Community-Led Approaches to HCV Testing, Treatment and Care

Technical Briefing 2023
Introduction to the European Network of People who Use Drugs (EuroNPUD)

Vision Statement
Promoting health and defending the rights of people who use drugs in Europe.

Network Principles:
EuroNPUD operates to the same principles as the International Network of People who Use Drugs (INPUD), reflecting our shared vision and aligned strategic approach:

- Pro drug user rights
- Pro self-determination
- Pro harm reduction and safer drug use
- Respecting the rights of individuals who use drugs
- Anti-prohibitionist
- Pro equality

Aim
To ensure that Europe respects the rights of people who use drugs and supports the health of people who use drugs with science-based and rights-compliant harm reduction, drug treatment and healthcare services both domestically and around the world.

Objectives
- To enable people who use drugs to be meaningfully involved in the design, delivery and review of drug policy and practice in Europe.
- To support drug user organisations to mobilise together across Europe to promote the health and defend the rights of people who use drugs.

Donors
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Executive Summary

The key argument for community-led approaches to hepatitis (HCV) testing, treatment and care is that they are highly effective in increasing HCV testing and treatment uptake and retention rates among people who use drugs due to their unique advantage in providing privileged access. This access is a crucial pathway, allowing for multiple points of entry essential for reaching both the treatment and non-treatment populations.

As highlighted in the case studies included in this Technical Briefing, the impact of peer workers and drug user activists on the expansion of HCV testing, treatment and care is substantial. Their dedication aligns seamlessly with the strategic objective of saturating peer networks with essential resources and knowledge, thereby facilitating broad access to comprehensive HCV testing, treatment and care. This briefing includes two case studies that spotlight successful community-led approaches in Portugal and Norway, offering valuable insights into the effectiveness of integrating peer-led initiatives into HCV healthcare strategies.

Acronyms and Abbreviations

DDAs – Direct-acting antivirals
EMCDDA – European Monitoring Centre for Drugs and Drug Addiction
GAT – Grupo de Ativistas em Tratamentos (Treatment Activist Group)
HBV – Hepatitis B virus
HCV – Hepatitis C virus
HIV – Human immunodeficiency virus
P2PN – Peer-to-peer naloxone
SICAD – Serviço de Intervenção nos Comportamentos Aditivos e nas Dependências (General Directorate for Intervention on Addictive Behaviours and Dependencies)
WHO – World Health Organisation
Introduction

The landscape of hepatitis C (HCV) testing, treatment and care is undergoing a transformative shift—one that places the power of community at its core. This briefing presents community-led approaches to HCV, where people with lived experience (peer workers) play a key role in the provision of HCV services. These approaches mark a departure from traditional models, embracing a philosophy that recognises the unique experiences, insights, empathy and understanding peer workers bring to the table.

At the heart of community-led approaches to HCV lies a recognition of the power inherent in shared experiences. Peer workers, individuals who have personally experienced drug use and/or lived with HCV, are catalysts for change, bridging the gap between the healthcare system and those seeking support and breaking down barriers that often hinder access to HCV services. Their lived experiences bring authenticity to the services provided and empower others to seek HCV testing, treatment and care. This briefing presents the ways in which peer workers contribute to building a supportive environment by highlighting the strategies and success stories from Portugal and Norway, which underscore the great impact of community-led approaches to HCV testing, treatment and care.

What Is Hepatitis C Virus?

Hepatitis C is a viral infection impacting the liver, causing both short-term (acute) and long-term (chronic) illness, which can be life-threatening. The virus spreads through contact with infected blood, often occurring via shared needles or syringes and unsafe medical procedures like transfusions with unscreened blood products.

Common symptoms include fever, fatigue, loss of appetite, nausea, vomiting, abdominal pain, dark urine and jaundice. Although there’s no vaccine for hepatitis C, antiviral medications can effectively treat the infection.

Early identification and treatment are crucial in preventing severe liver damage and enhancing long-term health. Acute HCV infections are typically asymptomatic, with approximately 30% spontaneously clearing the virus within six months without treatment. However, the remaining 70% progress to chronic HCV infection, with a cirrhosis risk ranging from 15% to 30% within 20 years.

HCV Testing and Diagnosis

Diagnosing HCV infection involves a two-step process:

1. **Testing for anti-HCV antibodies:** A blood test identifies individuals who have been exposed to the virus by detecting anti-HCV antibodies.

