>2.0 RESEARCH QUESTIONS</td>
<td>07</td>
</tr>
<tr>
<td>3.0 RESEARCH METHODOLOGY &amp; RESEARCH METHODOLOGY</td>
<td>08</td>
</tr>
<tr>
<td>3.1 SSI Participant Characteristics</td>
<td>09</td>
</tr>
<tr>
<td>3.2 FGD Participant Characteristics</td>
<td>11</td>
</tr>
<tr>
<td>3.3 Study Limitations</td>
<td>12</td>
</tr>
<tr>
<td>3.4 Results &amp; Discussion</td>
<td>13</td>
</tr>
<tr>
<td>4.0 CONCLUSION</td>
<td>54</td>
</tr>
<tr>
<td>5.0 APPENDIX 1: PICO QUESTIONS</td>
<td>56</td>
</tr>
<tr>
<td>6.0 APPENDIX 2: SEMI-STRUCTURED INTERVIEW &amp; FOCUS GROUP GUIDES</td>
<td>57</td>
</tr>
<tr>
<td>6.1 Semi-Structured Interview Guide for People who Inject Drugs</td>
<td>57</td>
</tr>
<tr>
<td>6.2 Focus Group Guide for People who Inject Drugs</td>
<td>64</td>
</tr>
</tbody>
</table>
1.0 BACKGROUND & RATIONALE

1.1 WHO IS INPUD?
The International Network of People Who Use Drugs (INPUD) is a global, peer-based network that seeks to promote the health and protect the rights and dignity of people who use/have used drugs including people who inject drugs. (For more information about INPUD see: www.inpud.net)

1.2 STUDY PURPOSE & AIMS
Recent global research shows that people who inject drugs continue to be at increased vulnerability to HIV, viral hepatitis C (HCV), viral hepatitis B (HBV), tuberculosis (TB) as well as drug-related overdose. In 2020 the United Nations Office of Drugs & Crime (UNODC) reported that of the estimated 11 million people who inject drugs globally, approximately 8% (or 1.4 million) are living with HIV. A recent global systematic review found that an estimated 6.1 million people with recent injecting drug use (within previous 12 months) aged 15-64 years are living with HCV globally with the greatest numbers in East and Southeast Asia (1.5 million), Eastern Europe (1.5 million) and North America (1 million). Further the World Health Organisation (WHO) states that approximately 10% of new HIV infections globally (UNAIDS, 2020) and almost 40% of new HCV infections are estimated to be among people who inject drugs. They also identify that 1 in 3 HCV deaths globally are among people whose HCV infection is attributed to unsafe injecting practices. In some regions such as Eastern Europe and Central Asia prevalence rates of both HIV and HCV are particularly high.

In order to reduce HIV, HCV and HBV transmission as well as overdose deaths, it has been recommended by WHO, UNODC and UNAIDS (2009) that people who inject drugs require access to a comprehensive package of harm reduction interventions including:

1. Needle and syringe programmes (NSP)
2. Opioid agonist therapy (OAT) and other evidence-based drug dependence treatment
3. Naloxone for overdose prevention
4. HIV testing and counselling
5. Antiretroviral therapy

4. Ibid.
6. Prevention and treatment of sexually transmitted infections
7. Condom programmes for people who inject drugs and their sexual partners
8. Targeted information, education and communication for people who inject drugs and their sexual partners
9. Prevention, vaccination, diagnosis and treatment for viral hepatitis
10. Prevention, diagnosis and treatment of tuberculosis\(^5\)

Although these interventions are supported by the WHO and other UN agencies and are considered essential to achieving global targets for ending HIV and achieving hepatitis C elimination goals, access to these interventions, particularly those that are priority interventions for people who inject drugs, such as needle and syringe programmes (NSP) and opiate agonist treatment (OAT) are far from being adequate in many countries and regions. Indeed, less than 1% all people who inject drugs live in settings with high coverage of both NSP and OAT\(^6\). In particular, structural barriers such as criminalisation of drug use and the associated stigma and discrimination against people who inject drugs contributes to the ongoing transmission of HIV, viral hepatitis and TB among people who inject drugs and, acts as a significant barrier to accessing harm reduction and other health services. The WHO states that:

“In many settings, harm reduction programmes are simply not available or are extremely limited in accessibility and availability due to restrictive and ineffective policies and laws. Global coverage of harm reduction interventions is extremely low: less than 1% of people who inject drugs live in settings with sufficient, combined and high coverage of these services.”

It is against this backdrop, that INPUD has agreed to collaborate with the WHO Department for Global HIV, Hepatitis and STI Programmes (HHS) in a global qualitative study to inform the updating of the WHO 2016 Consolidated Guidelines for HIV prevention, diagnosis, treatment, and care for key populations. The four key populations participating in the study are: gay and bisexual men and other men who have sex with men, female, male and trans sex workers (sex workers), people who inject drugs and trans people. Prisoners, as the fifth key population were identified as being cross-cutting across our networks, given the level of criminalisation faced by our communities. These populations are defined as key because as according to 2020 UNAIDS estimates\(^7\), the majority of new HIV cases (62%) occur amongst key populations and their sexual partners. Although the 2016 Consolidated Guidelines have a specific focus on HIV, the updated guidelines will (for the first time) also address viral hepatitis and STIs.

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Across April/May 2021, each of the four key population global networks have conducted separate peer-driven qualitative research studies into the values and preferences of their communities in relation to HIV, viral hepatitis and STI interventions and programmes. This report represents an overall summary and the key findings from the INPUD qualitative values and preferences study with people who inject drugs. The key findings from this report will form part of a combined report with the other key population networks to be submitted to WHO to inform the updating of the 2016 Consolidated Guidelines. Once updated, the guidelines will provide guidance for countries about designing and implementing health packages for key populations. It is crucial that any potential new recommendations in the updated guidelines understand and take into account the specific values and preferences of each of the key populations because ultimately, they are the intended end beneficiaries of the updated Consolidated Guidelines.
2.0 RESEARCH QUESTIONS

The research questions for the qualitative study were based on the 7 PICO questions that form the basis of the systematic evidence-based review component of the guidelines updating process (see Appendix 1: PICO Questions). Specifically, this qualitative arm explores the interventions and services investigated in the PICO questions in relation to key population members’ values and preferences for how services/interventions are provided, where they are provided and by whom as well as perceived harms, disadvantages and advantages of different services and approaches. Additionally, key population members’ values and preferences have also been assessed in relation to structural and other barriers and interventions, in order to provide an understanding of the context of implementation for HIV/HCV/STI interventions. Community responses to the research questions highlight how structural and contextual factors influence participants’ interest, engagement, and perceptions of efficacy.

The specific interventions, service models, structural barriers and other issues covered by the qualitative research questions with people who inject drugs were:

- Preferences in relation to Chemsex and for behavioural interventions to reduce vulnerability to HIV, viral hepatitis and STIs among people who inject drugs
- Values and preferences in relation to peer and drug user-led responses (i.e., services and programmes run and managed by peers);
- Preferences for face-to-face interventions compared with digital/online interventions;
- Effect of criminalisation of drug use on uptake of HIV, HCV & STI prevention, testing, linkage to treatment and treatment retention;
- Enabling interventions to address structural barriers, including criminalisation, in relation to increasing access to health services;
- Effect of stigma and discrimination on uptake of HIV, HCV and STI prevention, testing, linkage to treatment and treatment retention;
- Preferences around HCV testing, diagnosis and HCV DAA treatment;
- Community preferences around HIV prevention technologies and commodities including PrEP in relation to people who inject drugs.
3.0 RESEARCH METHODOLOGY & STUDY DESIGN

The data for this report was collected both through individual semi-structured interviews (SSIs) and focus group discussions (FGDs). 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. The RFPs were identified, selected and briefed to ensure the research would include broad representation from people who inject drugs across different WHO regions, age and gender demographics and key population inter-sectionalities. All Principal Investigators (PIs), RFPs and sub-regional community consultants have significant experience working with people who inject drugs, are experienced with organising and conducting SSIs and FGDs and have expertise in community consultations. The PIs conducted an online briefing and training session with all RFPs prior to the commencement of data collection.

INPUD was fully involved in the development of the research protocol, interview guides and associated research materials in consultation with WHO and the other global key population networks (GATE, MPact and NSWP). Separate guides were developed for the individual SSIs and the FGDs (see Appendix 2: Interview & Focus Group Guides). Both interview guides were piloted. All feedback was considered and as appropriate, incorporated to improve the validity, accessibility, and suitability of the guides and other research materials. Ethics approval was provided by the WHO Research Ethics Review Committee.

A purposive sampling approach was used by the Principal Investigators and RFPs to identify potential participants for the individual SSIs and FGDs. Eligibility criteria were designed to ensure diverse geography, gender, and age demographics. All research participants were required to be able and willing to provide verbal informed consent for participation in the research, able to communicate in English, Spanish, French or Russian, willing to self-identify as person who injects drugs, be at least 18 years of age; and be a member or associate of a local, national, regional, or global organisation or network of people who use drugs. In total, fifty-four (n=54) individuals participated in either a semi-structured interview or a focus group discussion from four (4) WHO regions and twenty-seven (27) countries. Gender breakdown for the 54 participants were: 17 (31%) cis-female, 30 (56%) cis-male, 6 (11%) non-binary and 1 (2%) other gender non-conforming identity. Further details and breakdowns of participant numbers and characteristics by research method is outlined below.

**Semi-structured Interviews (SSI)**

Individual semi-structured interviews (SSI) were conducted with people who are opinion leaders in their communities of people who use/inject drugs and are directly
affiliated with drug user-led organisations and networks. A total ten (n=10) SSIs were conducted with selected community leaders from five (5) WHO regions and nine (9) countries. Participants included five (5) males and four (4) females and one (1) gender non-binary participant. The age-range for the SSI participants was 26 - 65 years with 20% (n=2) between the ages of 26-35, 40% (n=4) between 36-45 years and 30% (n=3) between 46-55 years of age and 10% (n=1) between 56-65 years of age (no SSI participants were between 18-25 years old or over 65 years old). Interviews were conducted virtually through online communication platforms (Zoom, WhatsApp, Teams). All interviews followed the SSI interview guide (see Appendix 2: Interview & Focus Group Guides) and included an approved informed consent process designed to maintain confidentiality for all participants. Interviews ranged from 60 – 120 minutes duration and were conducted in English, French or Russian as appropriate for the participant. Detailed participant characteristics for the SSI participants including WHO region, country of residence, gender and age breakdowns are included in the table below.

### 3.1 SSI PARTICIPANT CHARACTERISTICS

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>WHO Region</th>
<th>Country of Residence</th>
<th>Gender*</th>
<th>Age Range</th>
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<td>2</td>
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<td>3</td>
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<td>10</td>
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<td>46-55</td>
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</tbody>
</table>

*Female* and *Male* identified participants are all cis-gendered

All SSIs were conducted by one of the PIs, one of the RFPs or another experienced community researcher selected and engaged by the RFPs. Notes were taken during the interviews and the interviews were electronically recorded (with consent) and transcribed verbatim. Immediately following each interview, the note-taker(s) and community researchers developed a written Summary Report using a template provided by INPUD. The audio recording/transcript was then checked to identify any discrepancies and select relevant quotes for inclusion in the Summary Report. The responses were then coded using an inductive, thematic analysis approach based on an analytical framework developed by INPUD and the other key population networks focusing on perceptions, values, and preferences in relation to the seven PICO questions. The summary reports, transcripts, thematically code responses, and participant logs were
then securely uploaded and stored and checked by one of the principal investigators (AM) for consistency.

**Focus Group Discussions (FGD)**

Focus group discussions (FGD) were conducted with grassroots community members nominated by INPUD affiliated drug-led organisations and networks in line with participant criteria. All FGDs were held after the SSIs, to allow for deeper discussion on key issues and gaps identified by opinion leaders in the SSIs. A total of eight (n=8) FGDs were conducted across five (5) WHO regions and twenty-four (24) countries. Each FGD included between 4 – 8 participants with a total of forty-four (44) participants across all FGDs. The gender breakdown for FGD participants included 57% (n=25) males, 30% (n=13) females, 11% (n=5) gender non-binary participants and 2% (n=1) other gender non-conforming participant. Age range for the FGD participants was between 18 - over 65 years with 5% (n=2) between the ages of 18-25 years, 20% (n=9) 26-35 years of age, 36% (n=16) between 36-45 years, 32% (n=14) between 46-55 years of age, 5% (n=2) between 56-65 years and 2% (n=1) over 65 years old. The duration of the FGDs were between 60 to 150 minutes each and were conducted in English, French or Russian depending on the needs of the population group. The FGDs were conducted via online communication platform (Zoom, WhatsApp, Teams). All groups followed the FGD interview guide (see Appendix 2: Interview & Focus Group Guides) and included an approved informed consent process designed to maintain confidentiality for all participants. Detailed participant characteristics for the FGDs including WHO region, country of residence, gender and age breakdowns are included in the table opposite.
### 3.2 FGD PARTICIPANT CHARACTERISTICS

<table>
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<th>FGD No.</th>
<th>Number of Participants</th>
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</tbody>
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* "Female" and "Male" identified participants are all cis-gendered
** No further information provided
^ This was a designated women’s focus group
All focus group discussions were led and facilitated by either one of the PIs, by one or more of the RFPs or by another experienced community facilitator(s) engaged by the RFPs. Responses were documented by note-taker(s) and the community facilitator(s) and the FGDs were electronically recorded (with consent) and transcribed verbatim. Immediately following each FGD the note-taker(s) and community facilitators developed a written Summary Report using a template provided by INPUD. The audio recording/transcript was then checked to identify any discrepancies and select relevant quotes for inclusion in the Summary Report. The responses were then coded using an inductive, thematic analysis approach based on an analytical framework developed by INPUD and the other key population networks focusing on perceptions, values, and preferences in relation to the seven PICO questions. The summary reports, transcripts and thematically coded responses were then checked by a principal investigator (AM) for consistency and in relation to themes identified in the SSIs.

