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Values and Preferences Study
Communicable Diseases and People Who Use Drugs in Europe

Community-Led Monitoring &
Services Development Focus Group Discussions

European Network of People who Use Drugs
February 2024

Grant Agreement #: 101079910
D2.7: Summary focus group report
T2.10: Analyse data and prepare report

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Representing the interests of people who use drugs in Europe. EuroNPUD promotes the health and defends the rights of people who use drugs in the European Union and its neighbouring countries through self-organising, developing technical resources, capacity strengthening, and advocacy.

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Recognition of peers

Thank you to the peers who participated in the Focus Group Discussions and who shared with us their living and lived experiences, perspectives, and insights.
Without their valuable contributions this project would not be possible.

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Contents

Tables of figures

Abbreviations

cis	cisgender
DAAs	direct-acting antivirals
DCRs	drug consumption rooms (overdose prevention sites)
ECDC	European Centre for Disease Prevention and Control
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EuroNPUD	European Network of People Who Use Drugs
FGDs	focus group discussions
HCV	hepatitis C virus
HIV	human immunodeficiency virus
INPUD	International Network of People Who Use Drugs
NGO	non-government organisation
NSP	needle-syringe programme
OAMT	opiate agonist maintenance therapy
PLHIV	person/people living with HIV
PEP	post-exposure prophylaxis
PLHCV	person/people living with HCV
PWID	person/people who inject drugs
PrEP	pre-exposure prophylaxis
PWUD	person/people who uses drugs
STIs	sexually transmissible infections
TB	tuberculosis disease
trans	trans and gender diverse
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Introduction

The EU4Health Boost Project aims to enhance the implementation of high-quality, community-based, and community-led communicable disease services. Our harm reduction approach is comprehensive, people-centred, and integrated.

Objective

To assess the practice and quality of community-based and community-led communicable diseases (Human Immunodeficiency Virus (HIV), viral hepatitis, sexually transmissible and – where relevant – tuberculosis) testing and linkage to care services for People Who Use Drugs (PWUD) in Europe.

- obtain an up to date overview of testing and good practices in harm reduction organisations;
- maintain and extend civil society monitoring of harm reduction to generate complementary information on integrated harm reduction initiatives, and
- assess awareness of, attitudes towards, satisfaction with, and barriers to testing at harm reduction service organisations among PWUD.

Task outline

Develop and prepare focus groups with PWUD and are at risk from HIV and / or viral hepatitis in the countries of the four (n=4) Lighthouse Project implementations (Belgium, Czechia, Finland, and Italy).

- recruit and train focus group facilitators and peer recruiters in consultation with partners;
- deliver focus groups;
- compile and analyse feedback from the different focus groups:
- peer facilitators from the different focus groups meet virtually to compar feedback from peers in different countries identifying common themes and issues;
- summarise findings and recommendations from focus groups, and
- discuss results with stakeholders in the different countries via video consultations.

Methodology

Development and planning

A model for the delivery of the focus groups was devised. Roles and responsibilities were developed and assigned. EuroNPUD allocated four Technical Coaches from its Executive to guide the delivery of the Focus Group Discussions (FGD) in the four (n=4) countries with Lighthouse Projects implementations (Belgium, Czechia, Finland, and Italy). The Technical Coaches each supported the delivery of the FGD in one country, guiding the work on the Country Team: Country Focal Point and Country Note Taker.

A FGD guide (see Appendix A – Focus Group Discussion Guide) was developed and was informed by Australian peer, activist, and researcher Dr Annie Madden and her values and preferences research methodologies among PWUD.[1] The discussion guide provided four major topics of interest: (1) access to harm reduction equipment and safer sex supplies; (2) Access to testing for HIV, hepatitis C (HCV), sexually transmissible infections (STIs), and tuberculosis (TB); (3) access to Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP); and access to treatment for HIV, HCV, STIs, and TB.

Country preparation meetings were held between the Technical Coaches and the Country Teams. Country Teams were provided a slide presentation (see Appendix B – Technical Guidance and Coaching for Country Focal Points) containing a) an overview of the focus group discussion and recruitment strategy; b) invitation letter for participants; c) outline of country roles and responsibilities; and d) FGD guide.

1 For example, Annie Madden, et al, 'Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia', Harm Reduction Journal 15(42) (2018). DOI: 10.1186/s12954-018-0248-4; International Network of People who Use Drugs (INPUD), Key Populations' Values and Preferences for HIV, Hepatitis and STI Services: A qualitative study, (Report, 2021) <inpud.net/key-populations-values-and-preferences-for-hiv-hepatitis-and-sti-services-a-qualitative-study/>.

Roles and responsibilities

Technical Coaches were responsible for project management, capacity-building, support, and technical advice on the delivery of the FDG in their allocated countries.
Country Focal Points were responsible for logistics, conducting research participant consent, and conducting the FDG.
Country Note Takers were responsible for taking notes in their home country language and then Google Translate to translate notes into English.

Recruitment

Purposive recruitment strategies were undertaken involving homogeneity (location specific PWUD), snowball (peers recruit participants from their networks), max variation (diversity of gender and living experiences), and opportunistic (peers connected to a service). Country Focal Points were instructed to recruit a cross section of participants: people who inject drugs (PWID) and PWUD: stimulants and sexualised drug use/chemsex; key populations such as women (cis and trans), sex workers, people living with HIV (PLHIV), people living with hepatitis C (PLHCV), people who have treated HCV, etc. A letter template was provided for country partners to provide to potential peer participants.

Conducting the focus group discussions

Peer participants were allocated a number by the Country Note Taker. The Country Focal Point along with a record of informed consent and basic demographic details (gender, drug use preferences and patterns, and whether they were accessing treatment).

Variations (fidelity)

Belgium

Participants were recruited through a low-threshold service that provides harm reduction services and OAMT through direct invitation and posters displayed in the service. A financial incentive of 20-euro dollars (€20) were provided to participants for their contributions and time.

Czechia

Participants were recruited through existing networks of the Country Focal Point using word-of-mouth and snowball strategies (participants were encouraged to bring peers from their networks). A financial incentive of 20-euro dollars (€20) and refreshments were provided to participants for their contributions and time. The FGD ran for a total of 90 minutes.

Finland

Participants were recruited through a low-threshold service that provides harm reductions services, communicable diseases testing, and food relief to PWUD. A financial incentive of 20-euro dollars (€20) and refreshments were provided to participants for their contributions and time. The FDG ran for a total of 60 minutes.

Italy
Recruitment was led by our contact at the NGO Partner, instructed to recruit indiscriminately and with a mix of genders. The venue was selected by the NGO Partner to ensure privacy, safety, the convenience of the location to PWUD, and to ensure participants felt welcome. The person assigned to the role of Country Note Taker, was not available on the day of the FGD, and so a participant volunteered to take on the role. A financial incentive of 20-euro dollars (€20) and refreshments were provided to participants for their contributions and time. The FDG ran for a total of 90 minutes.

Data validation and analysis

Independently, the Technical Writer checked the English notes against the home language notes for comprehension for Czechia and Italy. A descriptive analysis based on the Country Notes was written. The Technical Writer validated the descriptive analysis with the Country Team for each setting via online videoconference.
The Technical Writer also developed a debrief discussion guide as a quasi-process evaluation of the FDG and community-led monitoring approach (see Appendix C – FGD Debrief Discussion Guide). The process evaluation discussion was conducted within the online videoconference debrief with the Country Teams for Belgium, Czechia, and Finland. For Italy, the Technical Writer and Country Focal Point exchanged voice and text messages asynchronously via Facebook Messenger.

Terminology/definitions used in this report

We used the following definitions as the basis for programming discussed in the FGDs and this report. The definitions are informed by the UNAIDS Terminology Guidelines (2015),[2] the European Centre for Disease Control's and European Monitoring Centre for Drugs and Drug Addiction's Interagency Guidance (2023),[3] and the UNAIDS indicator for needles and syringes distributed per PWID.[4]

Harm reduction equipment and safer sex supplies
Provide sterile needles and syringes, stimulant inhalation kits, and other drug preparation equipment (cookers, filters, and water for injection), including in prisons and through pharmacies; condoms and lubricant; OAMT, including in prisons provide NSP in combination with OAMT.