2. **Confirmation of chronic infection:** If the anti-HCV antibody test is positive, a nucleic acid test for HCV ribonucleic acid (RNA) is necessary to confirm chronic infection and determine the need for treatment. This step is important because approximately 30% of those infected with HCV naturally clear the virus without treatment. Even though they are no longer infected, they will still test positive for anti-HCV antibodies.

Following a diagnosis of chronic HCV infection, the extent of liver damage is assessed through a liver biopsy or various non-invasive tests. The severity of liver damage plays a key role in determining treatment strategies and shaping the overall management of the disease.
HCV Treatment

Hepatitis C is treated with antiviral medications like sofosbuvir and daclatasvir. While some people can naturally overcome the acute infection, chronic hepatitis C always requires treatment. Lifestyle adjustments, such as abstaining from alcohol and maintaining a healthy weight, can also benefit those with HCV. Effective treatment usually results in a cure, enabling individuals to lead healthy lives.

The World Health Organisation (WHO) recommends direct-acting antivirals (DAAs) for everyone with chronic HCV infection, including people who currently inject drugs. These oral regimens are generally well-tolerated with few side effects. DAAs have a high success rate in curing HCV infection, and the treatment duration is typically short (12–24 weeks).

Methodology

This technical briefing was developed by EuroNPUD as part of the EU4Health BOOST Project, which aims to strengthen community-based and community-led organisations and boost communicable disease services as part of a comprehensive, people-centred harm reduction strategy for people who use drugs and related vulnerable groups. Find out more here: community-boost.eu.

The EuroNPUD BOOST project was managed by Lynn Jefferys and John Melhus. The information for the case studies was gathered through interviews with peer workers, service users, and service providers and in-person visits to community-led services. The interviews for Portugal were conducted by Lynn Jefferys with interpretation by Joana Canêdo, and the interviews for Norway were led by John Melhus. The whole project would not have been possible without the input from peer workers and staff of GAT InMouraria, ProLAR and the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA). The information for this briefing was supplemented by desktop research. Based on the data compiled by Lynn Jefferys and John Melhus, the briefing was developed and edited by Lana Durjava from Altlier.

What Are Community-Led Approaches to HCV Testing, Treatment and Care

Community-led approaches to HCV testing, treatment and care involve active involvement and participation of people who use drugs in the planning, implementation and evaluation of HCV healthcare services. These approaches recognise that community members, particularly those at higher risk, play a key role in shaping and sustaining effective HCV interventions.

Due to their lived experiences and relatability, peer workers enjoy privileged access within the communities they serve. This unique position allows them to establish trust and connection with individuals undergoing HCV testing and treatment. Their shared experiences create a sense of understanding and empathy, fostering an environment where people who use drugs feel more comfortable discussing their concerns, fears and questions related to HCV. Community-led outreach efforts go beyond traditional healthcare settings, utilising mobile testing units and targeted outreach programmes to reach populations facing barriers to accessing HCV services.

One challenge in the process of HCV eradication has been the lack of adaptation of traditional health services to the needs of people who use drugs. The inflexible schedules and inadequate knowledge about drug use, homelessness and withdrawal create barriers for people to attend appointments and access treatment. Peer-led and community-centred approaches address these barriers effectively.
Context for Community-Led Approaches to HCV Testing, Treatment and Care

Hepatitis C virus is widespread among people who inject drugs in Europe, with HCV antibody prevalence ranging from 18% to 80%. Since HCV infection becomes chronic in approximately 70% of people infected with HCV and is often asymptomatic for many years, those affected may be unaware of their status, contributing to a hidden epidemic.

Proportion (%) of HCV infections among people who inject drugs that are genotypes 1 or 4

Privileged Access

Community-led approaches to HCV testing, treatment and care thrive on the unique advantages that peers who have personal experience with drug use bring to the forefront. Peer workers, drawn from the community of people who use drugs, establish themselves as trusted members within drug-using venues, seamlessly integrating into the local drug supply system.

Regardless of the specific substances they use or their current drug-using status, all peer workers use their privileged access to engage with and assist people who use drugs. Those with direct lived experiences in injecting drug use, actively participating in the spaces where injecting drug use occurs, and people who have past or current experience of living with HCV offer invaluable insights and unparalleled access.

Even in the absence of formal drug user groups, informal mutual aid networks naturally form among people who use drugs. Those who assume impromptu community caring roles often evolve into potent peer educators and workers. Internationally, autonomous drug user groups have taken charge, distributing vital resources and delivering peer education through interconnected networks, especially in instances where policymakers lag in response.