During data analysis, areas of consensus and divergence within and between participants and any significant regional variations were identified and have been highlighted in the analysis contained in this report.

3.3 STUDY LIMITATIONS

This study has several key limitations including ongoing problems for participants and community-based networks in accessing technology and/or reliable internet connectivity and having to work across multiple time zones with very limited resources. Additionally, the timelines have been very tight across the entire study with subsequent implications for the number of interviews and focus groups that could be organised and conducted within the available timeframe.

Another notable limitation on this study has been, that the key focus on values and preferences in relation to HIV and viral hepatitis services and interventions meant a subsequent focus on people who inject drugs and therefore, some geographic regions were excluded due to injecting drug use being less relevant such as Latin America and the Caribbean. Further, although conducting the SSIs and FGDs in English, French or Russian ensured a greater level of participation in the study than if it was conducted in English alone, not including Chinese as a study language or language translation in the multiple other languages used in the region (Thai, Khmer, Vietnamese, Hindi) not only excluded countries in the Western Pacific region such as China but also countries in the South-East Asian region.

It is also important to note that, due to the heterogeneity of populations of people who inject drugs and the inherent subjectivity of values and preferences, the results of this study are neither representative nor generalisable. Notwithstanding the above limitations, this study offers a range of important insights into the values, preferences...
and perceptions of people who inject drugs who participated in the study and in doing so, provides useful data to inform the updating of the Consolidated Guidelines. The insights from this research may also supplement existing research evidence and/or provide a framework to guide future research with people who inject drugs as a highly marginalised and criminalised population.

3.4 RESULTS & DISCUSSION

1. Perceptions of Behavioural Interventions

All participants were asked two questions about their values and preferences in relation to behavioural interventions. ‘Behavioural interventions’ can carry a wide range of meanings in different contexts including being used to describe interventions aimed at reducing and/or ceasing drug use. In this study, participants were specifically asked to think about interventions (including counselling and education measures) aimed at reducing the risk of HIV, STI and viral hepatitis infections rather than on reducing drug use. The first question related specifically to ‘Chemsex’, and the second question was focused on HIV, STI and viral hepatitis ‘behavioural interventions’ more broadly.

a. Values & Preferences in relation to Chemsex

To commence discussion, participants were initially asked a question about the extent to which Chemsex is relevant for them and their community. In response to this question, some participants indicated that Chemsex was not/not really relevant for them or their community, with comments such as: “I don’t have any experience of Chemsex”, “It’s not really relevant for me” and “For us it has relevance but it’s not the most important thing”. In line with this last comment, another participant offered the view that for some regions including Sub-Saharan Africa and Asia, although Chemsex might be widely practised, it hasn’t really been put forward as a priority by the drug using community to date, largely due to a greater focused on addressing more pressing human rights violations.

For other participants in this study however, including several participants who identified as gay or bisexual men, ‘Chemsex’ was viewed as highly relevant both to them as individuals and for their communities and furthermore, they were interested in engaging in a nuanced and sophisticated dialogue on a wide range of topics in relation to Chemsex (see further detail below). This is not to say however, that Chemsex was only seen as relevant by participants identifying as gay and bisexual men and indeed, there was discussion among participants about how the term ‘Chemsex’ is too often discussed as if it only relates to gay and bisexual communities but in fact, using drugs to enhance sexual experiences has been happening for a long time and takes in a broad range of practices not only among LGBTQIA+ communities but also among heterosexual populations as well - even if the term ‘Chemsex’ is not specifically used:
“The first point that was clear to me that people think the term ChemSex is only related to certain populations such as LGBTQIA+ individuals. It should be defined in a much larger context and definitions. I have used drugs to enhance sex practically my whole life, but it because it’s predominately hetero-sexual couples [having sex with people other than their partner] that we stay away from using the term in the general population.” Female drug user, the Americas region.

“Religion and African culture do not teach their children about sex and the usages of drugs. Some people use Tramadol as Viagra to increase their libido. The use of Tramadol is very common among young people.” Male drug user, Africa region.

Other participants also spoke about young people (from multiple identities, backgrounds and regions) and the use of psychoactive substances to enhance sexual experiences at music festivals and events. They highlighted that these events are often held over multiple days in isolated rural environments with highly variable access to education and counselling in relation to HIV, STI and hepatitis prevention and harm reduction supplies. Participants also spoke about ‘Chemsex’ practices among closed groups of young people who go to clubs and venues and predominantly use psychostimulants, and therefore differ from the often older, opioid using experienced peer educators in HIV, STI, hepatitis prevention and harm reduction education:

“These are closed groups (formed from well-known and trusted participants), in which the risks of HIV, STI and Hep transmission while practicing unprotected sex are added to the risks of injecting drug use. There is an obvious lack of trained and competent “peer” opinion leaders from this group who are the basis for behavioural interventions.” Male drug user, European region.

Even though practices associated with ‘Chemsex’ or using drugs to enhance sexual experiences are well recognised among gay and bisexual men in some context and regions, participants highlighted that this does not necessarily mean that ‘Chemsex’ is always recognised or even openly acknowledged within gay and bisexual communities which in turn, can create barriers to effective harm reduction responses. In this regard, participants highlighted the importance of setting and context, and that what is recognised and addressed in private settings such as private homes can be very different to what is acknowledged in more public settings such as clubs and SoP venues where drugs may be used to enhance sexual experiences but there is no open acknowledgement of such practices due to laws, regulations and other barriers. For example, peer outreach workers participating in this study spoke about venues where
Chemsex occurs but is not acknowledged and anti-drugs attitudes and laws result in peer outreach workers having to hide what they are doing which fundamentally undermines the work they are trying to do:

“...they’re like you can give out condoms but if the owners see you handing out snorting straws or G kits or the injection kits, they’re like, you will get kicked out. So, you have to keep them in your backpack. And like, no one can see that you have it... It is really frustrating.” Male drug user, the Americas region.

Participants also drew attention to the silences and lack of acknowledgement that occurs in the space where Chemsex interacts with hook-up apps and hook-up/real-time sex spaces that say they are drug-free and have zero-tolerance policies and therefore, ban any talk of Chemsex and harm reduction on these apps. This can have negative impacts on access to HIV, STI and hepatitis prevention as well as on attempts to provide access to harm reduction information and supplies through peer outreach in these settings.

Other gay and bisexual male participants also drew attention to the complexity surrounding concepts of ‘Chemsex’ including that using drugs to enhance sexual experiences is engaged in by gay and bisexual men from many age groups, backgrounds and knowledge levels. These participants added that there can be many different reasons why people engage in ‘Chemsex’ that affect the types of behavioural interventions, education and support that might be required. As one example, a participant from the European region explained that some older gay and bisexual men might engage in ‘Chemsex’ to enhance sexual performance and pleasure in the context of the physical aspects of ageing. This can mean that men who perhaps have never injected before, find themselves doing so in the context of ‘Chemsex’ without adequate education or access to harm reduction supplies and it can be very difficult to reach them due to multiple barriers including drug-related stigma, shame and repressive drug policies.

Several participants also raised the importance of listening to community and the language and terminology communities prefer to use and find most empowering in relation to conversations about ‘Chemsex’ and HIV, STI and hepatitis prevention. For example, participants raised concerns about perceptions of ‘risk’ and ‘harm’ and how such concepts are not somehow universal but rather, are relative and that one person’s potentially risky or harmful practice can be another person’s source of pleasure, meaning and connection. Therefore participants, raised the importance of not always or only focusing on ‘risks’:

“...because there’s this idea that like, gay sex is inherently risky. So, when you use like the word risk, like five or 10 times in the middle of a sentence, trying
to talk about gay sex and substance use, like all you’re doing is reinforcing fear when you can have the same messaging, but from like a more positive spin like, we can talk about how we can protect ourselves, prevent things, as opposed to these are the risks and these are why it’s risky.” Gender non-binary drug user, Americas region.

“We never talk about pleasures and how to, maybe, mediate or balance, pleasure and risk. When it comes Chemsex, it’s seems solely to be focused on the regulation of risk.” Female drug user, European region.

The first participant above, also raised the problems associated with sexual health and drug use being very separated and siloed in relation to interventions and services stating that: “...I think that’s a huge piece when we’re talking about Chemsex, right? Like how can you not have them together? You know, here go to this sexual health clinic to talk about sex and then go walk down the street to get your, you know, drug education.” Participants highlighted that this could mean that guys who engage in Chemsex might know a lot about HIV prevention, PrEP, even STI screening, but know nothing about overdose prevention or naloxone or why they might need it. Ultimately, these participants were interested in ways to eliminate the traditional siloing of information and services and to remove the negative reinforcements in relation to both sex and drugs and to focus instead on how to successfully engage people in a way that is empowering for them and supports them to getting access to information, supplies and services they need.

In this context, a number of participants spoke in more detail about contemporary approaches and emerging work in the “Chemsex” space particularly in relation to gay, queer and bisexual men and how programs and approaches are increasingly being shared and adapted between regions. For example, participants from Australia gave the example of drawing on modelled programs from Europe and Asia. These participants also highlighted that language in some contexts is now far more focused on terms such as “PnP” including “Party & Play” and “Push & Play” than on using terms such as ‘Chemsex’ which is now being used much less in these contexts.

The term ‘sexualised drug use’ was also raised as an alternative to the ‘Chemsex’ terminology. ‘Sexualised drug use’ was explained as being focused far more on “pleasure and fun”, “fluidity”, “creating cultures of care” and “being a good host” that can create pathways to HIV peer testing and other brief and peer-based interventions around STIs and drug use. These participants felt that these broader concepts such as ‘sexualised drug use’ and ‘cultures of care’ also 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.
Finally, in relation to preferences for how services/interventions are provided, where they are provided and by whom there was a general consensus among participants that interventions and services in relation to Chemsex/PnP/sexualised drug use need to be 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.

To the extent that specific behavioral interventions were suggested these could be briefly summarized as including:

1. Adopting gender-affirming health care and broader cultures of care in relation to ‘sexualised drug use’ practices/’PnP’/’Chemsex’ to support inclusive, non-stigmatising, HIV, STI and hepatitis prevention and harm reduction approaches;
2. Tailored and focused peer-led education and information for specific groups and communities, different contexts and venues and various practices and drugs used (as discussed above) including nuanced information that acknowledges pleasure and fun and not just potential risks;
3. Access to kits or packs (such as “hosting packs” or “safety kits” that are comfortable, easily carried and encourage people to “plan to be safe”) including sterile injection equipment, male and female condoms, lubricants, drug testing strips, naloxone, devices for measuring heart rate and fluid levels in the body, HIV, STI, hepatitis prevention and harm reduction (including overdose prevention & response) information, and other materials as identified by communities.

Further, participants also stressed the need for more comprehensive services that provide linkages and pathways to care for issues that extend beyond basic HIV prevention and STI screening:

“...we talked to guys who are engaged in Chemsex and they have so many priorities, that never get addressed, like managing mental health crisis, managing psychosis and dealing with someone going into distress or overdosing... Um, if you’re dealing with the rate of racialized folk who are in PNP, the trans folks, the non-binary folks, like there’s so much other stuff that comes into it, but HIV [prevention] like proper condom use and PrEP that’s like shoved down our throats a lot.” Male drug user, the Americas region.
“There is a need for more psychosocial services at the Men’s Clinic to educate on the risks and other issues related to sex and drug use” Male drug user, Africa region.

Finally, participants highlight the centrality of community, connection and culture and the key role of peer-based harm reduction and leadership approaches not just in sharing information and learning from other each other, but in building positive and empowering communities. Among the conversations about Chemsex and peer-based harm reduction, however, was the fact that some participants felt that to date, Chemsex hasn’t been tightly connected with the drug user rights movement. Some participants felt that this is partly due to the fact that some people who engage in Chemsex do not wish to identify as people who use drugs, primarily due to stigma and discrimination. These participants expressed the view that this internalised stigma and the fear of stigma and discrimination from others can mean that the principles and practices of harm reduction do not always reach into Chemsex communities. Participants felt there should be more efforts by drug user-led and harm reduction programs to address this issue in the future. There was also a strong view that this should be led by peer workers who are part of Chemsex communities themselves to conduct ‘in-reach’ or ‘outreach’, engage people and provide services, including peer support and counselling services:

“It is necessary to educate a new generation of outreach workers, peer-to-peer consultants that are a part of this generation and of this subculture, etc.” Male drug user, European region.

Although not a behavioral intervention, it should also be noted that many participants also stressed the critical importance of policy and legislative reforms to remove structural barriers specifically repressive drug policies and stigmatising and discriminatory policies and practices, so that people do not have to hide and can maintain safety and fully access available approaches to reduce any potential harms associated with sexualised drug use practices/’PnP’/’Chemsex’.

a. Behavioural Interventions to Reduce Risks in relation to HIV, STIs and HCV

Participants were asked about behavioural interventions they thought could be helpful to reduce risk behaviours associated with HIV, STIs and viral hepatitis among people who inject drugs. Although participants were asked to focus specifically on health education and counselling interventions, it is important to acknowledge that several participants raised the need for WHO to better define what is meant by “behavioural interventions” especially in the context of the review and updating of the 2016 Consolidated Guidelines. With that said, when focusing specifically on health education and counselling interventions in relation to HIV, STIs and viral hepatitis
among people who inject drugs, a majority of participants broadly expressed the view that while such interventions can be helpful, it is the approach and then the skills, training and attitudes of those delivering the education and/or counselling that is most important:

“What really matters, you know, is who is doing the counselling, do they have enough skills and training? Are they able to do it in an effective manner that’s not patronising and again, in relation to health education, who is delivering it and how it’s done and in what ways are they delivering the key messages? I guess my main concern about behavioural interventions, when it comes to people who use drugs is, what is the ultimate purpose and I find a lot of them usually are about counselling or giving education with the ultimate aim of abstinence or, you know, recovery and I think when it’s done in that way it can be very off putting.” Female drug user, European region.