2 UNAIDS, 'UNAIDS Terminology Guidelines', (Report, 2015) <https://www.unaids.org/en/resources/documents/2015/2015_terminology_guidelines>.

3 European Centre for Disease Prevention and Control and European Monitoring Centre for Drugs and Drug Addiction. Prevention and control of infectious diseases among people who inject drugs: 2023 update, (Report, 2023), <https://www.ecdc.europa.eu/en/publications-data/prevention-and-control-infectious-diseases-among-people-who-inject-drugs-2023>.

4 'Needles and syringes distributed per person who injects drugs', HIV Indicators Registry, UNAIDS (Webpage, 2023), <https://indicatorregistry.unaids.org/indicator/people-who-inject-drugs-prevention-programmes>.

Testing for communicable diseases

Routinely offer voluntary, confidential testing with informed consent for HCV and HIV, HBV to those with no/incomplete vaccination, STIs (e.g. syphilis, chlamydia, gonorrhoea) to those with STI symptoms and/or those with higher risk (e.g. multiple sexual partners, sex work), TB for those with TB signs and symptoms, and/or those with higher risk (e.g. have an exposure or predisposing underlying condition). People diagnosed positive are linked to care and treatment.

PrEP and PEP

PrEP for HIV should be accessible and affordable to all people in need of HIV prevention, where clinically appropriate, as part of combination prevention services. PrEP is highly effective in preventing sexual transmission of HIV, acknowledging that injecting risk and risk associated with multiple sexual contacts or sex work may overlap. PEP for HIV and STIs should also be available.

Treatment for communicable diseases

Offer antiviral treatment for those who are diagnosed with HCV; antiretroviral treatment for those diagnosed with HIV; anti-TB treatment to those with TB disease; TB preventive treatment for people with TB infection after ruling out TB disease; and treatment for STIs and bacterial skin infections. Ensure there is cooperation between service providers dedicated to PWID communicable diseases care to increase linkage to care; and involve peer mentors to increase adherence to HCV treatment.

Needles and syringes distributed per PWID

The total number of needles and syringes distributed per PWID per year (PPPY), based on population estimate of PWID for that country.

- low coverage: less than n=100 syringes PPPY;
- medium coverage: between n=100–200 syringes PPPY; and
- high coverage: greater than n=200 syringes PPPY.

Results

Summary Infographic

harm reduction equipment & safer sex supplies

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
	MED	HIGH	HIGH	LOW
	▪▪▪	▪▪▪	▪▪▪	V
	V	▪▪▪	V	V
	▪▪▪	▪▪▪	▪▪▪	▪▪▪
	?	?	?	▪▪▪
	▪▪▪	▪▪▪	▪▪▪	▪▪▪

communicable diseases testing

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
	V	V	HCV ONLY	V
	V	▪▪▪	?	V
	V	V	▪▪▪	▪▪▪
	?	▪▪▪	▪▪▪	?
	–	–	▪▪▪	▪▪▪

legend

- V — accessible & available
- ▪▪▪ — study result
- X — not applicable
- ? — was not discussed
- access to fibroscan
- blood test for HCV, HIV, STIs
- conditional/ restricted access to DAAs
- condoms & lubricant
- cost barriers e.g. pharmacies
- gender-based barriers (structural)
- geographical barriers
- inhalation/ smoking kits
- level of know-ledge about PrEP & PEP
- needle & syringe programmes access
- peer support
- rapid or dry-blood spot test for HCV, HIV
- self-test options for HCV, HIV, STIs
- stigma & discrimination barriers
- universal access
- urine & swab tests for STIs
- woman
- men
- gender-diverse

PrEP & PEP

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
	LOW	LOW	LOW	LOW
	V	V	V	V

treatment for HCV, HIV & STIs

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
	V	V	...	...
	V	V	V	...
	V	V		

gender & no. of peer participants

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
♀	1	3	2	1
♂	5	2	7	14
⚧	-	-	-	-
TOTALS	6	5	9	15

stigma & discrimination

	Antwerp BELGIUM	Brno CZECHIA	Helsinki FINLAND	Rome ITALY
	...	...	...	...

Belgium

Country Focal Point — Anton Van Dijck
Country Note Taker— Independent researcher in medical sciences
Country Coach — Mat Southwell

The FGD was conducted in Antwerp, Belgium and provides a snapshot of the experiences, perspectives, insights, and knowledge of PWUD in Antwerp. Eleven (n=11) peers were recruited and of those, six (n=6) attended the FGD. The FGD was moderated by health promotion workers from the GIG-Project whose background was research on substance use and policy. One (n=1) of the peers was a woman and five (n=5) were men. Peers told us they had lived experience of injecting heroin and other opiates, as well as stimulants like amphetamines and cocaine. All peers had lived experience of HCV and HCV treatment, and some peers were enrolled in OAMT programmes.

Access to harm reduction equipment in Antwerp

Peers told us that they had access to a range of harm reduction equipment, available from needle and syringe programmes and that access had improved compared to the past. Some peers criticised distribution thresholds when not exchanging used injecting equipment for unused equipment. We heard that peers valued NSPs, and the anonymity and confidentiality of the service provided.
Peers conveyed the need for drug consumption rooms (DCRs), prescription heroin (hydromorphone), drug-checking services, and distribution of naloxone to reduce overdose risk for people who use opiates.

> “ Antwerp houses the second biggest port in Europe and therefore is called the economic centre of Flanders, the northern part of Belgium. Traditionally, Antwerp has always been a socialist city. However, this changed in 2016, when Bart De Wever of the nationalist Flemish party, became the mayor of Antwerp and subsequently called for a harsher policy on drugs, literally referred to as a ‘War on Drugs’. ”

We heard that stigma and discrimination are barriers to accessing harm reduction equipment and services, as well as the impact of local ‘war on drugs’ laws and policies.[5] Peers told us that the policies have led to an escalation of street violence by organised crime and greater police presence on the streets profiling and surveilling PWUD. Police actions attempting to break solidarity among PWUD has limited the ability of PWUD to meet in public and use the public domain.

5 For example, Barbara Moens, ‘Belgium’s most powerful politician has a drugs problem’, Politico, (Webpage, 11 January 2020) <https://www.politico.eu/article/belgium-most-powerful-politician-drugs-problem-bart-de-wever/>.

Testing for HIV, hepatitis C, and STIs in Antwerp

Peers told us that HIV and HCV testing services were provided by Free Clinic and other health services that offered rapid HIV / dry-blood spot testing for HIV and HCV. We heard that since DAA treatments became available, testing for HCV has been intensified.

Peers conveyed their high satisfaction with HCV testing, access, state-of-the-art methods, and (in many cases) near instant results delivered to PWUD (speaking about rapid tests). We heard that there could be more public awareness of HCV, for example, tough public health messages and social marketing. Peers highly valued C-Buddy project and being able to get tested for HCV at any time of day met peer's preferences.

Access to PrEP and PEP in Antwerp

Nearly all peers had no knowledge of PrEP and PEP. One peer had broad knowledge of PrEP. There was a discussion about the potential benefits and risk of PrEP and PEP.

Access to treatment in Antwerp

Peers told us that they had access to HCV treatment, particularly in Flanders where treatment was provided at no-cost to individuals. Peers valued that access to HCV treatment was inclusive of all PWUD, irrespective of their patterns of drug use. We heard that although initially restricted to those with advanced cirrhosis of the liver, DAAs were accessible irrespective of liver function. One peer who had cleared HCV using the interferon-based treatments reflected that he may have waited for treatment if he knew DAAs and their benefits were going to be an option for treatment.

> " I would have waited if I had seen what is possible nowadays "

Peers unanimously valued the role of peer support tough the entire care cascade, specifically the C-Buddy project, and the project's ability to adapt to the local circumstances, setting, and context. Many peers reflected that they could not have finished HCV treatment without the peer support from the C-Buddy project.

> " I couldn't have done it without the buddies "

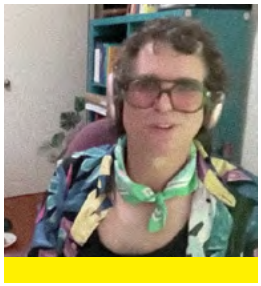
There was a strong preference among peers for health care practitioners, nurses, and services that were friendly, warm, and without judgement. One peer commented it was like a "breath of fresh air" when referring to non-stigmatising services.