In stark contrast to prohibitionist drug policies that seek to disconnect people who use drugs from the environments and cultures of drug use, harm reduction strategies recognise these social contexts as crucial resources for intervention. Such programmes capitalise on the expertise, experience and social connections cultivated by people who use drugs through their lived experiences. By placing value on this collective knowledge, these initiatives align with harm reduction goals, fostering a sense of community and individual and collective self-worth.
Country Case Study

Norway

Hepatitis C has posed a significant public health challenge in Norway, with 21,105 registered cases between 1990 and 2018 and an estimated 10,000–12,000 people living with chronic hepatitis in 2019. The majority of these cases were linked to injecting drug use, prompting the Norwegian Ministry of Health to formulate the ambitious "National Strategy Against Hepatitis 2018–2023" to reduce HCV incidence by 90% by the end of 2023 and prevent HCV-related deaths.

At the forefront of this battle has been ProLarNett, a drug-user-led and member-based organisation dedicated to ensuring safe opioid agonist treatment (OAT) in Norway. Since 2013, ProLarNett has been addressing the urgent issue of HCV among people who use drugs, initially focusing on awareness through brochures and a website. However, their most groundbreaking initiative came to fruition in the form of the "Hepatitis Bus", a mobile testing station to reach people who do not engage with conventional healthcare services.

The Hepatitis Bus

ProLarNett initially gained financial support from Gilead, AbbVie and MSD (each contributed an equal share) and later secured a project grant from the Ministry of Health, which enabled ProLarNett to transform a camper into a mobile testing station – the Hepatitis Bus. Manned by peers and a professional nurse equipped with cutting-edge testing tools and ultrasound liver scanning equipment, the bus aimed to reach those avoiding regular health services.

Initially, the project focused on visiting institutions and prisons in Norway. Later on, its scope broadened to include low-threshold measures, shelters and meeting places for people who use drugs.

From 2019 to 2020, the Hepatitis Bus extended its reach to over 40 different municipalities. During this time, 317 people underwent testing, revealing 102 cases of chronic HCV. Out of these, 87 individuals received prescriptions through the initiative, with 78 successfully completing the treatment. In 2022–23, the HCV prevalence among the clients tested was around 20%. In recent weeks, there was a surge in cases (the prevalence was more than 30%). The team attributes this rise to an increased number of people using the bus who may not use conventional health services.

During the COVID-19 pandemic, the Hepatitis Bus also served as a COVID Bus that distributed hand sanitisers, EuroNPUD flyers and harm reduction materials such as needles, syringes, filters and sterile water.

“Better than having to go to the doctor – I am afraid of doctors and hospitals.”

— The Hepatitis Bus user
Bus Operation Process

The operational process of the Hepatitis Bus involves meticulous planning and collaboration:

- **3 weeks to a month before arrival:** ProLarNett contacts service providers in the designated area.
- **1 week before arrival:** Service providers inform the local population about the upcoming visit, displaying informational material.

The Hepatitis Bus operates on a first-come, first-served basis. Upon arrival, the process consists of the following steps:

1. **General information recording:** Personal details such as name, address, phone number and date of birth are recorded.
2. **Blood sampling:** A small needle is used to collect a blood sample from the finger.
3. **Screening test:** The first step involves a screening test using dried blood.
4. **Diagnostic testing:** A more detailed test is conducted to establish the presence of current HCV infection, providing results within an hour.
5. **Ultrasound of liver:** In cases of a positive test and age below 40, an ultrasound of the liver is performed.
6. **Prescription and follow-up:** A positive test triggers an immediate notification to the service provider, who promptly prescribes the necessary medication. Clients can obtain the prescription the next day, with ongoing support from service providers for medication administration.

At the close of each day, the bus is strategically parked in public spaces to ensure widespread distribution of harm reduction equipment.

The Impact

After investing time in building connections with various doctors across multiple healthcare facilities, ProLarNett can efficiently request prescriptions with a simple phone call. This streamlined process has been incredibly beneficial.

The Hepatitis Bus project has garnered positive responses from both people who use drugs and healthcare personnel. Service users appreciate the peer-driven approach, fostering trust in the testing process and providing a preferred alternative to traditional hospitals. Health personnel commend the initiative for its cost-effectiveness, saving them from multiple hospital drives and allowing them to focus on comprehensive care.

ProLarNett are also planning to introduce dry blood spot testing. This test can be done at home and reflects ProLarNett’s commitment to devising innovative approaches to reach people who, despite the low threshold, do not use the Hepatitis Bus.