Once participants had established that the core principles and foundations of any behavioural interventions among people who inject drugs must be focused on a harm reduction approach, most participants expressed the view that health education interventions needed to mainly focus on safer injecting drug use practices. Specifically, participants stressed that people who inject drugs need to have access to sterile needles and syringes and other injecting equipment through NSP, but at the same time, participants also stressed the parallel priority of education/information about safe injection practices, reducing unsafe injecting related health risks including abscesses, hepatitis C, HIV and hepatitis B and education about safer sex practices:

“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, we got to provide people with information. If I don’t have the information, then I can’t protect myself anyway.” Female drug user, the Americas region.

Participants also stressed the importance of key messages and accurate peer education that follows harm reduction principles such as not sharing or reusing injecting equipment, having your own kit, not injecting others and general blood awareness during injecting, hand washing, etc. Having said this however, many participants also highlighted that depending on the context, education messaging can be ‘best practice’ and delivered by peers but that does not mean that people who inject drugs have the means to implement these strategies:

“It is one thing to give people who inject drugs safer injecting education messages but do they even have access to new injecting equipment and even if
they do, do they have enough access to put the messages into practice?”
Male drug user, Western Pacific region.

Other participants particularly in LMICs stressed the importance of ongoing health education that is delivered through a variety of different mechanisms and formats to account for different levels of access, knowledge and literacy and to combine this with counselling and other psychosocial supports for maximum effectiveness:

“Continuous education where this will be repeated many times and not just giving people pamphlets but explaining to people as some are illiterate, having psychosocial interventions where they can even have classes and be taught a skill which will be combined with the learning objectives.” Gender non-binary drug user, Africa region.

The need for increased access to specific health education interventions for people who inject drugs in relation to hepatitis C in LMICs was also raised by several participants who reported that despite the availability of information at a service level, there are ongoing and significant gaps in people’s knowledge about HCV prevention, testing and treatment:

“The information about hepatitis C is not known at a community level, even when accessing services, it is still limited.” Male drug user, Africa region.

As already outlined above, several participants highlighted the importance not just of who the counselling is being provided by but the underpinning philosophy in relation to harm reduction rather than promoting abstinence from drug use per se. While participants acknowledged that individuals may wish to access counselling to reduce and/or cease drug use, they did not believe this should not be the primary aim of counselling for HIV, STI and hepatitis prevention among people who inject drugs as this can force people away from essential services and programs. In fact, when participants were asked about whether counselling is more helpful on a one-on-one basis or in a group setting, several participants linked their responses back to these same key issues relating to context, who is doing the counselling, who is in the group and what perspectives and philosophies in relation to drug use:

“You know, it just depends on where you are and what you’re doing and what I mean is that counselling is never effective if it’s required. Like forcing people into counselling negates what counselling is altogether.” Female drug user, the Americas region.
This participant then continued to talk about group counselling:

“...and so, if I’m just thrown in some rehab with a bunch of people, and you’re just doing this to waste time or to pass time, that’s not useful either. So, the only time a group would be useful to me is if I respect the people in the group and I think it’s really important that I view the people in the group as peers, people that have the same ethos as I do, people that think about substance use in the same way I do. I wouldn’t be able to sit in a group of people who believe that drug use is inherently bad, and that, you know, there’s no way to use in a safe way because I would be so busy, like thinking about all the reasons they’re wrong, that I wouldn’t be able to think about the ways that what they’re saying could help me.” Female drug user, the Americas region.

Furthermore, a few participants from different regions also specifically recounted experiences of being denied access to HIV counselling 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 for a range of healthcare, and especially if you are opioid user.” Male drug user, Western Europe region.

Other participants highlighted the need for a range of different counselling approaches (and other behavioural interventions) to ensure that people have access to the specific types of support and services they need at different stages of their health and life journeys. One participant referred to the idea of a “tool-box” to equip people with the information, skills and supports they need to manage their health and stay well over time:

“It depends on the individual subject. I guess with HIV it’s a lot more difficult to talk to a group. It took me 10 years to admit to myself that I had it, let alone anybody else. So, the thought of me sitting in a group and discussing things... like this wasn’t happening. So, I guess a range of options in each intervention for people so the option to do it as an individual or as a group whether that be HIV counselling, naloxone [for overdose] prevention, relapse prevention. All these little things that give you tools to carry in your tool-box to avoid the harms and risks and reduce that risk.” Male drug user, European region.

Finally, although participants in some settings identified counselling during HIV, STI and hepatitis testing and other psychosocial support particularly provided by peer-led, community-based services as very helpful, but other participants pointed out that
counselling is only helpful it is readily available. One participant spoke to the ongoing gaps in the availability of counselling for people who inject drugs particularly in LMICs:

“Initially, when we had enough staff, it was effective, as people who would have otherwise engaged in risky behaviour had that structure to know that there is somebody they can talk to but right now it is not effective because we don’t have enough counsellors.” Female drug user, Africa region.

2. Modes of HIV/STI/Hepatitis Service Delivery

All participants were asked a series of questions about service delivery, and specifically questions about how services are delivered including questions on the value and impact of peer navigators, the role of drug user-led services and participants' views on using online tools and platforms for HIV and viral hepatitis among people who inject drugs.

a. Perceptions of Peer Navigators and their Impacts on Initiation and Retention in Treatment and Prevention Programs

“If it was provided by a peer, I would be more willing to listen” Female drug user, Africa region.

In many ways the above comment summarises most of the participant responses to this question about perceptions of peer navigators and their impact on initiation and retention in treatment and prevention programs. For the majority of participants in this study, regardless of country or region, peer navigators were viewed as “essential due to their lived experience”. There was a very high regard and valuing of peer navigators/peer workers/peer educators in the context of HIV, STI and hepatitis prevention treatment and care. In terms of discussing these issues at a global level, it is important to acknowledge that a number of participants in the focus groups stated that they were not familiar with the term “peer navigators” but once explained, they were universally supportive of the concept of peer navigators and their capacity (if properly supported and resourced) to “act as a bridge between two different worlds”, to connect with people who inject drugs, facilitate their access to prevention and treatment and importantly, to support people to commence and continue treatment:

“I think there has to be a kind of bonding figure, that immediately starts to care with you, not doing the walking for you, but 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.
In line with comments made in relation to ‘Chemsex’ above, another participant stressed the idea of ‘care’ and that not all peer-based service delivery is done in formal settings or even through a funded program, but that at the heart of peer education and support is the concept of being motivated to care for each other:

“Again, for me it is all about cultures of care whether that is peer distribution and having enough equipment for my mates to come and get it from me when they run out, or having naloxone or distributing naloxone to my friends... So, it’s a conscious thing and it might just be informal but it’s there and it’s about a culture of care.” Gender non-binary drug user, Western Pacific region.

In relation to the specific characteristics that make for successful peer navigators, participants reported a range of views largely depending on context and geographical region, but the most common characteristics included: “having passion”, “being a good communicator”, “a supportive listener”, “trustworthy”, a “team worker” and being “empathetic” and “dedicated”. While no participants stated that peer navigators/peer workers should come from outside of the community, some participants in some contexts thought that peers with previous experience of injecting drug use can work in certain contexts, but others stated that peer navigators should be “active users” due to the potential to lose connection to community and for an individual’s drug using knowledge to become out-of-date or irrelevant:

“As a former peer, the people in the community identified with her and knew that when they told her something she would understand and will help them to the best of her ability and addresses them at their level and speaking in their language.” Female drug user, Africa region.

“I get that someone who doesn’t inject drugs anymore might have a lot to offer but are they peer? It’s all about connection I think, because practices and even the drugs being used change all the time and knowledge needs to be current but I’m also aware criminalisation can make it hard for people to be out in many contexts...” Female drug user, Western Pacific region.

In addition to highlighting the importance of connection to community and currency of knowledge, the above comment also foregrounds the complexities in relation to peer navigators/workers and the impact of structural factors such as criminalisation and systemic stigma and discrimination on the capacity of peers to make the most of the support and connection to services they can provide. Linked to questions of currency and relevance of knowledge is the issue of age and whether it matters in relation to peer navigators and their ability to connect with people who inject drugs and gain
trust. For many participants in this study, peer navigators are seen as role models but while some participants stated that “older peer navigators are respected more”, others believed that being of a similar age (and sex) is critical to how people who inject drugs connect with, understand and build trust with one another and with peer navigators:

“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. In Asian countries, their traditions are very much honored, and we have a respectful attitude towards older people from childhood. This is why young people will not accept a consultant of the older age, because with his way of life, he will break their idea of respecting the age. Young people need peer consultants of the same sex and age.” Female drug user, European region.

Another participant made the point that depending on who you are trying to reach then that is who your peer navigators/workers need to be. For example, if you are doing outreach to young people, you need young people. If you are doing outreach to old people, you need old people. He added:

“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.

Participants were also asked about whether they had any concerns about using peer navigators. For the most part, the concerns reported by participants focused on the impact of being ‘out’ as a drug using peer and the potential negative implications this can have for those individuals including coming to the attention of police while trying to do their job:

“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.

Others highlighted how just the word “peer” or even the title of “peer worker” or “peer navigator” can ‘out’ people as people who use drugs and can have negative implications for those individuals depending on the context involved:

“For starters we can’t just say “peers” for people with lived/living expertise of a drugs. When we are called peers, it automatically outs us as either a
person who uses drugs and sometimes even what drugs the person is consuming. Why do we have to put more labels on people?” Female drug user, the Americas region.

Linked to the above concerns about people being ‘outed’ and coming to police attention or experiencing stigma and discrimination, was the issue of how peers or people with direct lived experience of drug use can be treated when they are the only or one of very few peer workers in a more mainstream health service. These participants raised the need for stigma and discrimination training for health service providers as a prerequisite to engaging peer navigators or workers:

“Peer workers are often treated really poorly by mainstream services. I mean, what’s the point of sending peers into a service where they are not wanted, to work with people who don’t really want to be treated in that service? Ultimately, there is a real need for stigma training for frontline services in working with and respecting peers before they have access to peer workers.” Female drug user, Western Pacific region.

Finally, participants were also asked to reflect on when they thought that peer navigators/workers are most impactful. Most participants who offered a view on this question stated that peer navigators/peer workers can be some of the most impactful workers in the context of HIV, STI and hepatitis prevention, treatment and care services including comments such as people who inject drugs “do not trust neither law enforcement agencies (LEAs) nor doctors – a peer-to-peer consultant will be the most effective.” Another participant, referred to research showing that peer-based NSP services deliver significantly better psychosocial outcomes for people who inject drugs than non-peer based NSP service models in relation to HIV and hepatitis prevention.

Several participants however also highlighted that there are many factors that can work to undermine the effectiveness and impact of peers. In particular, participants highlighted the importance of providing peer navigators/workers with adequate resourcing including being paid fairly and equitably in relation to other non-peer workers in the same service or organisation. Participants referred to peers being “not seen as professional”, “undervalued”, “unpaid” and not recognised in the same way as other workers and not given adequate training and support:

“What we see is that the peer worker is always a peer worker and never is being seen as a professional with technical knowledge. And usually, they are engaged just in these positions and they cannot go farther than that. For me, I’m really struggling with that.” Female drug user, European region.
“Peer workers need to be trained and supported and properly paid so that they can avoid exposing people to burnout and stress.” Female drug user, European region.

Ultimately, despite the many nuances and complexities, two participants summed up the key ‘take-away’ messages in relation to peer navigators in the following ways:

“I am a really big believer in recognising peers as experts or professionals in their own lives, because one, they’ve got the empathy, support and connection already - peer to peer, and then two, give them the tools like motivational interviewing, even CBT and suddenly, you’ve got access to injecting equipment and safer using done, naloxone provision done, HCV testing and treatment done, I could go on... but I mean, it’s amazing” Male drug, Western Pacific region.

“...there are always going to be ‘new’ drugs and ‘sub-groups’, and you will always need an experienced cadre of peer workers who know that specific context. Being able to use the language of the community is critical to building relationships.” Male drug user, Americas region.

b. The Role of Drug User-Led Responses and their Impacts on Initiation and Retention in Treatment and Prevention Programs

“I mean there’s no other way to do it. No other way to do it effectively. So, any discussion about doing this without having people who use drugs involved – it’s just garbage! Okay.” Female drug user, Americas region.

In line with the comments made above by participants in relation to peer navigators/workers and their value and importance, the majority of participants also expressed the view that drug user-led responses are critical to the ability of people who inject drugs to address their needs in relation to HIV, STI and hepatitis prevention, testing, treatment and care. Further, participants stated that drug user-led responses were not only important for improving access especially to BBV prevention programs but also to people’s ability to access treatment for HIV and hepatitis C and then to remain on HIV treatment in the longer term:

“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, because a lot of the time, the fear of what to expect is why people don’t get tested... and
peer groups are vital to that I think because a lot of people aren’t even engaged in treatment. And that’s what a lot of services miss, they have a vital resource there that they generally don’t use.” Male drug user, European region.

“Nowadays, the treatment of hepatitis C in [in my country] gets widely spread not by the state, but by the community. People who have hepatitis C as well as the experience in using drugs, have started their own NGOs dealing with hepatitis treatment and are now working directly with generic manufacturers and providing treatment for everyone in need all around the country. Thanks to these NGOs, the threshold for hepatitis C treatment [in my country] is now quite low.” Female drug user, European region.