Process, experience, and efficacy of FGD in Antwerp

The Country Focal Point was experienced at conducting FGD and qualitative research interviews with PWUD – these previous professional experiences enabled effective conduct of the FGD. The peers were known to the Country Focal Point, which facilitated instant rapport and trust. Privacy, confidentiality, anonymity, and safety were emphasised and prioritised so that peers felt they could contribute without fear of disclosure outside of the FGD. These values were important due to the drug policies and their negative impacts on PWUD in Antwerp and Flanders.

The Country Focal Point reflected that they expected the peers to have a higher level of knowledge and awareness of PrEP and PEP, due to separate work with gay, bi+, and men who have sex with men and chemsex (sexualised drug use) where there is a high level of health literacy about ART-based prevention of HIV. However, the Country Focal Point posited that effectiveness of PrEP and PEP for condomless sex is far greater than that for injecting-related risk of HIV, which may account for differences in knowledge between key populations.

When considering what could have been done differently, we heard that increasing the heterogeneity of the participants would be necessary to ensure a cross section of PWUD were represented in the FGD. This could be achieved by inviting more participants (assuming 30% will turn up to the FGD), reaching into different networks and settings, as well as working in partnership with peer-based NGOs for key populations that intersect with PWUD. The peers were thoughtful and respectful of each other and contributed equitably to the discussion. We heard that the material incentive was appropriate and not insignificant for the peers. Participants were grateful for having been involved and indicated interest in attending future FGDs and consultations, demonstrating acceptability of CLM processes for PWUD.



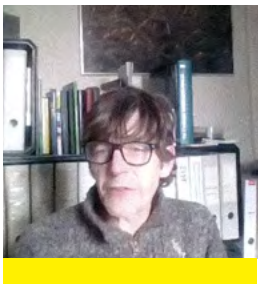


Figure 1:
Anton & Joël during the FGD debrief for Antwerp

Czechia

Country Focal Point — Bára Demková
Country Note Taker — Zuzana Nott
Country Coach — Lígia Parodi

The FGD was conducted in Brno. Twelve (n=12) peers were recruited and of those, four (n=4) attended the FGD. The Country Focal Point facilitated the FGD and provided her own contributions as a peer, resulting in a total of five (n=5) participants for the FGD. Three (n=3) of the peers were women and two (n=2) were men. Peers told us they used buprenorphine, methamphetamine, and alcohol.

Access to harm reduction equipment in Brno

Peers told us that they access a full range of harm reduction equipment and safer sex supplies except stimulant pipes. It was mentioned that the quantity of safer sex supplies was inadequate for sex workers. Peers accessed harm reduction equipment from a contact centre (Káčko centrum), outreach workers – either calling for the service or visiting the worker's house, and the Field Programme (Terénní Programy), delivered out of an ambulance (sanitka) parked on the streets.

> "I know where to go."

Peers reflected that there was more knowledge among the community about communicable diseases compared to the past. Peers talked about the shared responsibility for the prevention of HIV, HCV, and STIs. Peers talked about service availability in the community and that treatment for HCV was easier than in the past. When discussing risks for communicable diseases, many peers commented about non-sterile injecting equipment discarded on the streets.

> "I first got infected through my own negligence."

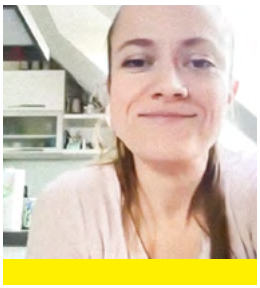
Peers described the informal peer support and harm reduction activities they provided to people in their networks. Peer distribution of sterile injecting equipment (secondary distribution), providing health promotion and education, and supporting peers to access testing, were examples of informal peer support provided.
We heard that peer outreach workers were effective at reaching PWUD and communicating information about hep C treatment. Peer outreach workers also contributed to disposal of discarded injecting equipment. There was consensus that the peer roles were valued, however, there could be more peer workers, including peer workers from sex workers community-based organisations, such as Pleasure Without Risk (Rozkoš Bez Rizka).

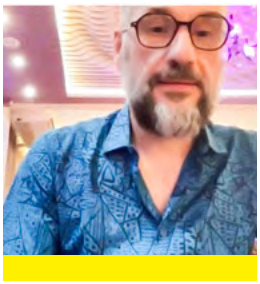
Testing for HIV, hepatitis C, and STIs in Brno

Peers named services where they were able to access HIV, hepatitis C, and STIs testing: a contact centre (Káčko), an alcohol treatment service (Na Vlhké), the Remedis clinic (a non-state health service), and at hospitals. While testing was relatively easy, we heard that some PWUD were unwilling to test because health is a lower priority for them and to avoid stigma and discrimination. Peers said that more awareness of the options for testing would benefit communities.

We heard that experiences of hospital-based testing services were more likely to be stigmatising and discriminatory towards PWUD and while it has improved, non-state-based services were preferred services to access testing for HIV, HCV and STIs compared to hospitals. Peers stated a strong preference for the ease of self-testing and peer-testing options. Benefits described by peers were that self-testing and peer-testing options mitigated wait times for test results, provided privacy/confidentiality, and reduced contact with health services to only for confirmation of positive results, resulting in a reduction in the risk of stigma, discrimination, and prejudice.

Consensus about preference for self-testing and peer-testing kits to be distributed by coming to PWUD rather than requiring PWUD to come to services was high. Financial incentives and food voucher were suggested as motivators for PWUD to test. Peers could be better supported through capacity-building (e.g. manuals for testing) and community resources.





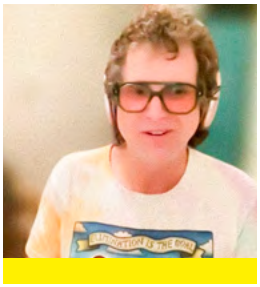


Figure 2
Zuzanna, Bará, Mat & Joël during the FGD debrief for Brno

Access to PrEP and PEP in Brno

There was no knowledge about PrEP and PEP among peers and communities of PWUD in Brno.

We heard that PWUD perceived their risk of HIV relative to their location, while understanding the potential risks arising from the migration of refugees from countries where HIV prevalence among PWUD is higher than in Czechia.

Access to treatment in Brno

Peers knew people living with HIV (PLHIV) and that PLHIV had accessed HIV treatment. Some of the peers had lived experience of HCV and HCV treatment (interferon-based and DAAs more recently) and knew peers who had recently treated and cleared HCV. We heard that social support (formal and informal), particularly peer support, was an enabler to accessing and completing HCV treatment.

Process, experience, and efficacy of FDG in Brno

While initially disappointed by the number of participants, the Country Team reflected that having more peers in the room may have been difficult to manage and that the smaller number of participants allowed all peers the opportunity to contribute to the discussion. Rapport with peer participants was facilitated by the Country Focal Point's personal and professional relationships with peers. The Country Team Members reflected that the peers felt safe to be themselves, evident in one participant's physical humour at the beginning of the FGD, as well as peers bringing their dogs into the FGD, albeit at times unpredictable.

The Country Team Members told us that they had set-up a peer-based NGO

for PWUD, the Union of People with Experience of Addiction (Unie lidí se zkušeností se závislostí) one-year ago.[6] Engaging peers to participate in the FGD was a priority for the Union.

We heard that peer participants had provided positive comments about their experience of the FGD. Many of the peers reflected that they had never been asked about their opinions or perspectives informed by their living or lived experience and that they were grateful for the opportunity. One peer stated they felt privileged to have been a part of the FGD.

When asked about the experience of conducting the FGD, country members reflected that the stories shared were not polished stories, like in a film or literature, but rather real world stories that were emotionally touching.

6 'The Union of People with Addiction Experience was born' ('Zrodila se Unie lidí se zkušeností se závislostí'), Renadi (Webpage, 30 November 2022), <https://www.renadi.cz/cs/zrodila-se-unie-lidi-se-zkusenosti-se-zavislosti>.

Finland

Country Focal Point — Juha Tukikohta
Country Note Taker — Kim EHYT
Country Coach — John Melhus

The FGD was held in Helsinki, Finland. A total of nine (9) participated. Two (2) of the participants were women and seven (7) were men. Information about the substances people used was not discussed. Nearly all participants were enrolled in OAST programmes.