Other participants spoke about the unique capacity of drug user-led responses to not only be flexible and to ‘meet people where they are at’ (rather than where a service might prefer them to be) and therefore, be truly ‘person-centred’, but also their capacity to reach and gain the trust of a wide range of people who inject drugs from various 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 managed by peers and 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.

One of the main issues raised by participants, however, was that despite their importance and the critical role these response play in the health of people who inject drugs, in many of the regions involved in this study, participants felt that in many contexts there is an insufficient commitment to community led responses and identified a general lack of support for organisations and services led by people who use drugs:

“We have a long and proud history of peer-based drug user-led organisations in my country and it has definitely been that our organisations and services have been central to efforts towards ending HIV and eliminating HCV among people who inject drugs, but it’s often not recognised or supported.” Female drug user, Western Pacific region.

In particular, participants highlighted the lack of interest from government and “the state” in relation to involving drug users in decision-making processes related to their health and life, despite the fact that the community can and is ready to act as an equal partner in the fight against HIV and viral hepatitis epidemics:
“Since [our drug user-led organisation] was created, we have been trying to establish interaction with the state, but everything is going pretty slow. You’d think that the state should be interested in our feedback on how to effectively spend the budget on treatment and prevention of HIV and hepatitis in order to reduce the burden of epidemics. But in fact, we are forced to offer ourselves to the state, because it’s all about our health and life. We hope that our interaction with the state will develop as the PUD community mobilizes and gets professional.” Female drug user, European region.

Even where drug user-led organisations and services exist, many participants spoke about a lack of capacity and that their organisations are chronically under-resourced for the roles and services they are expected to provide. Participants identified the need for training and workforce development for drug user-led organisations and services including “core information and skills in relation to BBVs” (including the latest clinical and research evidence), “developing and maintaining professional boundaries” and “engagement and education techniques” (including motivational interviewing, CBT and teaching and learning approaches). Other participants simply identified the need to broadly build the capacity of drug user-led organisations and services because they are too often working without adequate resources and support in isolation:

“We need to improve community-led services by building the capacity and skills of community members” Male drug user, Africa region.

Despite the barriers and lack of proper resourcing, participants agreed that drug user-led responses definitely improve entry and retention in services. They felt that when organisations and services are run by people who use drugs, practical developments such as increased opening hours, drop-in functions and designing services to meet people’s needs and lifestyle are some of the improvements that can result because there is a greater understanding of how services should be designed to attract and retain clients.

Participants also felt that peer-led advocacy also has an important impact on ensuring that the lived experiences of people who inject drugs are taken into account by using advocacy to communicate, put pressure on and hold program managers and decision-makers more accountable. They stated that drug user-led advocacy is able to push back on harmful policy making and program development and implementation and that by undertaking this work, drug user-led organisations are effective and much-needed watchdogs for the community. Furthermore, they argue that drug user-led organisations focus on issues that more general civil society organisations do not, because they are not as close to real experiences and on the ground issues.
c. People Who Inject Drugs Using Online Tools and Platforms to Access Services for HIV, STIs and HCV

In response to a question about accessing online services for HIV, STIs and HCV, the majority of participants stated that ideally people who inject drugs should have access to an appropriate mix of face-to-face/in-person services and online/digital tools and platforms with comments such as “I think a mix of both is needed” and “online and face to face - both have a place”. Having said this however, some participants expressed the perspective 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 online security concerns (see more below) and to facilitate empowerment and in particular, 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.

This participant continued...

“It is not all PWUDs who have access to technology of information with gadget like smart phone or computer. Online tools help to share information or to know where we can find services. But the community cannot use only the online and digital access to the services, they have to go where are located those services.” Male drug user, Africa region.

Others also added reflections on barriers and limitations...

“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.

“It’s mostly impossible with technologies, because you lose your telephone, you lose your email. We have been trying different things and we have computers there and people can check their emails. But also, with 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.
Another participant from a different region also raised concerns about an over-reliance on online or digital platforms and tools for people who inject drugs and that a balanced approach is needed and attention to the psychosocial implications of using online technologies and platforms for these types of services and information:

“I mean, online tools are wonderful, but they need to be used carefully and they need to be used along with other tools. One of the things that can happen is we can become so dependent on online services that we can like them because they allow us to have the distance from people that we feel uncomfortable with. We don’t have to move, we don’t have to go out in the community, all of that and make it easy for ourselves. There’s nothing about this job that’s easy... human beings’ lives are messy and often online services just don’t capture that...” Female drug user, the Americas region.

Having said this however, other participants highlighted that the advent of COVID had pushed them as peer-based, drug user-led services to provide online tools and access to online BBV and harm reduction services that they had previously only provided in-person, and that COVID forced them to innovate in the direction of online services. They added that some of the outcomes and impacts of these innovations have been quite surprising in that they have significantly opened up service access to groups not previously well-reached through the provision of HIV and hepatitis C related harm reduction services including online ordering combined with postal services for NSP/harm reduction supplies. A recent evaluation of one of these new peer-driven combination web-based/postal NSP services has found that these online services are attracting more young and female drug users, as well as drug users from culturally diverse backgrounds in comparison to their traditional face-to-face services:

“Our recent NSP online/mailout service survey has shown that we are reaching much larger numbers of people in the 18-25 age group, followed by 25-35 age group. And our male to female ratio is almost equal, which is almost unheard of at face-to-face NSP services. We are also seeing a higher rate of people for whom English is not their first language. This data is really incredible and shows what can be achieved through a mix of different service models.” Female drug user, Western Pacific region.

Others however highlighted that COVID has also caused problems in relation to using online tools and platforms including how these approaches can work to undermine or at least roll-back some of the important gains made towards recognising the inherent value and professionalism of peer educators and advocates. Specifically, participants drew attention to how a shift to using online tools and platforms for peer-based advocacy and training for mainstream service providers, has led to an
expectation that peers will provide their unique lived experiences and their specialist expertise and knowledge for free largely because it is now being provided in an online environment:

“You know, one of the other problems with online tools is we are less likely to pay our peers and our folks for speaking and talking, because all they have to do is show up on the computer. So, whereas we had worked really hard and gotten to a place where drug users were getting paid for their services. Now, I feel like we’ve rolled back on some of that. I know myself, I’ve spoken on many different webinars over the past year that have been unpaid, whereas all of those gigs would have been paid prior to COVID.” Female drug user, the Americas region.

Several participants also made the point that we should refrain from making blanket assumptions that people who inject drugs are unlikely to have access to data (due to poverty and/or a lack of access to technology) or simply that they don’t understand or engage with online platforms like others do. While participants acknowledged that some people who inject drugs may not have regular or ready access to data or may not be very familiar with online spaces and tools, many other people are. To this end, participants believed that it is really a matter of acknowledging that like all communities, people who inject drugs are a highly heterogenous population with diverse experiences, skills, resources and needs. In this regard, some participants highlighted the need to focus on improving the online environments that are available with information and tools to meet people’s specific needs rather than continually focusing on whether people who inject drugs have access or not:

“We should focus on improving online platforms with specificities of each group of key populations.” Male drug user, Africa region.

“When we ask people rather than make assumptions, we find that people who inject drugs are very engaged in online environments and we just need to make sure that we provide a broad range of different access points so no-one feels excluded.” Female drug user, Western Pacific region.

These participants highlighted that online and digital platforms could potentially work very well in relation to providing access to HIV, STI and HCV prevention for people who inject drugs, but that many community-led organisations do not have access to the tools and resources to support service delivery and information sharing provided in this way. These participants also stated that in their view face-to-face interventions have some particular advantages in relation to building connections between people, but that they could see some real potential to use digital tools to support the use
of more visual and graphic education materials particularly for people with literacy issues, so it is really a matter of balance and choice:

“There’s a certainly a place for it, but not as a standalone. For some people it helps because you don’t have to trek to city center or across country to speak to their key worker. For some, people prefer not to have contact at all. The key issue is choice.” Male drug user, European region.

In addition to the many potential benefits associated with an increase in online services, participants in some settings also highlighted that the shift towards providing services online due to COVID has also exacerbated existing structural inequities among highly marginalised people who inject drugs who are often living in poverty with less access to digital technologies. Participants raised concerns about online security including the increasing use of digital footprints for greater 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 should been seen simply as another environment that brings with it a variety of potential advantages and potential disadvantages in relation to providing access to services for HIV, STIs and hepatitis. Further, as one participant specifically highlighted, there are people who inject drugs who have considerable online knowledge and skills and utilising this available knowledge base will be critical for the future of peer-based and drug user-led services and organisations:

“PWUD should be leading each and every PWUD program including online platforms, we are more than just PWUD many of us know a lot about website development, graphic design, case management, service provision, and cryptocurrency.” Female drug user, the Americas region.

These ideas also link to some specific comments made by participants from a number of different regions about the “Darknet” and the potential opportunities and risks in this environment for providing access, particularly to HIV and hepatitis C education materials and harm reduction information for people who access this environment:

“...drug consumers visit Darknet stores much more often than syringe exchange points. Therefore, it is important to collaborate with the shopkeepers of these stores so that they post harm reduction information inside their advertisements. Buyers of substances will read this information when entering the online store. In addition, getting information online is safer for them - the degree of anxiety is reduced. I believe that this is a separate and promising topic for community advocacy today.” Female drug user, European region.
Regardless of whether peer-based drug user-led organisations and services engage in the “Darknet” or simply in the mainstream internet through various online tools and platforms, it is clear from the participant response to this study, that providing access to HIV, STI and hepatitis prevention, testing and treatment services through online mechanisms is only going to grow in the future but there remain many issues to consider in relation to the use of online tools and platforms among people who inject drugs.

3. Structural Barriers and Enabling Environments

All participants were asked a series of questions about interventions which are aimed at addressing structural barriers to accessing health services for people inject drugs including criminalisation, stigma and discrimination and violence. Participants were also asked about the enabling interventions that they thought could help address these structural barriers to service access for people who inject drugs.

a. Perceptions of how Criminalisation of Drug Use Affects People’s Access to Services and Ability to Stay in Treatment for HIV, STIs and Viral Hepatitis?

The overwhelming response from most participants in relation to the above question was straightforward and direct. For the vast majority of participants, 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 use/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 like decent to chaos, get the police involved. I mean, criminalisation is the worst thing you can do to a person and court and jail and all that is one good way of just destroying someone’s life.” Female drug user, the Americas region.

“Criminalisation is the main barrier in access to services and treatment for HIV, STIs and hepatitis, since it immediately portrays the drug user not as a patient suffering from drug addiction, but as a criminal, to whom the society, including health workers, have an appropriate attitude.” Female drug user, European region.

“Our lives end when we are left with nothing but criminal records, we can’t even find housing or employment.” Female drug user, the Americas region.

As indicated above, the vast majority of participants regardless of country or region, reported that criminalisation is the main barrier for people who inject drugs in accessing HIV and hepatitis services and treatment. In addition, many participants made a point of...
stressing that in one way or another, all other barriers experienced by people who inject drugs largely flowed out of or are a consequence of the criminalisation of drug use:

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

“We all know that people who inject drugs in particular don’t come forward for all sorts of health and social support services because of criminalisation. It creates so many barriers. It almost doesn’t matter what it is. If it is negative and it impacts on the health of someone who injects drugs, you can almost guarantee that it is due to criminalisation.” Male drug user, Western Pacific region.

Participants highlighted how criminalisation isolates individuals from their community, makes it difficult if not impossible to access prevention, testing and treatment but also to stay in treatment because of fears of being arrested or worse. Participants also recounted how criminalisation contributes to stigma and discrimination in even in health facilities:

“Even in the medical centre there is a sense of criminalisation, if I am found taking methadone outside the centre then the punishment is severe.” Male drug user, Africa region.

“In our country, we still face criminalisation even having OST programs. OST is not dispensed to the patient, there are no distribution points in small localities, you cannot continue to stay in the OST program if you go to prison. With such a high threshold of access to OST, many are forced to use street drugs, falling under criminalisation.” Female drug user, European region.

Given the significance of this issue for the focus of this study, we have opted to include an expanded participant account from one of the participants from the European region that we believe highlights the impact of criminalisation on access to services and ability to stay in treatment for HIV, STIs and viral hepatitis for people who inject drugs:

“I have been using drugs for 35 years and have lived in a country with a repressive drug policy, where there’s no OST programs. I have been living with HIV for 22 years and for 32 years with hepatitis C. Criminalisation greatly affected the quality of my life, because instead of taking care of my health, visiting medical institutions, receiving HIV treatment, from the early morning I was forced to look for money for drugs in a criminal way, and then look for drugs themselves. The withdrawal symptoms ruled my whole life, and the only thing I could think about was how I can get rid of withdrawal symptoms as soon as possible without getting into the police sight. The last thing I
thought about was treating HIV and hepatitis, as this wasn’t my basic need. The treatment of tuberculosis for people with HIV and drug addiction is a huge problem. Narcological aid is not provided in the TB dispensary, this is why it is impossible to stay there with withdrawal symptoms and treat HIV and tuberculosis. A person is forced to leave and look for drugs risking to be discharged for violating the regime. Female drug user, European region.

Finally, it is interesting to note that a number of participants also referred to the way that criminalisation not only negatively impacts the lives and health of people who inject drugs, but also has negative implications for the community-led organisations that represent people who use/have used drugs. This in turn, affects the capacity of these organisations to effectively advocate for and provide services to the very community it is there to represent:

“Criminalisation not only affects drug users but also organisations working with them, as the services, especially informing about risk and harm reduction are often viewed as drug propaganda.” Female drug user, European region.

b. Perceptions on Enabling Interventions to Help Address Structural Barriers to Accessing Services for People Who Inject Drugs

Once again, the key response from most participants in relation enabling interventions was the need for decriminalisation to address the many barriers and inequities outlined above. Although several participants did note some of the so-called ‘decriminalisation’ measures that have been much celebrated in various countries undertaking such reforms, in line with INPUD’s recent research report⁸, 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. You can use, but you cannot buy your drugs or sell in the streets. It’s not true. They are talking about decriminalisation and it’s not a real thing. There are other ways to criminalise people anyway. How do you differentiate, when you know that most of the people need to do these other things, in order to use drugs? Here we have been de-penalizing 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.

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In the context of decriminalisation and enabling interventions, several participants stressed the critical need to secure a safe drug supply as the first and primary 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 and that allow people who inject drugs to build self-esteem and confidence in the general health system and as members of the community generally. In particular, they stressed the need for sensitisation training with the police and the broader 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 and the need for law reform. They also emphasised the importance of adequate gender-based violence (GBV) structures and training including for perpetrators:

“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.

“Drug law reform is an essential precursor to improving the way that people who inject drugs are treated in society. As long as the drug laws treat us like second-class citizens there will always be stigma and violence and barriers to accessing health services.” Gender non-binary drug user, Western Pacific region.

c. Perceptions on the Impact of Stigma and Discrimination on Access to Prevention, Testing, Linkage to Treatment and Ability to Stay in Treatment for People Who Inject Drugs

“The point of criminalisation is to stigmatise.” Male drug user, the Americas region.

For the majority of participants in this study, issues related to stigma and discrimination for people who inject drugs are so inextricable linked to criminalisation that participants did not have a great deal more to add in response to this question other than what has already been detailed above and elsewhere across this report. Indeed,
research has found that in the context of criminalisation, experiences of stigma and discrimination are so pervasive that they are almost a universal experience for people who use drugs\textsuperscript{9}. In this context, it is hardly surprising that in response to this question, 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, they’re the linchpin. I mean, that is 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 are 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.

“I think people can’t really even imagine how bad the stigma and discrimination is for people who inject and just how much it effects people’s ability to access services and stay well. You really have to experience it first-hand. It’s so relentless and people just give up.” Male drug user, Western Pacific 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.

It is perhaps also not surprising that participants viewed the need to address stigma and discrimination 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 inject 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 or similar ridiculous hoops and punishments. So, I think we need to move to complete decriminalisation of drugs as the only pathway to make sure that people who use and inject drugs have their right to health realised. I also think it, as long as drug use is criminalised that 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.

4. Values & Preferences Surrounding HCV Testing and Treatment
In relation to the hepatitis C virus (HCV), participants were asked about their views and preferences in relation to two specific aspects of HCV testing and treatment. First, participants were asked to consider the availability of the new generation pan-genotypic Direct Acting Antivirals (DAA) and whether people who inject drugs should be offered DAA therapy immediately upon diagnosis. Follow-up questions were also explored on barriers to treatment, potential concerns about immediate treatment and possible models and support services. Secondly, participants were asked about preferences/willingness to be retested for the presence of HCV in their blood (viremia or RNA PCR testing) following a negative result due to successful treatment or clearance without treatment. If participants expressed a willingness towards retesting, follow-up questions were explored in relation to frequency of viremia testing and potential models of service delivery.

a. Values & Preferences in relation to HCV DAA Treatment
In response to questions about the availability of the new generation pan-genotypic Direct Acting Antivirals (DAA) and whether people who inject drugs should be offered DAA therapy immediately upon diagnosis, perhaps not surprisingly participants overwhelmingly answered “yes” to this question. Indeed, one facilitator summarised the response of the focus group to this question as “They all answered YES!”. This strong preference was also echoed in some of the specific participant responses:

“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.

“Is this a serious question? Of course people who inject drugs should have access to the best available HCV treatment if they want it.” Gender non-binary drug user, Western Pacific region.

“To deny treatment or health is not a solution.” Male drug user, European region.

Given the high cure rates, good tolerability, low pill burden, less drug interactions and significantly less side-effects than the previous therapies, many participants viewed access to the new therapies as a very straightforward matter. In fact, many participants expressed strong preferences for reducing barriers to treatment and making HCV DAA treatment as accessible as possible for people who inject drugs including people who may have already been successfully treated and subsequently contracted a new HCV infection:
“I feel very lucky to live in a country with universal access to DAA treatment that is heavily subsidised by the government, so it is affordable. It has meant that so many people can now get treated without the need for expensive genotyping or even a fibro-scan in most cases. This is not rocket science as they say... if the person has the virus, they should be offered treatment - simple.” Female drug user, Western Pacific region.

“Treat anyone who has HCV, plain and simple.” Male drug user, the Americas region.

Despite this overwhelming preference for immediate treatment, significant ongoing problems and barriers to HCV DAA treatment remain in many contexts. Although participants in some countries spoke about having high levels of access to HCV DAA treatment, participants in many other countries and regions in this study are still experiencing significant ongoing barriers to HCV DAA treatment 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.

“I was at this conference, you know, and like all these countries were talking about how they had basically eliminated hepatitis C. And I was like, wow man, it’s totally possible to do this. And we just don’t have the political will to get it done. And it’s sad, it’s heartbreaking...” Female drug user, the Americas region.

“If a patient does not have HIV status, then they need to pay for medications for HCV treatment. They’ll be advised about treatment options and then can buy these medications at the pharmacy (from different manufacturers and at different prices), but this is only if they have the desire and financial ability.” Female drug user, European region.

“In some countries hep C treatment just isn’t possible or is unavailable or it’s too expensive. There are also policies against people who inject drugs even being able to access HCV treatment or you know, drug use is a criterion for being able to access the treatment. This is just unacceptable when treatments are so effective and hep C related deaths continue to be high globally” Female drug user, European region.

The issue raised above about barriers to HCV treatment due to the poor attitudes of health professionals and specifically OAT and other drug treatment providers was
raised by several other participants as an ongoing problem. 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\textsuperscript{10} and that ‘re-infection’ should not be used as a reason to withhold therapy from people with ongoing injecting drug use\textsuperscript{11}, AOD clinicians in some contexts continue to use cessation of injecting drug use (and sometimes 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.

In addition to barriers outlined above, participants from Africa also raised problems with health professionals with-holding access to HCV treatment for people who inject drugs living with HIV. This situation is highly concerning given that there are very few clinically important interactions between current HCV DAA medications and ART regimens. Nevertheless, even if these practices are based in concerns about the potential for treatment interactions, these participant comments at the very least suggest a lack of information and communication with people who inject drugs about why certain approaches might be taken in relation to treating HIV/HCV co-infection. Unfortunately however, it may also indicate an ongoing reluctance to make HCV treatment available to people who inject drugs without discriminatory barriers and regulations and/or assumptions about treatment adherence/completion:

“If you are already HIV positive and not on [HCV] treatment yet, they will let you get the medication for HCV only when you have taken the HIV treatment for 3 months.” Other non-gender conforming drug user, Africa region.

In relation to strategies to address barriers to HCV treatment, there was strong support among participants for opening up HCV DAA treatment through a wide range of treatment options and settings including at NSPs, harm reduction services, health services, drop-in centres, OAT clinics as well as GP and hospital settings to maximise access and reduce barriers as much as possible.


In particular, participants also highlighted the importance of drug user-led organisations and peer-based service models for both HCV testing, treatment and follow-up. This coincides with research studies that have found that peer-based models can increase HCV treatment uptake and outcomes among people who inject drugs.12 Several participants from programmes in the Global North spoke about developing peer-based models (often as part of formal research pilots) that are based around using peer-led Point of Care (PoC) RNA Testing with the DBS test able to be ordered online for self-testing or through NSP, peer-clinic, drop-in or outreach services for peer-supported testing. Testing is completed on the spot and posted to pathology. Diagnosis is delivered over the phone with peer support available at each stage as requested. If the result is positive, support to commence treatment immediately is available and treatment medications can be collected in-person or posted. Financial and other incentives are also being used to encourage testing, getting the result, commencing treatment, achieving SVR and bringing in or referring a peer or buddy. With further developments in rapid PoC RNA testing and service models, these peer-based approaches are working towards same day HCV diagnosis and DAA treatment initiation in the near future:

“It’s absolutely the way to go – low barrier, no judgment and people are supported all the way along as much or as little as they want. Our peers love doing this work and we want to expand what we offer but we are under-resourced, and the service is popular so we are struggling to meet demand for this peer approach.” Male drug user, Western Pacific region.

Although these innovative peer-led models are increasingly being shown as critical to reaching hepatitis C elimination goals in these countries, they also serve to underscore the ongoing and growing disparities in access to HCV testing and DAA treatment between countries in the Global North and those in the Global South. Participants in this study expressed the strong view, that these ongoing barriers to HCV testing and treatment access for people who inject drugs in countries in the Global South must be addressed as a matter of urgency. This call is also strongly supported by INPUD as the global network for people who use/inject drugs.

In addition, as already emphasis in the above section on values and preferences in relation to HIV and HCV behavioural interventions, major barriers to HCV prevention among people who inject drugs remain in many contexts (in the both the Global South and Global North) 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 decriminalisation reforms, etc. Along with

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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 the acquisition of new HCV infections (or what is often referred to as “re-infection”) post-cure:

“Hepatitis C treatment and harm reduction services go hand-in-hand. That has to be a given. I think a lot of people talk about access to [HCV] treatment and leave the prevention side out, or they expect that once someone gets [HCV] treatment that they will remain abstinent and that’s not always the case all the time. So, you know, the prevention programme always needs to be linked to the treatment because obviously health services and treatment don’t exist in a vacuum.” Female drug user, European region

Finally, no participants expressed concerns about the potential for over-treatment associated with offering immediate treatment either among people who are treatment naïve or for re-treatment. Rather, a few participants expressed the concern that it is dangerous to deny access to treatment purely on the basis that some people will spontaneous clear (without treatment) – not only for the health of the individual concerned (and potential loss to follow-up) but also due to the potential for further transmission. Indeed, it would be fair to say that participants in this study were vastly more concerned with the ongoing lack of access to the highly effective HCV DAA treatments in certain countries and regions than about any hypothetical risk of over-treatment.

Finally, although it was 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 particularly in the context of an overwhelming lack of access to sterile injecting equipment and other harm reduction measures in most prisons globally coupled with the levels of incarceration associated with drug-related offences.

b. Values & Preferences in relation to HCV RNA Re-Testing Post-Treatment/Clearance

Although there is a growing body of research in relation to people acquiring new HCV infections following successful treatment or viral clearance highlighting the importance of early detection and retreatment, there appears to be minimal focus on encouraging regular hepatitis C assessment among people who inject drugs following successful HCV treatment/viral clearance. Indeed, participants from various regions and contexts raised a range of issues relating to both understanding of and access to HCV testing

14. Ibid.
and post-treatment re-test/monitoring. For example, a participant from Southern Africa raised the following concerns about access to HCV testing at all:

“In relation to hepatitis C testing, only private hospitals have hepatitis services [in my country], it’s not like HIV services where you can get it anywhere. Even with the education around hepatitis, it is very limited, people do not know about it – they only worry about HIV.” Male drug user, Africa region.

Several other participants raised other frustrations about access to HCV testing but in this case, raised concerns that even many health services and providers are not clear about where HCV testing efforts should be focused with one participant from the Americas region asking, “Why are we even still doing HCV antibody testing?” This participant and participants from other regions raised concerns that limited available resources are continuing to be used for HCV antibody testing when the focus should be on rapid HCV RNA testing to quickly establish HCV status, opening up pathways to immediate treatment and minimising the potential for people to be lost to follow-up particularly among marginalised groups of people who inject drugs.

Having said this, INPUD does recognise the importance of antibody testing for engagement purposes and that quickly being able to establish HCV exposure, particularly using PoC brief intervention approaches and in low HCV prevalence environments, can be an important engagement tool with people who might otherwise not be aware of or fully understand their HCV status. In this context, some participants spoke about peer-based PoC brief intervention protocols being used (including in environments where not all service users are people who inject drugs e.g. homeless services) to quickly assess for potential HCV exposure (or not), followed with rapid PoC antibody testing. This brief intervention is then followed with the provision of ongoing harm reduction information and services and/or follow-up HCV RNA testing and associated information, DAA treatment and support as appropriate. These participants identified that these models can be very useful for initial engagement and at least informing people of their HCV status in contexts where people may not be willing or able to wait and/or return for RNA testing which takes longer and can result in loss to follow-up and potential for ongoing transmission.

These more general conversations about HCV testing, segued in the interviews and focus groups into discussions about HCV re-testing specifically. 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 with HIV is encouraged:
“I mean why don’t we treat the potential for hep C re-infection in much the same way as ongoing HIV monitoring? We should be encouraging people who have done treatment or cleared the virus and who continue to inject drugs, to regularly get re-tested to make sure they are still hep C free and if not, we should be offering immediate re-treatment. It should just be made super-easy and normalised, not stigmatising people or blaming people for getting re-infected.” Male drug user, Western Pacific region.

Another participant also raised issues about HCV re-infection and needing to ensure that people who might come forward for HCV re-testing do not face judgments and that education about the potential for new infection following treatment should be regularly and routinely discussed as a core aspect of service delivery for people who inject drugs:

“I received HCV treatment due to a free program in the clinic and a few years later I got infected again. People’s thinking is stereotyped. We need to mention that secondary, tertiary and quaternary HCV exposure is possible, and this should be a part of the primary counselling. It is important to keep in mind all these points about re-infection and re-communication.” Female drug user, European region.

Several other participants spoke about concerns associated with coming forward for HCV RNA testing following treatment or viral clearance particularly if they are currently on OAT due to concerns about having to admit to concurrent injecting drug use and/or having that assumption made in any event, because the clinician will automatically assume they are injecting drugs because otherwise they would not need to be re-tested for presence of the hepatitis C virus. These participants discussed the risk of being ‘punished’ such as losing take home doses or even being removed from the OAT program all together. These risks they said, create significant potential barriers to people who inject drugs being willing to come forward for HCV RNA re-testing post-cure:

“It’s ridiculous, my health is being put at risk because I can’t talk to my OST prescriber about re-testing because he knows I’ve done treatment and if I’m not meant to be using, why would I need to be regularly re-tested for hep C? I can’t risk my take aways. It’s a catch-22.” Male drug user, Western Pacific region.