Access to harm reduction equipment in Helsinki

Peers told us that access to harm reduction equipment was dependent on what area you were living / using, with most of the participants sharing with us that they needed to travel, including by various modes of public transport, to get to needle and syringe programmes (NSPs). Peers described a mobile NSP service but due to changes to stopping patterns and a lack of outreach to where PWUD live, few participants had used this service. There was consensus among peers that NSPs could offer more services than dispensing harm reduction equipment, such as health education and counselling.

> "Those who have kids are afraid of child protective services – what if they took their children away? Some are afraid of legal consequences. There could be police outside NSPs."

We heard that there were two groups of PWUD drugs who were not accessing harm reduction equipment – women and young people. For women, the risk of interaction with child protection services was a major barrier accessing NSPs. Peers told us that young people were often unaware of NSP services, and for those under 18 years old, access harm reduction equipment was inconceivable. Peers reflected that for some PWUD in employment,

stigma was a barrier to accessing NSPs, and that some PWUD didn't access NSPs because of the risk of legal consequences.
Peers valued the privacy and confidentiality provided by NSP workers, however, that NSP workers who also worked in health services raised concerns, mistrust, or confusion about the delineation of roles, as well as fear of breach in privacy and confidentiality. There was consensus among participants that better access to harm reduction equipment would be facilitated by the dissemination of information about the services: their locations, schedule of locations for mobile services, and operating hours including longer hours of service. Peers told us that mobile services would be more accessible if located closer to where PWUD live.

> "In some services there are peer workers who are highly respected. But if peer workers are the only ones, that's not a good thing. There should also be professionals, especially health professionals."

We heard that peer workers were highly valued and respected in their roles providing harm reduction equipment, however, participants expressed a preference for peer workers working in partnership with health care practitioners.

Testing for HIV, hepatitis C, and STIs in Helsinki

Peers told us that they were able to access testing for HCV relatively easily, however, that it was difficult to access testing for HIV and STIs. Although testing for HCV was accessible, access to HCV treatment was only available for PWUD in opiate agonist maintenance therapy (OAMT) programmes.

> "[I prefer to] take all the tests at the same time as taking the hep C test"

We heard that peers had a preference to be tested for all communicable diseases when testing for HCV (and that NSPs could play a role in providing PWUD communicable diseases testing alongside providing harm reduction equipment. Peers reiterated that accessing OAMT was an enabler to accessing testing and treatment. Peers also suggested that DCRs would be a suitable site for testing and discussion about results.

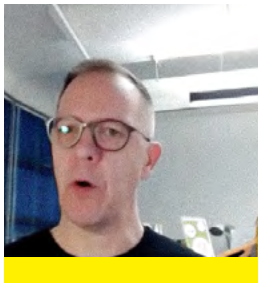
Access to PrEP and PEP in Helsinki

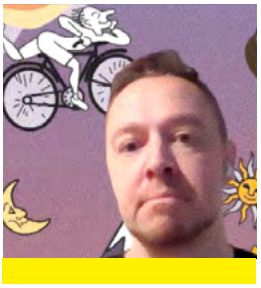
Peers had little to no knowledge about PrEP and PEP. There was a short discussion about PrEP and PEP being offered to PWUD in custodial settings. One participant recalled their experience of receiving PEP after a needle-stick injury. Barriers to accessing PrEP and PEP were not discussed due to the low levels of familiarity with ARV-based prevention tools.

Access to treatment in Helsinki

We heard that peers saw OAMT as their preferred service to access HIV, HCV, and STI treatment, due to the coordination of care and support provided by nurses. Peers felt that services were not coordinated and were geographically distanced, requiring travel from service to service. There was a strong preference for collocated services. Peers told us that DCRs could be ideal for treatment access and saw DCRs as providing other social services like housing support. Participants knew people within their networks and communities who had accessed and treated HCV and reflected good treatment experiences on the DAAs.

On the role of peer workers and drug user groups, participants reflected there could be more engagement from PWUD in informal peer support and sharing harm reduction and health information. Peers reiterated a collaborative model of peer workers and health workers, doubting the knowledge of peer workers to provide, for example, a positive test result. Participants conveyed their concerns about confidentiality if peer workers were involved in support for treatment of communicable diseases.





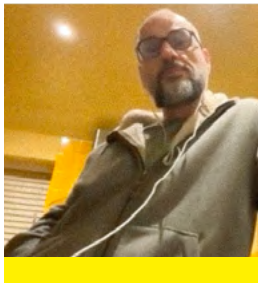


Figure 3
John, Juha, Kim, Mat & Joël (off-screen), during the FDG debrief for Helsinki

Process, experience, and efficacy of FDG in Helsinki

The Country Team Members reflected that the FGD took longer than anticipated to organise as scheduling of the FDG and availability of team members had been difficult to coordinate. That said, on the day of the FGD, participants were waiting at the venue when the team members arrived.

We heard that the team members had a brief discussion about the ethics of inclusion of participants who were intoxicated and decided that because participants were recruited from a low-threshold service, the same principles and values should apply. Participants who were intoxicated were included and contributed equally to the discussion.

The conduct of the FGD was seamless as participants kept each other accountable to the group rules, such as ensuring the person contributing was the only person talking while the group listened. Peers shared that they were grateful for the material incentive because this was the first time their participation in research had been compensated; peers felt like their contributions were valued.

The Country Focal Point reflected that before the FGD they were concerned that their lived experience was in the past and that it could impact on rapport and trust with peers. However, these concerns were unfounded, and the Country Focal Point said “it felt like coming home” conducting the FGD among PWUD.

We heard that peers and the Country Team Members were ready for further engagement and mobilisation, and that they were ready to start discussions about forming a peer-based network / organisation for PWUD in the coming year.

If conducting another FGD in the future, the Country Team Members told us that involvement of PWUD with living experience (current use) could be beneficial, as well as recruitment of peers who were not represented (e.g. more women). Implementing these lessons learned could mean that the engagement and discussion with PWUD is deeper and richer content.

Italy

Country Focal Point — Valentina Mancuso
Country Note Taker — peer volunteer
Country Coach — Lynn Jefferys

The FGD was held in Rome, Italy. Fifteen (n=15) peers were recruited, one (n=1) was a woman and n=14 were men. Peer told us they used heroin, cocaine, and crack cocaine including injecting drug use. One participant was living with HIV and most participants had experience of HCV. Some peers had accessed OAMT.

Access to harm reduction equipment in Rome

Peers described a diversity of experiences in accessing harm reduction equipment like injecting equipment and stimulant inhalation kits. Peers identified services where they could access sterile injecting equipment at no-cost, including Villa Maraini, open 24/7, and a mobile van operating 7-days per week in the Tor Bella Monaca neighbourhood and at Roma Termini, Rome's central train station.

> “ Cocaine is there a lot but today we talk more about crack, there is no exchange of the syringe but there is the exchange of the pipe. ”

We heard that PWUD could purchase injecting equipment from pharmacies, however, that cost was often a barrier to access. Peers told us that some groups of people are more likely to be refused equipment by pharmacies, such as women and young people. While pharmacy workers communicate that the refusal of equipment is supposed to benefit the peer, refusal forces a peer to reuse a needle and syringe, creating the potential for greater harm. Peers explained that pharmacies did not have all harm reduction equipment including limited access to naloxone.

❝ They used to sell the syringes to you lose, today they sell them in packs of 50 and they cost money. Once the pharmacy was 100 lire short, there was no problem, they would give it to you. A lot of times I would go there and say I need one and they would give it to me. ❞

We heard that no-cost injecting equipment was not widely distributed geographically; those peers living closer to services centrally or in the south had better access than those who lived in the north, east or west areas of Rome, or outside of Rome. Some peers told us that they didn't feel safe travelling through some areas to where harm reduction services were located, for example, the temptation of people selling drugs when travelling to access OAMT daily tested peers' goals to reduce or abstain from drug use.

❝ If you are coming from north/west/east Rome you either really want to come here (to the harm reduction service) or on the route from there to here, you find alternative possibilities and they are often unsafe. ❞

Peers had a high level of knowledge about risks for HIV and HCV as well as risk reduction practices. We heard that peer distribution facilitated harm reduction among networks where access to injecting equipment was not possible due to cost or distance to services. We heard that some people engage in opportunistic sex work ("sex for swap") for example, the exchange of sex for substances and harm reduction equipment.
We heard that sharing injecting equipment was common practice in juvenile and adult custodial settings. Peers told us that there was an increased risk of TB transmission in prisons.