As discussed in more detail below, participants also highlighted that these issues draw attention to the critical importance of peer-based and community-led HCV testing and treatment services to reduce these barriers to access in the mainstream health system. Some participants also raised the issue of self-testing and how HCV RNA technologies in the self-testing/home testing space could also be an important aspect of reducing barriers to HCV RNA re-testing for people who inject drugs:
“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.

Issues about the potential risks associated with coming forward for HCV RNA re-testing were also linked to broader discussions among some participants about the entire concept of ‘willingness’ and how that can mean very different things in different contexts and depending on people’s individual circumstances. Participants 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. In this context a few participants also referred to a “double-standard” and a “set of different rules” for people who inject drugs that not only result in people feeling bad about themselves but can significantly deter people from coming forward even to access services that they know they could benefit from due to fears about potentially punitive requirements and responses:

“…because it involves drug use, there’s a different cultural landscape around that where people are more abusive around making testing recommendations, like they get turned into requirements.” Female drug user, the Americas region.

In this regard, it was made clear to participants that in asking for their views on ‘willingness’ to access HCV RNA re-testing and the frequency of such testing, that a baseline assumption was being made that all HCV testing services must be fully voluntary and based on consent. It is clear from comments made by several participants however, that these principles are not necessarily taken as ‘given’. For example, participants from a range of different contexts specifically raised questions about the nature of consent for people who inject drugs and/or felt the need to clarify that we were definitely talking about testing that would be fully voluntary and based on consent before they were willing to offer any views on willingness to access or frequency of HCV RNA re-testing:

“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.

“When I was homeless and living on the streets, they offered to test us and said they will give us R100, I only went because of the money, not the test.” Other gender non-conforming drug user, Africa region.

“When you are criminalised person informed consent is not always real, you can be made to agree to do something because you need something else more. Is that voluntary? Is that consent?” Male drug user, European region.
“Before I answer about how often, can I check that we are talking about testing that would be voluntary and with consent here right?” Gender non-binary drug user, Western Pacific region.

In relation to the issue of frequency or how often participants should be offered HCV RNA participants offered a range of potential timeframes but, it was also clear from participant responses that a majority of participants had never really given the matter much prior consideration – perhaps because they have never been formally asked their views on this issue before? Although there wasn’t really a clear consensus among those participants who expressed a specific view on willingness and frequency to be re-tested, a number of participants did state that potentially every 3 months for the first year after successfully completing treatment/clearing the virus (largely based on the window period for new infections) and then, either every 6 or 12 months after the first year might be a good approach:

“This should be done on a case by case; off the top of my head, I would say 1-3 months for the first year and once SVR is complete then twice a year.” Female drug user, the Americas region.

“I think probably they should be tested once every 3 months, as HCV can clears by itself from one’s system.” Other gender non-conforming drug user, Africa region.

“I would say everybody should be retested every three months for the first year after treatment and then once a year from there.” Male drug user, European region.

“If a person is at higher risk, he should be re-tested once every 3 months in any case, or at least once every 6 months. His willingness to take the HCV test will depend on how well he is informed about it by the outreach worker.” Female drug user, European region.

As touched on by the participant above, some participants also stressed that engagement in risk practices such as injecting drug use should be a key consideration in (re)testing protocols and a very important factor in considering what types of services, the frequency of testing and how that might be made available:

“...a person’s drug use history, I think has a big fact factor into it. You know, if we know that they’re doing good, they’re working, they’re not using, they should still get tested. But I think compared to the person that went right back to using after they finish their treatment or they never stopped using,
that’s where we’re going to find the re-infection rates.” Gender non-binary drug user, the Americas region.

“If we engage in risk behaviour daily and sharing needle, a rapid test should be available at every health care facility.” Other gender non-conforming drug user, Africa region.

As outlined above, participants also highlighted the importance of peer-based service models and developing approaches that encourage but also educate people who inject drugs about HCV (re)testing and why post-treatment monitoring is important. In the context of the comments above about the risk of punitive responses and concerns about consent, peer-based testing models were viewed as critical for a group of people who are highly criminalised, often marginalised and disaffected from the mainstream health system and frequently living in poverty:

“It all goes back to us as peers, to educate them about these things and offering incentives.” Other gender non-conforming drug user, Africa region.

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

“It if I have cured HCV and do not engage in risky behavior, then I have no need to be retested. But if a person has a risky lifestyle, then he must have access to the retesting service - but, again, what kind of access is this? If a person needs to go to the laboratory 2 times a year, pierce a vein, go through the queues and often see the disgruntled faces of nurses, then in this case the person will not go to be retested, even if it is free. And when it is SELF testing (like for HIV) or a peer worker, then people will retest at any time... Then there is no need to go to the doctors, whom we all dislike.” Female drug user, European region.

5. Health Priorities of People Who Inject Drugs

All participants were provided with visual diagram that included a framework for prioritising health interventions and were asked, with reference to this diagram to identify health concerns that are a priority for people who inject drugs and for other thoughts on the best interventions or approaches to address these concerns. In this context, the key priorities identified including:

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.

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”.

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”.

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 be fully incorporated into an approach that views 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 their health and address their health”.

Sexual Reproductive Health: was identified by participants as a priority for women who use 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 centers, run by peers. Participants again emphasised that peers are central, and community empowerment needs investment. Communicated 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.

All participants were asked about their views and preferences in relation to different HIV prevention methods and technologies including condoms and lubricant, harm reduction supplies, opioid substitution therapy, long-acting buprenorphine, post-exposure prophylaxis (PeP), pre-exposure prophylaxis (PrEP) and HIV treatment-as-prevention (U=U). Discussions commenced with a question about HIV prevention methods and technologies more broadly and then were asked a more targeted question about PrEP specifically.

a. Values & Preferences in relation to HIV Prevention Methods & Technologies

“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.

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

In addition to what can best be described as a broad consensus among study participants in relation to their views and preferences for a core set of HIV prevention methods and technologies such as NSP, harm reduction supplies, OAT and overdose prevention, a small number of participants also raised the importance of HIV prevention services remaining up-to-date. Specifically, participants from different regions also 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 that they’ll be seen and then before the know it, their children are being removed from them. So, they re-use needles and syringes all the time. But services need to be thinking about these issues and finding ways 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 ongoing problems associated with police creating barriers to people who inject drugs accessing HIV prevention services by “hanging around outside NSPs” despite policies meant to prevent this, people who inject drugs “being stopped and searched after leaving the NSP” and people who inject drugs "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.

b. Values & Preferences in relation to PrEP

Before asking participants for their views, interviewers/facilitators provided participants with some brief explanatory information about PrEP including its purpose, recommended approaches and a brief explanation of the key modalities and recent developments. Even with this background information provided, a small number of participants stated that they did not feel sufficiently informed on PrEP to offer a view in relation to values and preferences. Although this was only a small minority of participants, the responses from these participants show a reluctance to form an opinion on PrEP largely due to a lack of knowledge and may indicate the need for more information on PrEP specifically for people who inject drugs:

“I really don’t know enough about PrEP to comment or give an informed opinion really.” Female drug user, Western Pacific region.

In fact, even among the majority of participants who did feel able to comment on PrEP as a HIV prevention technology, there was still evidence of gaps in participants’ knowledge, particularly in relation to new developments in PrEP modalities. Linked to this, participants from several regions identified the need for greater education and training for community-led and peer-based services in relation to PrEP, its efficacy and how it should be made available as part of addressing the knowledge issues for people who inject drugs more broadly:

“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.

Among some of these participants, issues were also raised about unanswered questions and gaps in the research. Specifically, a number of participants raised questions and
concerns about what they thought might be gaps in the evidence-base in relation to both the efficacy and suitability of PrEP for people who inject drugs. While some of these participants are leaders in drug user-led networks and therefore arguably have more awareness of possible gaps in research, this issue was not only raised by experienced members of networks. Indeed, it could be argued that the fact that participants raised these questions at all, further indicates the need for greater discussion, education and training within drug user-led networks and their members 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, like studies anyway with people who inject drugs. I mean, 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.

Issues about the ongoing lack of research in relation to people who inject drugs and new developments in PrEP, also link to comments in the data about gaps in relation to preferences and availability. For example, several participants raised the fact that although oral PrEP is already available through community-led organisations in some contexts, other forms of PrEP such as injectable, long-acting modalities are either not available to people who inject drugs or people are unaware of its availability or how to access it. This is despite preferences for such modalities due to greater perceived efficacy, tolerability and convenience when compared to daily oral PrEP (particularly for people who find the side effects and pill burden associated with daily oral PrEP difficult to manage). Participants from Africa and European regions in particular raised concerns about the lack of availability of modalities beyond oral PrEP:

“PrEP is a solution but for us PWUDs but the side effects are too much, such as sweating. It is a 60/40 situation, but the side effects are overwhelming. If they could develop PrEP that can last for 3 months as PWUDs do not stick to the routine.” Male drug user, Africa region.

Female participants from the Eastern Europe & Central Asia region also raised issues related to more recent developments in relation to PrEP modalities including vaginal rings, but once again highlighted that despite awareness of potential HIV risks practices and interest in and preferences for these options, they are once again, either not available or women are unsure about their availability despite being approved for use and recommended by WHO. These participants highlighted the need to provide specific services for women drug users including for female sex workers and/or using novel psychoactive substances in the context of sexualised drug use:
“I think it is so. If we hypothetically assume that I get into the marathon every week from Saturday to Sunday, I get high and I have some promiscuous sex. I am aware that a condom could possibly break, and if I know I can surely take PrEP, that would be great. I can’t say that it’s very common, but if a service of this kind is possible, it would be of a great help. I have come across information before about some of the WHO recommendations: there’s a need in access to vaginal rings, especially for women who have sex work or drug users, especially for those who use new drugs. A woman can use this kind of ring before getting into a two-day marathon.” Female drug user, European region.

Further to concerns raised above, women participants also raised ethical concerns about merely giving women drug users information about the existence of PrEP without ensuring that appropriate services are available and accessible to act on that information. In addition, they highlighted how problems with the availability of medications can lead to further stigma and discrimination against people who inject drugs due to entrenched attitudes and values among health professionals about who is ‘most deserving’ of access to these technologies:

“In our region, we need to figure out about these kind of services... We provide information about PrEP, we talk about existence, but we do not offer about the access to those services, because it is not offered. Although, there are documents proving the access should be provided, but there is not enough quantity of medications, and the doctors always tell us: “Are you crazy? What kind of PrEP for drug users do you want us to provide?”” Female drug user, European region.

Despite the above problems with availability of preferred modalities and generalised concerns about the ongoing lack of research with people who inject drugs, ultimately a majority of participants across the interviews and focus group discussions expressed the view that PrEP is a potentially helpful HIV prevention intervention for people inject drugs. Participants stressed however that PrEP must be offered as part of a suite of HIV prevention approaches and alongside other interventions. In this context, these participants also raised the importance of avoiding over-medicalised and simplistic responses but rather, ensuring that interventions are delivered in ways that are context specific and take account of people’s individual needs and circumstances:

“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.
“Just be careful of the one-size-fits-all approach. Tailor the method to each individual and their context.” Male drug user, European region.

“In some circumstances PrEP might seem like over-kill, but there are other parts of the world where HIV rates are high among people who inject drugs and they don’t have access to a range of options – that’s where PrEP could be useful. It’s about individuals, the context and what else is available.” Female drug user, Western Pacific region.

In line with comments in the sections above about preferences for drug user-led and peer-based services, several participants also highlighted that community-led and peer-based responses need to be central to how PrEP is positioned and made available to people who inject drugs. Participants highlighted that structural barriers including ongoing criminalisation and high levels of stigma and discrimination mean that HIV interventions such as PrEP need to be delivered either by or in full partnership with drug user-led services to remove barriers and ensure full and informed consent. But making community-led responses central to the design and delivery of PrEP and other HIV prevention approaches requires proper support and resourcing for these community-led organisations and peer-based services – a situation that is currently inadequate globally:

“We know what our community needs and the best way to deliver an intervention like PrEP to people who inject drugs in context, and how that might work alongside NSP for example, but we need more support and resources to do that effectively.” Male drug user, Western Pacific region.

“Safe, sterile syringes first, then PrEP, if they want it!” Female drug user, North American region.

The final participant comment above, draws attention to a broader conversation that was evident in several participant transcripts in relation to the availability of PrEP for people who inject drugs and what one participant called “the elephant in the room”. Specifically, some participants were concerned about the potential for developments and discussions in relation to PrEP to distract from what they viewed as the far more pressing concern about ongoing gaps in the availability of sterile injecting equipment and other essential harm reduction supplies in many countries. For these participants, although they see PrEP as a useful HIV prevention technology that should be properly researched with people who inject drugs and then made available as appropriate, these efforts should not distract from the urgent need to address inadequate access to existing, highly efficacious, cost-effective and evidence-based HIV prevention interventions among people who inject drugs globally such as NSP and OAT.
4.0 CONCLUSION

In concluding, the first overarching point to make in relation to the findings of this research is that, regardless of whether we are discussing behavioural, bio-medical, structural interventions in relation to HIV, HCV, STIs or broader health priorities for people who inject drugs, there must be a primary focus on ensuring genuine person-centred care approaches. This means that the design, development and delivery of all interventions and approaches should be driven by what works best for and is most acceptable to the person, the individual involved. With that said, from INPUD’s perspective providing person-centred care is inextricably linked to peer-based and drug user-led approaches due to the critical role that peer workers play in reaching people and supporting them to access services. In short, peer led responses and community mobilisation are fundamental to ensuring that the design, development and delivery of interventions align with community and individual needs and priorities – they work hand-in-hand.

Furthermore, it is also clear from these findings that context and setting are also key. Specifically, in this study participants have 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. We simply cannot afford to continue to ignore or underestimate what participants have unequivocally told us in this research, which is that criminalisation is at the heart of the stigma, discrimination and violence against them. Moreover, participants have stressed that these experiences are not rare or infrequent, but rather are a pervasive, routine, and frankly relentless, aspect of their everyday realities constantly reinforced through harmful, punitive and repressive laws and policies. For too long, we have allowed these injustices and inequities to continue unabated despite longstanding evidence of how these factors diminish the capacity of people who inject drugs to access vital services and undermine their ability to protect their health and wellbeing.

Fortunately, there are opportunities to take “urgent and transformative action” to rectify this unacceptable situation. These opportunities for action come in the form of “10-10-10 Social Enabler Targets”15 that were passed as part of the UN “Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030” at the High-Level Meeting (HLM) held in New York on 8 June 2021. These targets specifically call on member states to end all inequalities faced by people living with HIV, key and other priority populations by 2025 and specifically expresses:

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"...deep concern about stigma, discrimination, violence, and restrictive and discriminatory laws and practices that target people living with, at risk of and affected by HIV... and "commit[s] to eliminating HIV-related stigma and discrimination, and to respecting, protecting and fulfilling the human rights of people living with, at risk of and affected by HIV...by creating an enabling legal environment by reviewing and reforming, as needed, restrictive legal and policy frameworks including discriminatory laws and practices that create barriers or reinforce stigma and discrimination...”16

Together, the 10-10-10 Social Enabler Targets build on other commitments in the Political Declaration and the Global AIDS Strategy including the “80-60-30 Targets” that also commit to increasing the proportion of HIV services that are led and delivered by communities including ensuring that by 2023, 60% of programs support the achievement of social enablers. These targets provide not just the impetus, but the clear basis for action in this much needed area of rights and reform for key populations including people who inject drugs.

When the participants responses to key questions in this study are taken together, what they emphasise above all else, is the right to health, that is, appropriate health services for people who inject drugs and the critical importance of listening to their values and preferences to guide services and interventions. Ultimately what is represented in this data reflects what INPUD consistently hears, which is that peer navigators are too often being asked to be part of programmes that do not want them and/or are hostile to their very presence, and where individual people who inject drugs do not wish to and are not welcome to attend. This fundamentally needs to change.

There is much talk about enabling interventions, such as peer-led responses, community mobilisation, decriminalisation and reducing and/or eliminating stigma and discrimination. INPUD of course, fully welcomes these discussions and commitments. The problem however, is how such change will be realised when we are still yet to see comprehensive access to well-accepted, cost-effective, evidenced-based HIV and HCV prevention and treatment interventions among people who inject drugs in so 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 (although this is certainly critical), 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.

5.0 APPENDIX 1: PICO QUESTIONS

This research aims to inform the key populations guidelines in relation to community values and preferences around the PICO questions for which systematic reviews have been undertaken. The relevant PICO questions are:

**PICO Q.1.** Do behavioural interventions reduce harms associated with Chemsex?

**PICO Q.2.** Do behavioural interventions reduce risk behaviours associated with HIV, STI and viral hepatitis?

**PICO Q.3.** Do peer navigators improve key population initiation and retention in HIV and viral hepatitis treatment and prevention programmes?

**PICO Q.4.** Does providing services online improve uptake of prevention, testing, linkage to treatment and treatment retention for key populations?

**PICO Q.5.** Should HCV treatment with pan-genotypic DAAs as recommended by WHO be offered immediately to people with ongoing risk behaviours and recent HCV infection (including recent HCV reinfection)?

**PICO Q.6.** How often should people with ongoing risk behaviours be retested for evidence of HCV RNA/cAg after documentation of a negative RNA/cAg test?

**PICO Q.7.** Among gay and bisexual men and other men who have sex with men, trans people and sex workers, should pooling of samples from three anatomic sites (urethra, anal and pharynx) be used for STI laboratory screening of gonorrhoea and chlamydial infection over individual samples from three anatomic sites.

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17. UNAIDS uses the following definition: Behavioural interventions for HIV prevention are applied to promote change in sexual behaviour, and to increase HIV service utilisation and adherence to HIV services and behaviours. To achieve this, they commonly address knowledge, attitudes, risk perception, norms, HIV service demand and skills. Interventions mostly include interpersonal and media communication, but they may also include financial and other incentives. Platforms for implementation can be community outreach, schools, health facilities, workplaces or other settings. See: The effectiveness of behavioural interventions to prevention HIV. A compendium of evidence. Geneva: Global HIV Prevention Coalition; 2017, updated 2019.
6.0 APPENDIX 2: SEMI-STRUCTURED INTERVIEW & FOCUS GROUP GUIDES

6.1 SEMI-STRUCTURED INTERVIEW GUIDE FOR PEOPLE WHO INJECT DRUGS

Key populations’ Values, and Preferences for HIV, hepatitis and STI services: A Qualitative Study

This interview guide is intended for generating and guiding key informant interviews with members of the community of people who inject drugs.

DISCUSSION QUESTIONS

Note to the interviewer: The order of the questions in which the questions are asked may be adapted according to the flow of conversation, but all questions should be covered in the semi-structured interviews.

BEHAVIORAL INTERVENTIONS

We would like to discuss two questions in the area of behavioral interventions with you.

Q.1. To what extent is Chemsex a concern for your community?

a. If Chemsex is a concern, what behavioral interventions would be helpful in order to reduce harms associated with Chemsex in your community?

Prompts/probes:
• Which risks are known to you in relation to Chemsex?
• Are there other ways, beyond behavioral interventions, that risks could be reduced?

Note to the interviewer: Please start by explaining the terms behavioral intervention (BI) and Chemsex. In this case, behavioral interventions refer to interventions, such as counselling and educational measures, which are aimed at reducing the risk of HIV, STI, and viral hepatitis infection by impacting on behaviors and increasing use of health services, rather than interventions aimed at reducing drug use. Interventions mostly include interpersonal and media communication but may also include financial or other incentives. Behavioral interventions typically address knowledge, attitudes, risk perception, norms, and skills.

‘Chemsex’ refers to the use of drugs during sexual activities, which are used to enhance sensations. The most commonly used drugs for Chemsex are methamphetamines, GHB/GBL, mephedrone, cocaine, and ketamine.
Q.2. Which behavioral interventions do you think could be helpful to reduce risk behaviors associated with HIV, STI and viral hepatitis?

a. Why do you think these behavioral interventions are effective?

b. How do these behavioral interventions reduce risk behaviors associated with HIV, STI, and viral hepatitis?

Prompts/probes:

- Do you think counselling is helpful?
  - Is counselling more helpful if provided in a group or individually?
  - How about health education, if this helpful?
    - If so, how do you think it should be provided?

Note to the interviewer: For this question explain that there are many ‘behavioral interventions’ which have been used in programmes to try and support safer sexual and drug injection practices. We would like to understand your community’s experiences as to what interventions have been helpful and what has not been useful.

SERVICE DELIVERY

We now would like to discuss questions that are related to how services are delivered that include questions on peer navigators, peer-led services and online services for HIV and viral hepatitis.

Q.3. In your view, what impact do peer navigators have on your community’s access to treatment, and ability to stay in prevention and treatment programmes for HIV, STI’s and viral hepatitis?

Prompts/probes:

- What characteristics make a successful peer navigator (from your community, from outside the community, older, younger etc.)?
- Are there any concerns about using peer navigators?
- When are peer navigators most impactful?

Note to the interviewer: Please explain peer navigators (PN) – PNs are community members specifically trained and educated around HIV, STIs and viral hepatitis treatment and prevention. They are not usually medically trained doctors and/or nurses, but they have undergone specific training to deliver adequate and up to date information about the treatment and prevention of HIV and viral hepatitis.
Q.4. Do community-led responses (i.e., services and programmes run and managed by people who use drugs) improve community initiation and continuation in HIV and viral hepatitis treatment and prevention programmes?

a. How do drug user-led responses affect your community’s ability to access prevention programmes?

b. How do drug user-led responses affect your community’s ability to stay in treatment?

c. How important is it for you that services and programmes for HIV, STI, and viral hepatitis treatment and prevention are drug user-led?

Prompts/probes:
- What are the important components of drug user-led services (for example training and support, link to other services, confidentiality measure in place etc.)?

Note to the interviewer: Please use the recent definition of community-led responses as developed by UNAIDS or refer to the INPUD/UNODC ‘Implementing Comprehensive HIV and HCV Programmes for People who Inject Drugs for further information.

Q.5. What are your thoughts on people who use drugs’ using online tools and platforms to access services for HIV, STIs and hepatitis?

a. How does (or could) the use of online tools affect your community’s access to services?

b. How does (or could) the use of online tools affect your community’s ability to stay in treatment?

Prompts/probes:
- What are the key advantages and disadvantages of face-to-face interventions compared with digital interventions?
- Which types of online tools and/or platforms would be most useful?

STRUCTURAL BARRIERS AND ENABLING INTERVENTIONS

Next, we would like to ask about interventions which are aimed at addressing structural barriers to accessing health services faced by people who inject drugs, such as criminalisation, stigma and discrimination, and violence. These interventions can include law reform, community empowerment initiatives, and violence prevention measures which aim to address the structural causes of vulnerability.

Q.6. How does criminalization of drug use affect your community’s access to services and ability to stay in treatment for HIV, STIs and viral hepatitis?

a. How do other forms of criminalization, such as the criminalization of sexual orientation, gender identity, and drug use affect your community’s access to services and ability to stay in treatment?
Q.7 Which enabling interventions could help address structural barriers to accessing services for people who inject drugs?

a. What impact do community empowerment initiatives have on access to services for HIV, STIs, and viral hepatitis? Which types of community empowerment initiatives are most impactful, and why?

Prompts/probes:
Why do you think (either) decriminalization/stigma and discrimination/addressing violence/community empowerment initiatives would help address barriers to service access?

Note to interviewer: Explain that WHO has four recommendations for enabling interventions that address structural barriers which affect key populations and their access to health services: combating criminalization, stigma and discrimination and violence and to support community empowerment.

Q.8. What kinds of impact does stigma and discrimination have on people who inject drugs’ access to prevention, testing and linkage to treatment, as well as their ability to stay in treatment?

HEPATITIS C TESTING AND TREATMENT
We would like to discuss two questions in the area of Hep C Testing and Treatment

Q.9. Do you think people who inject drugs who have recently contracted HCV (including recent re-infections) should be offered HCV DAA treatment immediately?

a. Do you think people who inject drugs who engage in ongoing risk behaviors should be offered this type of treatment?

Prompts/probes:
• Why or why not do you think this treatment should be offered immediately to people who inject drugs?
• What are the barriers for people who inject drugs to receive this treatment?
• Are there any concerns about offering immediate HCV DAA treatment?
• What other services should be provided along with treatment?

Note to interviewer: Before asking the question on HCV DAA treatment (Q.9 above) explain that pan-genotypic direct acting antivirals (DAA) is a new generation of DAA that treat a broader range of different strains of Hep C infection. Some of these new regimens have higher cure rates, good tolerability (low side-effects), low pill burden and less drug interactions. WHO recently updated its guidelines to recommend pan-genotypic DAA's
for chronic HCV infection. Also explain that due to developments in HCV treatment, WHO is now assessing the possibility to recommend offering immediate treatment to people upon diagnosis, as well as for those who continue to be at risk of (re-)infection and transmission. One of the concerns with this approach is that may include some level of overtreatment as some people may clear the virus without treatment.

**Q.10.** How often do you think people who inject drugs who engage in on-going HCV risk behaviors and have been previously treated for HCV or cleared HCV without treatment should be re-tested for the presence of the hepatitis C virus in their blood (viremia or RNA PCR testing)?

Prompts/probes:
- Do you think people would be willing to be re-tested regularly? If so, how frequent/how often should this viremia re-testing occur?
- Are there any concerns about viremia re-testing?
- What other services or supports should be available along with viremia re-testing?

*Note to interviewer:* Before asking the question on HCV viremia re-testing (Q.10 above) explain that HCV is an RNA virus. It is increasingly recommended that people who have been treated and cured or have cleared HCV without treatment be re-tested for the presence of hepatitis C virus in their blood regularly (this is called a viremia or RNA PCR test). Although this approach is increasingly being recommended, access to viremia testing is not always available particularly in low-threshold and community-led services, etc.

**PRIORITIES OF PEOPLE WHO INJECT DRUGS**

**Q.11.** Which health concerns are a priority for your community?

Prompts/probes
- Why are these a priority?
- What interventions or approaches are best to address these concerns?

*Note to interviewer:* To guide this discussion please refer to the priorities outlined in Figure 4. the Interview Protocol

**HIV PREVENTION**

Next, we would like to ask you about your thoughts on different HIV prevention methods and technologies. These may include: condoms and lubricant, harm reduction supplies for people who inject drugs, opioid substitution therapy, long-acting buprenorphine for people who inject drugs, post-exposure prophylaxis (PEP), pre-exposure prophylaxis (PrEP), and HIV treatment-as-prevention.
Q.12. Which HIV prevention technologies should be offered to people who inject drugs in all settings?

a. What are the advantages and disadvantages of the different HIV prevention technologies for people who inject drugs?

Prompts/probes
- Where should these technologies be made available, and why? (e.g., medical facility/health clinic, community-based facility, pharmacy, peer outreach delivery, other)
- What barriers do your community experience to accessing and using different HIV prevention technologies?

Note to interviewer: Provide definitions of the various methods, as necessary.