Testing for HIV, hepatitis C, and STIs in Rome

Peers were able to name several services where they could access testing for HIV, HCV, and TB (Spallanzani, Tor Vergata, and Villa Maraini). Peers told us that access to testing for HCV, HIV, and TB was determined by how close to a service you were geographically located. Therefore, access to testing was greater for those living closer to services, whereas, peers who lived in the north, east or west areas of Rome, or outside of Rome, had more difficulty accessing testing. We heard that STI testing at no-cost was harder to access and there was limited knowledge about what services offer STI testing at no-cost among some participants.
Some peers felt that awareness of communicable diseases has improved among some services, however, felt that some service operators (e.g. serts) had a lot of power in how they ran the service ("I run my own house").
Peers expressed a preference for less bureaucracy (paperwork) around testing, stating that unnecessary or difficult paperwork is a barrier to testing.

Access to PrEP and PEP in Rome

There was no knowledge about PrEP and PEP among peers participating in the FGD. There was a discussion about the potential benefits and risks of PrEP and PEP, as well as where peers could access PrEP and PEP at no-cost.

Access to treatment in Rome

All peer participants had accessed DAA treatment for HCV, except for two participants who had accessed interferon-based treatments in the past and had cleared HCV. We heard that treatment access was facilitated by harm reduction services and drug treatment services (sert). Peers told us that they had been refused service at local pharmacies when attempting to have DAAs dispensed, which meant that peers had to travel to a suitable service to get HCV treatment.

Among those living with HIV in the FGD, we heard they had access to HIV treatment and care. Peers felt that there was not enough effort on HIV prevention and conveyed that they felt services were more interested in treatment. PLHIV talked about not disclosing their HIV status due to internalised stigma, discrimination, and fear of transmission.

Peers were able to access OAMT but discussed barriers such as geography and limitations on takeaways when travelling for work or vacation.

Process, experience, and efficacy of FGD in Rome

The Country Focal Point reflected that the organisation of the FGD went well, stating a high satisfaction with support provided by the Country Coach and NGO Partner. The person assigned to take on the role of Country Note Taker was not available – the Country Focal Point was able to adapt reflexively, and one participant volunteered to take notes, an opportunity for unplanned capacity-building and the willingness of peers taking on leadership roles.

The Country Focal Point reflected that they would not change anything if having to run a FGD in the future, however, reflected that attention on a more diverse gender mix among participants would be beneficial.

We heard that the conduct of the FGD was effective as all participants contributed to a series of reflective discussions and sharing. Peers reflected that they had enjoyed the process, that the discussion was relevant and of interest, and that their views were genuinely heard. Peer reflected that the material incentive was appropriate and that they felt valued. Participants told us that they were keen to stay in contact to hear the results and work collaboratively on priority actions. Peers were particularly grateful for the exchange of new information about PrEP and PEP.

Analysis & Discussion

Challenges and Opportunities

Theme: greater involvement of peers and peer workers

It is well documented that the greater, meaningful, and equitable involvement of PWUD (peers with living and lived experience) is essential to the success of, testing, prevention, and treatment of communicable diseases like HIV, viral hepatis, STIs, and TB.[7] We found that views of peer workers involvement in service delivery differed between focal countries. In Brno, peer workers were highly valued, and we heard that there was a strong preference for services delivered by peers; however, PWUD in Finland conveyed greater caution towards peer workers and stated strong preferences for the involvement of "professional" health care workers, reflective of Finnish cultural and social value placed on doctors and nurses. Whereas in Belgium, the C-Buddy project has been running for some time and has demonstrated efficacy, appropriateness, and acceptability among peers.

Peer workers are therefore a critical component of programme codesign, which could be further explored in each focal country. Peer workers need to be supported by the NGO service they are connected to – this could include: (a) comprehensive training packages to increase health knowledge, confidence, and competency of peer workers, (b) organisational policies and procedures that contribute to cultures that are culturally safe and competent (i.e. non-stigmatising language) for PWUD and peer workers, (c) ongoing support and debriefing to mitigate challenges of working with living and lived experience in a professional environment, and (d) systematic and routine reflective practices to continually improve service delivery and peer work approaches.[8] The Buddy-C Project's manuals for peer workers may be useful to guide workforce development in settings outside of Antwerp. Specifically, support to start and sustain networks of PWUD in each focal countries will be critical to the mobilisation of a peer workforce and PWUD in advocating for change to address structural barriers. For example, there was strategic alignment engaging members of the more recently formed Czech Union of PWUD to facilitate and conduct the FDG, whereas, in Belgium, community were ready to take first steps to forming a new network and movement among PWUD. Potential programmes could address different components of the framework for community empowerment, as discussed in the WHO Consolidated Guidelines Consolidated guidelines on HIV, viral

7 INPUD, Community-led monitoring for people who use drugs, (Report, 2023) <inpud.net/resources/community-led-monitoring-for-people-who-use-drugs>; UNAIDS, 'Do no harm: Health, human rights and people who use drugs' (Report, 2016) <www.unaids.org/en/resources/documents/2016/do-no-harm>; INPUD/United Nations Office on Drugs and Crime, 'Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs: practical guidance for collaborative interventions' (Report, 2017) <https://inpud.net/iduit-implementing-comprehensive-hiv-and-hcv-programmes-with-people-who-inject-drugs/>.

8 Zahra Mamdani, et al, "Running myself ragged": Stressors faced by peer workers in overdose response settings', Harm Reduction Journal (2021) 18(18). DOI: 10.1186/s12954-020-00449-1; Alissa Greer, et al, 'Peer' work as precarious: A qualitative study of work conditions and experiences of people who use drugs engaged in harm reduction work', International Journal of

hepatitis and STI prevention, diagnosis, treatment, and care for key populations in building the capacity of PWUD and NGOs to address structural barriers to communicable diseases prevention, testing, and treatment, and harm reduction. [9]

Theme: improved access to harm reduction equipment and safer sex supplies

Multiple barriers to harm reduction equipment and safer sex supplies were found in each focal country and peers understood the critical role that access to harm reduction equipment and safer sex supplies has on the prevention of communicable diseases. Peers were able to access a range of harm reduction equipment and safer sex supplies in some parts of the focal country, although challenges to access included: (1) the type, range of equipment and supplies, and quantities available (e.g. stimulant kits, quantities, safer sex supplies for sex workers); (2) the availability of the harm reduction service (e.g. geographical location, operating hours, and outreach stopping patterns, times, and locations); (3) stigma, discrimination, and uncertainty among peers on legal status of accessing sterile injecting equipment; (4) a lack of awareness of services; and (5) cost. Importantly, we heard that (6) some subpopulations were underrepresented in harm reduction services reach and penetration (e.g. women (trans and cis), pregnant people, parents/carers, young people, trans and gender diverse people, and people in custodial and other closed settings).

According to the European Centre for Drugs and Drug Addiction's European Drug Report, in 2022, Finland and Czechia had high coverage of needle and syringe distribution per PPPY, whereas Belgium had medium coverage (close to high coverage), and Italy had low coverage.[10] Peers in our FGDs confirmed these data. The WHO target for the number of needles and syringes distributed PPPY by 2030 is n=300, all focal countries will have to increase efforts to meet these targets.[11] It is clear that harm reduction initiatives that are context-specific and subpopulation-specific will enable greater access to harm reduction, piloting initiatives that are effective, appropriate, and acceptable, and adaptation of existing activities and programming to reflect the preferences and values of PWUD.

Secondary distribution of equipment by peers to underserviced subpopulations is one potential initiative that could be explored, where feasible. The initiative could be as minimal as NSP workers encouraging peers to take additional supplies for their networks, or an online order form for no-cost supplies via postal service, or more extensive like setting up key network contacts, providing bulk equipment and capacity-building to people who sell drugs and people who have access to networks of underserviced subpopulations.

EuroNPUD's Peer to Peer Needle and Syringe Programmes Technical

Drug Policy 85 (2020). DOI: 10.1016/j.drugpo.2020.102922; Lindsay Wilson, et al, 'Peer worker or client?: conflicting identities among peer workers engaged in harm reduction service delivery', Addiction Research & Theory 26(5) (2018), 361-368, DOI: 10.1080/16066359.2017.1410704; Zack Marshall, et al, 'Peering into the literature: A systematic review of the roles of people who inject drugs in harm reduction initiatives', Drug and Alcohol Dependence 151 (2015). DOI: 10.1016/j.drugalcdep.2015.03.002.