Depot-bupe is a new long-acting formulation of buprenorphine. There are two forms which come as injectables or as subcutaneous (under the skin) injections, which slowly release buprenorphine into the body. Though they are not currently available everywhere, they are being promoted in some settings, so it is important to collect values and preferences on this medication.

PrEP
Finally, I will now move on to discuss some questions with regards to pre-exposure prophylaxis and some recent developments in this area.


a. If your community has identified PrEP as a suitable HIV prevention technology for people who inject drugs, how would offering a range of PrEP modality options impact on the use and uptake of PrEP amongst people who inject drugs?

Prompts/probes
- What are the potential advantages and disadvantages of different PrEP dosing strategies and formulations for people who inject drugs?
- Where would your community prefer PrEP services be delivered, and why? (e.g., medical facility/health clinic, community-based delivery, pharmacy, other)

Note to interviewer: Please explain – Pre-exposure prophylaxis (PrEP) is the use of anti-retroviral drugs by HIV-negative individuals to reduce the chances of an HIV infection. WHO recommends daily oral PrEP containing tenofovir as an additional prevention choice for key populations since 2015 but is not currently widely used amongst people who inject drugs. Some prior concerns have been raised about acceptability, feasibility and suitability for people who inject drugs.
PrEP can be delivered in multiple ways, or modalities. These modalities include oral daily PrEP, event-driven PrEP (taken after an event which may lead to HIV transmission), injectable long-acting PrEP, and the Dapivirine vaginal ring.

The dapivirine vaginal ring (DVR) is a product which is inserted into the vagina to provide HIV protection for one month is approved for use and WHO recommends it as an additional option for ‘anyone at substantial risk’.

Long-acting injectable Cabotegravir (CAB-LA) is an injectable modality of PrEP. Recent studies CAB-LA to be superior to oral PrEP at preventing HIV acquisition in cis-gender gay and bisexual men and transwomen and cisgender adult women.

Event-driven PrEP involves taking a higher dose of oral PrEP before sex or drug use, followed up by a fixed schedule of follow up dosing. This means people can take this medication occasionally prior to a potential risk. Based on a lack of research, event-driven PrEP has not been recommended for people who inject drugs.

All options, oral PrEP, event-driven PrEP, the long-acting injectable and the Dapivirine vaginal ring have unfortunately not been tested and researched enough in people who inject drugs.

**CLOSING**

*Ask participants if there is anything else on the above topics they haven’t yet had a chance to say and would like to add before closing the interview.*
6.2 FOCUS GROUP GUIDE FOR PEOPLE WHO INJECT DRUGS

Key populations’ Values, and Preferences for HIV, hepatitis and STI services: A Qualitative Study

This focus group guide is intended for generating and guiding focus group discussions with members of the community of people who inject drugs

DISCUSSION QUESTIONS

Note to the moderator: The order of the questions in which the questions are asked may be adapted according to the flow of conversation, but all questions should be covered in the focus group discussions.

BEHAVIORAL INTERVENTIONS:

We would like to discuss two questions in the area of behavioral interventions with you all.

Q.1. To what extent is Chemsex a concern for you?

a. If Chemsex is a concern, which behavioral interventions would be helpful in order to reduce harms associated with Chemsex in your community?

Prompts/probes:
- Which risks are known to you in relation to Chemsex?
- Why do you think these behavioral interventions (discussed above) are helpful?
- Which behavioral interventions are not helpful?
- Are there other ways, beyond behavioral interventions, that risks could be reduced?

Note to the moderator: Please start by explaining the terms behavioral intervention (BI) and Chemsex. In this case, behavioral interventions refer to interventions, such as counselling and educational measures, which are aimed at reducing the risk of HIV, STI, and viral hepatitis infection by impacting on behaviors and increasing use of health services, rather than interventions aimed at reducing drug use. Interventions mostly include interpersonal and media communication but may also include financial or other incentives. Behavioral interventions typically address knowledge, attitudes, risk perception, norms, and skills.

‘Chemsex’ refers to the use of drugs during sexual activities, which are used to enhance sensations. The most commonly used drugs for Chemsex are methamphetamines, GHB/GBL, mephedrone, cocaine, and ketamine.
Q.2. Which behavioral interventions do you think could be helpful to reduce risk behaviors associated with HIV, STI and viral hepatitis?

a. Why do you think these behavioral interventions are effective?

b. How do these behavioral interventions reduce risk behaviors associated with HIV, STI, and viral hepatitis?

Prompts/probes
• Do you think counselling is helpful?
  • Is counselling more helpful if provided in a group or individually?
  • How about health education, if this helpful?
  • If so, how do you think it should be provided?

Note to the moderator: For this question explain that there are many ‘behavioral interventions’ which have been used in programmes to try and support safer sexual and drug injection practices. We would like to understand your community’s experiences as to what interventions have been helpful and what has not been useful.

SERVICE DELIVERY
We now would like to discuss questions that are related to how services are delivered that include questions on peer navigators, peer-led services and online services for HIV and viral hepatitis

Q.3. In your view, what impact do peer navigators have on your community’s access to treatment, and ability to stay in prevention and treatment programmes for HIV, STI’s and viral hepatitis?

Prompts/probes
• What characteristics make a successful peer navigator (from your community, from outside the community, older, younger etc.)?
• Are there any concerns about using peer navigators?
• When are peer navigators most impactful?

Note to the moderator: Please explain peer navigators (PN) – PNs are community members specifically trained and educated around HIV, STIs and viral hepatitis treatment and prevention. They are not usually medically trained doctors and/or nurses, but they have undergone specific training to deliver adequate and up to date information about the treatment and prevention of HIV and viral hepatitis.
Q.4. Do drug user-led responses (i.e., services and programmes run and managed by people who use drugs) improve community initiation and continuation in HIV and viral hepatitis treatment and prevention programmes?

a. How do drug user-led responses affect your community’s ability to access prevention programmes?

b. How do drug user-led responses affect you and your community’s ability to stay in treatment?

c. How important is it for you that services and programmes for HIV, STI, and viral hepatitis treatment and prevention are drug user-led?

Prompts/probes
• What are the important components of drug user-led services (for example training and support, link to other services, confidentiality measure in place etc.)?

Note to the moderator: Please use the recent definition of community-led responses as developed by UNAIDS or refer to the INPUD/UNODC ‘Implementing Comprehensive HIV and HCV Programmes for People who Inject Drugs for further information.

Q.5. What are your thoughts on people who use drugs’ using online tools and platforms to access services for HIV, STIs and hepatitis?

a. How does (or could) the use of online tools affect your access to services?

b. How does (or could) the use of online tools affect your ability to stay in treatment?

Prompts/probes
• What are the key advantages and disadvantages of face-to-face interventions compared with digital interventions?
• Which types of online tools and/or platforms would be most useful?

STRUCTURAL BARRIERS AND ENABLING INTERVENTIONS

Next, we would like to ask about interventions which are aimed at addressing structural barriers to accessing health services faced by people who inject drugs, such as criminalisation, stigma and discrimination, and violence. These interventions can include law reform, community empowerment initiatives, and violence prevention measures which aim to address the structural causes of vulnerability.

Q.6 How does criminalization of drug use affect your access to services and ability to stay in treatment for HIV, STIs and viral hepatitis?

a. How do other forms of criminalization, such as the criminalization of sexual orientation, gender identity, and drug use affect your access to services and ability to stay in treatment?
Q.7 Which enabling interventions could help address structural barriers to accessing services for people who inject drugs?

a. What impact do community empowerment initiatives have on access to services for HIV, STIs, and viral hepatitis?

b. Which types of community empowerment initiatives are most impactful, and why?

Prompts/probes
- Why do you think (either) decriminalization/stigma and discrimination/addressing violence/community empowerment initiatives would help address barriers to service access?

Note to moderator: Explain that WHO has four recommendations for enabling interventions that address structural barriers which affect key populations and their access to health services: combating criminalization, stigma and discrimination and violence and to support community empowerment.

Q.8. What kinds of impact does stigma and discrimination have on people who inject drugs’ access to prevention, testing and linkage to treatment, as well as their ability to stay in treatment?

HEPATITIS C TESTING AND TREATMENT

We would like to discuss two questions in the area of Hep C Testing and Treatment

Q.9. Do you think people who inject drugs who have recently contracted HCV (including recent re-infections) should be offered HCV DAA treatment immediately?

a. Do you think people who inject drugs who engage in ongoing risk behaviors should be offered this type of treatment?

Prompts/probes
- Why or why not do you think this treatment should be offered immediately to people who inject drugs?
- What are the barriers for people who inject drugs to receive this treatment?
- Are there any concerns about offering immediate HCV DAA treatment?
- What other services should be provided along with treatment?

Note to moderator: Before asking the question on HCV DAA treatment (Q.9 above) explain that pan-genotypic direct acting antivirals (DAA) is a new generation of DAA that treat a broader range of different strains of Hep C infection. Some of these new regimens have higher cure rates, good tolerability (low side-effects), low pill burden and less drug
interactions. WHO recently updated its guidelines to recommend pan-genotypic DAA’s for chronic HCV infection. Also explain that due to developments in HCV treatment, WHO is now assessing the possibility to recommend offering immediate treatment to people upon diagnosis, as well as for those who continue to be at risk of (re-)infection and transmission. One of the concerns with this approach is that may include some level of overtreatment as some people may clear the virus without treatment.

Q.10. How often do you think people who inject drugs who engage in on-going HCV risk behaviors and have been previously treated for HCV or cleared HCV without treatment should be re-tested for the presence of the hepatitis C virus in their blood (viremia or RNA PCR testing)?

Prompts/probes
- Do you think people would be willing to be re-tested regularly? If so, how frequent/how often should this viremia re-testing occur?
- Are there any concerns about viremia re-testing?
- What other services or supports should be available along with viremia re-testing?

Note to moderator: Before asking the question on HCV viremia re-testing (Q.10 above) explain that HCV is an RNA virus. It is increasingly recommended that people who have been treated and cured or have cleared HCV without treatment be re-tested for the presence of hepatitis C virus in their blood regularly (this is called a viremia or RNA PCR test). Although this approach is increasingly being recommended, access to viremia testing is not always available particularly in low-threshold and community-led services, etc.

HEALTH PRIORITIES OF PEOPLE WHO INJECT DRUGS

Q.11. Which health concerns are a priority for your community?

Prompts/probes
- Why are these a priority?
- What interventions or approaches are best to address these concerns?

Note to moderator: To guide this discussion please refer to the priorities outlined in Figure 4, the Interview Protocol

HIV PREVENTION

Next, we would like to ask you about your thoughts on different HIV prevention methods and technologies. These may include: condoms and lubricant, harm reduction supplies for people who inject drugs, opioid substitution therapy, long-acting buprenorphine for people who inject drugs, post-exposure prophylaxis (PEP), pre-exposure prophylaxis (PrEP), and HIV treatment-as-prevention (U=U).
Q.12. Which HIV prevention technologies should be offered to people who inject drugs in all settings?

a. In your opinion, what are the advantages and disadvantages of the different HIV prevention technologies for people who inject drugs?

Prompts/probes
- Where should these technologies be made available, and why? (e.g., medical facility/health clinic, community-based facility, pharmacy, peer outreach delivery, other)
- What barriers do you experience to accessing and using different HIV prevention technologies?

Note to moderator: Provide definitions of the various methods, as necessary.

Depot-bupe is a new long-acting formulation of buprenorphine. There are two forms which come as injectables or as subcutaneous (under the skin) injections, which slowly release buprenorphine into the body. Though they are not currently available everywhere, they are being promoted in some settings, so it is important to collect values and preferences on this medication.

PrEP

Finally, I will now move on to discuss some questions with regards to pre-exposure prophylaxis and some recent developments in this area.

Q.13. In your opinion, is PrEP a suitable HIV prevention method for people who inject drugs?

a. If you have identified PrEP as a method you would like to use, how would offering a range of PrEP modality options impact on your use and uptake of PrEP?

Prompts/probes
- What do you think are the potential advantages and disadvantages of different PrEP dosing strategies and formulations for people who inject drugs?
- Where would you prefer that PrEP services be delivered, and why? (e.g., medical facility/health clinic, community-based delivery, pharmacy, other)

Note to the moderator: Please go into more detail on the different PreP methods as necessary.

Pre-exposure prophylaxis (PrEP) is the use of anti-retroviral drugs by HIV-negative individuals to reduce the chances of an HIV infection. WHO recommends daily oral PrEP containing tenofovir as an additional prevention choice for key populations since
2015 but is not currently widely used amongst people who inject drugs. Some prior concerns have been raised about acceptability, feasibility and suitability for people who inject drugs.

PrEP can be delivered in multiple ways, or modalities. These modalities include oral daily PrEP, event-driven PrEP (taken after an event which may lead to HIV transmission), injectable long-acting PrEP, and the Dapivirine vaginal ring.

The dapivirine vaginal ring (DVR) is a product which is inserted into the vagina to provide HIV protection for one month is approved for use and WHO recommends it as an additional option for ‘anyone at substantial risk’.

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All options, oral PrEP, event-driven PrEP, the long-acting injectable and the Dapivirine vaginal ring have unfortunately not been tested and researched enough in people who inject drugs.

**CLOSING**

Ask participants if there is anything else on the above topics they haven’t yet had a chance to say and would like to add before closing the interview.
INPUD wishes to acknowledge and thank all the individuals who participated in this study either as key informants or focus group participants. INPUD would also like to acknowledge and thank the Regional Focal Points (RFPs), community researchers and drug user networks who acted in a consultancy capacity to organise and conduct the semi-structured key informant interviews and the regional focus group discussions and summarised and coded the data collected. As a global peer-based network, INPUD is only as strong as its community of people who use drugs. We thank all of the participants, RFPs and community researchers for their work and contributions to this study and in building our understanding of these key issues for our global community.