9 World Health Organization, 'Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment, and care for key populations' (Report, 2022). Licence: CC BY-NC-SA 3.0 IGO, <who.int/publications/i/item/9789240052390>

10 EMCDDA, European Drug Report 2023: Trends and Developments (Report, 2023) <emcdda.europa.eu/publications/european-drug-report/2023_en>. DOI: 10.2810/161905.

11 While recognising the limitations in estimating NSP coverage and the benefits of using community-led monitoring to inform gaps in data.

Briefing, provides case studies and guidance on these programmes in Europe.[12] Partnerships with peer-based NGOs and networks of PWUD, sex workers, and trans and gender diverse people, recognising the intersections of experience and group belonging/identity, could be explored to further ideas to enable access to harm reduction equipment and safer sex supplies. Peers engaged in the FGDs provided examples of low-cost initiatives that could enable greater access to harm reduction equipment and safer sex supplies. Greater dissemination of information on services that provide harm reduction equipment and safer sex supplies, location, operating/opening hours, stopping patterns for mobile/outreach services, and range of services provided, is one such example that could be implemented in focus countries.

Information could be in the form of posters, leaflets, oral communication among networks, and/or digital marketing, relevant to the context and setting.

Peers must inform the content and design of the resources, to ensure acceptability and appropriateness of health promotion messages to maximise penetration and adoption by PWUD. Resources could refer to the stated values of PWUD in accessing services, such as confidentiality, anonymity, and privacy.

12 EuroNPUD, 'Peer to Peer Needle and Syringe Programmes: Technical briefing' (Report, 2024).

Theme: increase utilisation of rapid testing technologies

Among peer participants, there was a high level of knowledge about HIV, HCV, STIs, and TB (where relevant), and the importance of regular testing for communicable diseases. Most but not all peers, could access testing for communicable diseases. Barriers to access included geographical location and experiences of enacted stigma, discrimination, and prejudice from health care workers, although we heard that community-based services like harm reduction services and NSPs were less likely to stigmatise PWUD and were the preferred settings for testing. In all focal countries, peers talked about PWUD in their networks who did not prioritise testing (and therefore treatment) of HCV, due to different priorities or internalised stigma leading to a lack of concern about their own health.

Peers were aware of and spoke to the benefits of rapid-result communicable diseases testing technologies. Among participants in each focal country, there were strong preferences for a range of testing technologies – at-home self-test kits, blood spot rapid HIV testing, and dry-blood spot testing for HCV and the involvement of peers and peer workers providing testing options and support.

Communicable diseases testing that doesn't require venous access is always beneficial to PWID, reducing the need for specialist phlebotomy techniques and minimising contact with health services to only when receiving a reactive test result. Testing technologies that are mobile or can

be used in peer outreach may be one approach to addressing geographical-based access to testing for communicable diseases.
Peers reflected that more information on where to get tested at no-cost would be beneficial. Like harm reduction services information outlined in the previous section, a range of communication approaches could be used to promote testing across networks of PWUD. Specifically, it could be useful to develop a health promotion campaign encouraging testing among people not currently accessing testing, which could include rapid testing and self-testing outreach, reducing the need to test at a service.

Theme: low knowledge of PrEP and PEP is consistent among PWUD

Across all FGDs, there was low or no knowledge about PrEP and PEP to prevent HIV among participants, even though there was a high level of knowledge about HIV risk. Although most Country Team Members were surprised by the level of knowledge among peers, access to PrEP and PEP by PWUD in Europe is heterogeneous, dependent on each state's policies and services.[13] Data on the efficacy of PrEP and PEP in preventing HIV among PWID, is sparce and mostly focuses on HIV risk reduction among sexual partners, raising ethical considerations about the appropriateness of ARV-based prevention among PWID to precent injecting-related HIV risk.[14] The barriers to access different forms of harm reduction and prevention of communicable diseases, namely, providing harm reduction equipment, OAMT, testing, treatment and optimised care, is not at high coverage in all focal countries – it is critical that effort and resources towards PrEP and PEP cannot come at the expense of comprehensive harm reduction, OAMT, testing, treatment, and optimised care, which would represent more efficient health care resource allocation and utilisation for the funder of the harm reduction services, and higher acceptability and appropriateness among PWUD.

Theme: remove unnecessary barriers to HCV treatment

Peers in all FGD had experience of both interferon-based treatments and DAAs treatments for HCV. There was a high level of acceptability of the DAA treatments among peers, with many reflecting positive outcomes after completing treatment. Most peers were able to access HCV treatment with relative ease and that formal and informal peer support provided to people seeking treatment was an enabler to successful completion of the treatment. However, we heard that in some settings, access to HCV treatment was conditional on OAMT programme enrolment, which may conflict with the individual goals and values of PWUD seeking treatment. While states may argue that due to the cost of treatment, the risk of a new HCV infection linked to injecting drug use, and subsequent courses of treatment represents efficient health resource utilisation, conditional access to HCV is not acceptable and raises ethical considerations about withholding life-saving treatments from

13 Graeme Shaw, et al, 'Pre-exposure prophylaxis (PrEP) for HIV prevention among people who inject drugs: a global mapping of service delivery'. Harm Reduction Journal 20(16) (2023). DOI: 10.1186/s12954-023-00729-6.

14 INPUD, Pre-Exposure Prophylaxis for People Who Inject Drugs: Community voices on Pros, Cons, and Concerns, (Report, 2016), <inpud.net/pre-exposure-prophylaxis-prep-for-people-who-inject-drugs-community-voices-on-pros-cons-and-concerns/>

PLHCV based on their current drug use. Moreover, without access to and coverage of harm reduction programmes for all PWUD, treatment-as-prevention alone will not achieve a decrease in the incidence and prevalence of HCV. In Rome, peers told us that as part of the treatment and care cascade for HCV, measurement of liver fibrosis via liver biopsy was common practice. A fibroscan is a more acceptable procedure for measuring liver fibrosis, as it is non-invasive, although, liver fibrosis scores are not needed to treat with DAAs in most cases. Advocating for changes to outdated practices for PLHCV will be important.

Theme: address stigma and discrimination

Stigma, discrimination, and prejudice were widely reported by peers in the FGDs. Systematic barriers to access harm reduction, testing, prevention, and treatment for communicable diseases like the criminalisation of drugs and drug use and gender-based violence contribute to stigma and discrimination. Peers valued services that were non-stigmatising, non-judgemental, and who modelled cultural competency and safety.

Public information campaigns about PWUD, or more directly about the impacts of stigma and discrimination at the general population level are unlikely to be effective at shifting attitudes and opinions without also advancing law reform to decriminalise and/or legalise drug use.[15] It may be useful to pilot stigma monitoring tools within future FGDs as a part of this project, as well as using stigma indicators with NGO and government services working with PWUD to track changes to stigma and discrimination over time.

15 For example, see Dan Howard, New South Wales Government (Australia) Special Commission of Inquiry into Crystal Methamphetamine and Other Amphetamine-Type Stimulants: Volume 1b (Final Report, January 2020) 230.

Theme: engaging PWUD in community-led monitoring

Underrepresentation of some subpopulations of PWUD was evident in three of four FGDs. Engagement of subpopulations not accessing harm reduction equipment should be prioritised to inform programming to address the access gap. When asked about strategies to engage more women, young people, and trans and gender diverse people, Country Focal Points suggested using communications and messaging codesigned for these groups, utilising key peer network connections, and emphasising the benefits of participation – altruistic (e.g. contributing to health initiatives for PWUD), personal (e.g. peer insights, perspectives, and knowledge), and material (e.g. cash incentives). Facilitating spaces that provide safety, privacy, and confidentiality for parents, particularly mothers, who use drugs could facilitate participation in future FGDs.

Peers in all FGD valued the material incentive for participation. As cost-savings from venue hire were saved and added to peer incentives, the increase from 10-Euro dollars to 20-Euro dollars, was acceptable to peers and the higher value was a stronger motivator than the lower value incentive. Recruitment into future FGDs could promote the incentive as a benefit of

participation.
Finally, longer lead times were mentioned by a couple of the Country Teams as a factor to enable successful recruitment and conduct of the FGDs.

Limitations

Sampling biases

Recruitment methods undertaken by each Country Team raise sampling bias, which limits the generalisability of the findings. Sampling techniques were purposive and included: homogeneity (PWUD in that setting), snowball (peers recruit participants from their networks), max variation (diversity of gender and living experiences), and opportunistic (peers connected to a service), each with their own benefits and limitations, described elsewhere.[16] Therefore, the results can be viewed as a snapshot of experiences informed by their context (rather than countrywide), acknowledging that there was underrepresentation of some subpopulations involved in each of the FGDs.

16 Laurence K Palinkas, et al. 'Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research'. Administration Policy Mental Health and Mental Health Research 42 (2015), 533–544. DOI: 10.1007/s10488-013-0528-y

Participant biases

The NGO Partner provided the venue for each FGD at no-cost to reduce costs for venue hire and increase the material incentive for peers. While every effort was made to ensure the privacy and confidentiality of the FGD, for example, in Brno, Czechia, NGO workers left the building while the FGD was conducted, there was the potential for sponsor bias and social acceptability bias.[17] Sponsor bias raises the limitation that peers may not have felt comfortable critiquing services provided by the NGO Partner, or conversely, that participants were overly positive of services provided by NGO services. Whereas social acceptability bias may have raised limitations insofar as some peers may have felt compelled to provide responses, they deemed to be socially acceptable or socially desirable answers.

17 José Patrício Bispo Jr, 'Social Desirability Bias in Qualitative Health Research', Revista De Saúde Pública 56 (2022) 101. DOI:10.11606/s1518-8787.2022056004164.

Researcher biases

Most personnel involved in this project have living or lived experience as PWUD. Understanding the cultural safety and cultural competency aspects of engaging PWUD is an advantage, as living and lived experience enabled peers to connect, build rapport, and trust the Country Team Members facilitating the FGD. Gaining trust is critical to engaging and collecting data among PWUD in CLM and research. Conversely, there is the potential for confirmation bias, however, the process of bringing in a Technical Writer from Australia to independently analyse data from the FGD and then validate the interpretation with Country Teams, mitigated or reduced the risk of confirmation bias.

Recommendations

1. Codesign communication campaigns to inform PWUD about harm reduction and communicable diseases testing and treatment services.
2. Pilot peer-to-peer distribution of harm reduction equipment and safer sex supplies, where feasible.
3. Explore harm reduction services utilisation and maximisation such as leveraging NSPs and DCRs as sites to access harm reduction, testing, and treatment referrals and peer support.
4. Support formal networks and organisations by and for PWUD: engagement, participation, capacity building, mobilisation, and empowerment.
5. Look for opportunities to increase peer workforce capacity.
6. Advocate for universal access to all communicable diseases testing, use of fibroscan, and DAAs for HCV treatment.
7. Disseminate the findings of this study among NGO partners, services, and PWUD.
8. Continue to monitor implementation and outcomes through community-led monitoring among PWUD, including implementing lessons-learned.

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Appendix A
Focus Group Discussion Guide

EU4Health Boost Focus Group Discussion Guide v2

Community-led Monitoring and Service Development: Communicable Diseases

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

Introduction

Instructions to moderator

1. ensure that all participants have given their verbal consent to take part in focus group discussions and have been recorded in the consent log.

2. start the discussion with a setting of “ground rules” for group iscussions including a reminder that all discussions are to be kept confidential (i.e. nothing discussed in the group about the personal experiences and opinions will be shared with others outside of this group; participants should let each other finish their sentences/do not interrupt each other; everyone is entitled to have their personal opinion/even if opinions do not align, we treat each other with respect, etc.). Explain about recording being used to validate note taking and will then be deleted and not kept beyond report production.

3. emphasise that while questions will address their personal use of drugs and engagement in helping services, the discussion remains confidential and they can make generalized comments about community experiences if this feels less exposing.

4 confirm that disclosures about use of illicit drugs for those currently on OAMT will remain confidential to study and will not be shared with their drug treatment provider.

5 if participants share sensitive info, such as personal experiences around violence, stigma, and discrimination, be prepared to guide and refer such participants to organisations for information support (see the referral list provided).

Instructions to the notetaker

1 When taking notes, please identify the question that goes with your notes. Sometimes participants will discuss things that answer a different question in the guide that hasn't been asked yet, or that can answer more than one question.

2 When capturing some of the key points from the discussion, including useful quotations, please identify the speaker in a general sense without using any names.

3 Audio recordings of the interviews will be available to cross-check notes. These will be securely stored and available only to the research team. They will be deleted once note taking shared with FGD lead (EuroNPUD Project Executive) and validated.

Brief intro script for moderator

Commence the recording of the FGD now.

“ Good morning/afternoon, my name is XX. Thank you for agreeing to take part in this focus group exploring community views communicable disease prevention, testing and treatment. Communicable diseases refers to HIV, Hepatitis C (HCV) and STIs. ”

“ We want to hear from you as a community member with experience of injecting drug use and/or stimulant drugs. We want to understand the quality of prevention, testing and treatment for HIV, HCV and STIs in your country. Community feedback will be used by EuroNPUD and its partners to help improve services related to HIV, HCV and STIs as part of an EU funded development project. This group discussion will last between 60 – 90 minutes. ”

“ Your participation in this study is totally voluntary and confidential. We don't need you to tell us personal issues about your life or drug use. You can also withdraw from the discussion at any time. The information you provide will be used for the purposes of this study only. Your feedback will be summarised into a report for the partners working on the Boost study without any personally identifying information. ”

“ Do you have any questions about the study? ”
“ Answer questions, then, begin. ”
“ Thank you for consenting to participate in this study. As discussed during the consent process, this FGD is being audio recorded for our research purposes. ”

Focus group discussion questions

Note to the Country Focal Point: The order 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.

Part 1 – Access to Harm Reduction Equipment (30min)
Country Focal Point: show information card showing 3 needles, syringes and injecting equipment, stimulant pipes, condoms and lubricants, and PrEP/PEP

1. Where do people who inject drugs get their harm reduction equipment (needles, syringes, pipes, condoms, lubricant, and injecting paraphernalia) in your local community? And what is it like for people accessing these services?
   (Probe: injecting equipment – NSP, pharmacies, outreach workers, DCR, through peer networks, preferences, homemade, health clinic, shops, ask them to offer them to give us a description of experiences accessing these services)
2. What barriers do people who inject and use drugs face in applying harm reduction and safer sex practices in your country?
   (Probe: ability to access plentiful supply of needles and syringes at the right time, access to stimulant pipes, access to condoms and lubricants, knowledge of harm reduction and safer sex practices, pressure from law enforcement, using drugs in street settings, rushed drug use)
3. Could peer workers or drug user groups play a role in distributing harm eduction equipment to prevent HIV, Hepatitis C and STIs? If yes, please describe what this could look like.
   (Probe: peer outreach, peer-to-peer needle and syringe distribution, providing equipment through drug suppliers, providing equipment in drug using venues – examples, chemsex outreach – online, dating apps, chemsex parties, sex worker projects, value of peer work, preferences to drug services, current role in your country, something to be developed, etc)

Part 2 – Testing for HIV, Hepatitis C and STIs

Country Focal Point: show information card showing 3 different types of HIV, Hepatitis C and STI testing - drawing blood, dried blood spot testing, and self-testing kits.

4 What are the different ways and places where people who use drugs an access HIV, Hepatitis C and STI testing in your country? How would you describe peoples experiences accessing these services (both positive and negative)

(Probe: knowledge of and attitudes to three different testing options, locations: fixed site drug services, testing through health clinics, testing by outreach workers using dried blood spot testing, online request and postal service, administering self-test)

5 In your local community, what would be the best way to help people who use drugs get tested for HIV, Hepatitis C and STI and get their results?

(Probe: comfort with outreach dried blood spot tests, comfort with self-testing, where would you like to be able to access, who would you like to deliver the tests)

Part 3 – Access to PrEP and PEP

6 Where can people who use drugs in your local community access PrEP and PEP and what do they think of this form of treatment?

(Probe: awareness of PrEP/PEP, attitudes to PrEP/PEP, perceived relevance of PrEP/PEP, knowledge of where to access to PrEP/PEP, preferences, etc)

7 Can you please describe any barriers that may exist for people ccessing PrEP and PEP?

(Probe: location, stigma of being seen accessing service, law enforcement etc)

Part 4 – Access to Treatment for HIV, Hepatitis C and STIs

8 Where would you like to be able to access the treatments for HIV, Hepatitis C and STIs?

(Probe: understanding of access points, preferences about different treatment settings, concerns about stigma and discrimination toward people who use drugs in different treatment settings, barriers to engaging in treatment)

9 Do you know peers who have successfully accessed this treatment? If so, please can you describe what made it easy for them to successfully access this treatment.

(Probe: experiences being shared within community, confidence in treatments, confidence in treatment settings, concerns about stigma

and discrimination toward people who use drugs in different treatment settings, barriers to engaging in treatment)

10 Do you believe peer workers or drug user groups could or should play a role in supporting people who use drugs to access and succeed with their HIV, Hepatitis C and STI treatment?
(Probe: peer education materials about HIV, Hepatitis C and STI treatment and local treatment services, peer guides who support community members access and engage in HIV, Hepatitis C and STI treatment, peer-led support groups for people with Hepatitis C / HIV, peers helping peers take their medications)

Closing

Ask participants if there is anything else they haven't yet had a chance to say on HIV, Hepatitis C and STI and related services.

Instructions to moderator

1 Thank all participants for their time and effort in this group discussion.

2 Remind people again that all discussions must be kept confidential and that all recorded notes and audio recordings will be kept under lock and key with restricted access. Audio recording will be destroyed after report completed.

3 Instruct participants about the steps following this group discussion (i.e., next phase of the study, how participants will be informed of the outcomes, etc.)

4 Let participants know how they can get in contact with us, if they have follow-up questions or experience any kind of discomfort in the aftermath of the group discussion (this is not expected to happen, but potential contact options should be provided).

5 Let people know where they can access the report once available.

6 Confirm who in the FGD would like to join peer initiative to work with XXX lighthouse project to support the implementation of findings and the development of peer-led responses to HIV, HCV and STI prevention, testing and treatment.

7 Find an acknowledging way to close the FGD.

Appendix B
Technical Guidance and Coaching for Country Focal Points

BOOST Focus Group Discussion Guide
Country Preparation Meeting

Focus Group Discussion

- 10 – 13 participants
- Mixed group – people who inject drugs, people who use drugs – stimulants, chemsex and other risk populations, gender balance and diversity of group, HIV+ and HCV+
- Anonymous and confidential
- Incentive payment - €20 – confirmed? Processing money
- Location: Rome Villa Marini
- 1.5 hours
- Invitation letter

Email template

Dear
[Add information about the project and link to EU]

This information will be used to advocate for and support the development of ..... EuroNPUD and introduce [Country Focal Point, Note Taker].

Thank you for agreeing to take part in the EuroNPUD focus group. The focus group will be for around 10 people. Everyone will be people who use and/or inject drugs. It will be a mixed group of your peers with different experiences about the prevention, testing and treatment of HIV and Hepatitis C from the drug using community in [Focal Country].

Venue
Date
Time

You will be paid €20 for attending this 1.5 hour focus group discussion. You will be asked to confirm to the people running the focus group that you understand and consent to taking part in the focus group. The moderator will sign a form that confirms that that this step has been completed. We will not ask you to sign or provide your name. You will be allocated a sticker with a number and the note taker will record your comments linked to this number. This is how we protect your confidentiality and anonymity. We will audio record the session to help the note taker. The recording will be destroyed after the notes have been completed.

We will be asking about your experience of risk, harm reduction, and HIV and HCV testing and treatment services. We will not be asking you to talk about personal or exposing issues.

The focus group is being organised with partners in local drug services. The group will be moderated by someone from the drug using community.

Country roles

Moderator:
Welcome and introduces FGD – script to guide
Guides group through questions
Prompts linked to each question
Flexibility to follow the questions
Note Taker:
Sign on sheet for participants – confirm consent and
Keep record of participants – basic demographics
Allocate number on sticker
Record comments in home language
Audio recording – help with notes – not full transcript
Smart phone or recorder – options and use like "talking stick"

Part 1 – Access to Harm Reduction Equipment (30min)
Country Focal Point: show information card showing 3 needles, syringes and injecting equipment, stimulant pipes, condoms and lubricants, and PrEP/PEP

1. Where do people who inject drugs get their harm reduction equipment (needles, syringes, pipes, condoms, lubricant, and injecting paraphernalia) in your local community? And what is it like for people accessing these services?
(Probe: injecting equipment – NSP, pharmacies, outreach workers,

DCR, through peer networks, preferences, homemade, health clinic, shops, ask them to offer them to give us a description of experiences accessing these services)

2 What barriers do people who inject and use drugs face in applying harm reduction and safer sex practices in your country?
(Probe: ability to access plentiful supply of needles and syringes at the right time, access to stimulant pipes, access to condoms and lubricants, knowledge of harm reduction and safer sex practices, pressure from law enforcement, using drugs in street settings, rushed drug use)

Part 2 – Testing for HIV, Hepatitis C and STIs

Country Focal Point: show information card showing 3 different types of HIV, hepatitis C and STI testing - drawing blood, dried blood spot testing, and self-testing kits.

3 What are the different ways and places where people who use drugs can access HIV, Hepatitis C and STI testing in your country? How would you describe peoples' experiences accessing these services (both positive and negative)
(Probe: knowledge of and attitudes to 3 different testing options, locations: fixed site drug services, testing through health clinics, testing by outreach workers using dried blood spot testing, online request and postal service, administering self-test)

4 In your local community, what would be the best way to help people who use drugs get tested for HIV, Hepatitis C and STI and get their results?
(Probe: comfort with outreach dried blood spot tests, comfort with self-testing, where would you like to be able to access, who would you like to deliver the tests)

Part 3 – Access to Treatment for HIV, Hepatitis C and STIs

5 Where would you like to be able to access the treatments for HIV, Hepatitis C and STIs?
(Probe: understanding of access points, preferences about different treatment settings, concerns about stigma and discrimination toward people who use drugs in different treatment settings, barriers to engaging in treatment)

6 Do you know peers who have successfully accessed this treatment? If so, please can you describe what made it easy for them to successfully access this treatment.
(Probe: experiences being shared within community, confidence in

treatments, confidence in treatment settings, concerns about stigma and discrimination toward people who use drugs in different treatment settings, barriers to engaging in treatment)

7 Do you believe peer workers or drug user groups could or should play a role in supporting people who use drugs to access and succeed with their HIV, Hepatitis C and STI treatment?
(Probe: peer education materials about HIV, Hepatitis C and STI treatment and local treatment services, peer guides who support community members access and engage in HIV, Hepatitis C and STI treatment, peer-led support groups for people with Hepatitis C / HIV, peers helping peers take their medications)

Part 4 – Access to PrEP and PEP

8 Where can people who use drugs in your local community access PrEP and PEP and what do they think of this form of treatment?
(Probe: awareness of PrEP/PEP, attitudes to PrEP/PEP, perceived relevance of PrEP/PEP, knowledge of where to access to PrEP/PEP, preferences, etc)

9 Can you please describe any barriers that may exist for people accessing PrEP and PEP?
(Probe: location, stigma of being seen accessing service, law enforcement etc)

Appendix C
FGD Debrief Discussion Guide

Version 2.0

Introductions

Purpose is to debrief, listen to how the focus group discussions went, review my descriptive analysis of the notes to validate, clarify the results. Process and experience
I want to understand the process and experience of running the focus group discussion. For the process, my questions will be about the steps you took to organise, recruit, and conduct the focus group discussion. For the experience, my questions will be about your personal experience of the focus groups discussions.

Process

1. How did you conduct the FDG? Can you talk me through the steps you took leading up to and on the day?
2. What went as imagined/planned?
3. What didn't go as planned? I.e. real world/adaptation
4. If you were planning and conducting another FDG, what would you do differently? I.e. lessons learned

Experience

5. How did you feel before, during, after the FGD? E.g. nervous, excited, proud
6. How was it like for you to work with peers in this way? E.g. effective, acceptable

Demographics

Gender, substances used, experiences of HIV, HCV, OAMT among participants.

Results

Validate results with Country Team and raise any specific points of clarification.