ProLarNett’s Hepatitis Bus serves as a symbol of hope in Norway’s fight against HCV. Through innovation, peer work and efficient healthcare delivery, this initiative has not only addressed the disease but also transformed the narrative around public health.

“Cost-effective and saves us from multiple drives to hospital with one person at a time.”

— Health service provider
Country Case Study

Portugal

In Portugal, HCV remains a pressing concern, and it is estimated that 40,000 people live with an active HCV infection. Among people who inject drugs, the HCV prevalence is estimated to be around 82%, but a significant portion remains undiagnosed or lost to follow-up after testing. With a high concentration of HIV and HCV infections in urban areas, particularly the Lisbon metropolitan area, there's a critical need for comprehensive HCV interventions.

GAT IN-Mouraria Harm Reduction Centre

In response to the health crisis among people who use drugs, the GAT IN-Mouraria project started in 2012 in Lisbon and has been instrumental in advocating for HCV testing and treatment for marginalised communities. GAT IN-Mouraria is part of the non-governmental organisation Grupo de Ativistas em Tratamentos (Treatment Activist Group – GAT). The GAT IN-Mouraria low-threshold, peer-led services are primarily aimed at people who inject drugs who are not reached by other existing services and at-risk populations, including migrants, homeless people and sex workers – although the centre is open to all people who require its services. Services are provided without an appointment (walk-in), free of charge and without the need for personal identification.

Most of the centre’s clientele comprises men, with an average age of 43 years. Most clients experience unstable living conditions, residing on the street, in shelters or in occupied houses. Over two-thirds of the centre’s clients (69%) report current or past drug use, primarily consuming cocaine, heroin, cannabis and alcohol. Approximately 41% of clients who use drugs report injecting.

The GAT IN-Mouraria project offers a range of services (including a community-led drug consumption room) that promote safer drug use, access to health and social services, the active participation of peo-

“Peer work is irreplaceable because it is the first communication with the clients to connect them to the service. The peer can identify and engage and communicate with people in a way others can’t.”

— GAT IN-Mouraria peer worker
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People who use drugs in decision-making processes, the rights of people who use or have used drugs, and research to improve evidence- and rights-based practices. The GAT IN-Mouraria project offers rapid testing for HIV, HCV, hepatitis B virus (HBV) and syphilis, along with nursing and medical appointments (including a decentralised hospital consultation for HCV treatment and mental health consultations), medication support and referrals to the national health service, including speciality consultations.

Peer workers play a crucial role in the GAT IN-Mouraria project. Peers are trained to perform rapid tests and to provide information and support to people who use drugs. An important part of their work is creating links between people who use drugs and social and health services by taking care of practical arrangements, such as booking appointments, escorting clients to the hospital and being present during conversations with doctors or staff from other support services. Through their knowledge and experience, they can create a strong and close connection with people who use drugs and serve as positive role models, which can empower people who use drugs to make informed decisions about their drug use and treatments.

An important component of GAT IN-Mouraria’s work is the drop-in approach. The centre offers a safe and welcoming space with peer support and access to basic services (including food supplements, clothes and hygiene products), distributes injecting and smoking materials for safer consumption, and provides access in situ to a nurse service daily and medical appointments twice a week. The centre also offers comprehensive social support, information and referrals covering various areas such as health, treatment, documentation, social benefits, legal matters, employment and training, and housing. To engage people who inject drugs and migrant populations, the centre employs strategies like peer-based outreach and referrals, collaborating closely with affiliated drug user and migrant associations to extend the reach of GAT IN-Mouraria services.

Financial incentives have proven to be beneficial in encouraging people to get tested and receive treatment. Clients have appreciated the 5 EUR incentive provided at GAT IN-Mouraria, as it compensates for their time and helps ensure their continued engagement with the service.

“I was really well treated. The doctor was very caring and worried about my situation throughout the process, from the test to the treatment and all the way until I finished the treatment. The doctor got in contact with my doctor and spoke with them and let them know about the situation. The workers at GAT were very helpful. I had a peer worker to help me to the appointments.”

— GAT IN-Mouraria service user
Impact
The GAT IN-Mouraria’s community-driven approach has proven to be effective in reaching out to people who use drugs and providing tailored services to meet their needs. Unlike conventional clinical settings, GAT IN-Mouraria’s flexible schedule, adapted to the community’s needs, has ensured better attendance and engagement.

The HCV testing data from August 2015 to August 2023 shows that out of the 3042 people tested, 2063 (67.8%) were men, with 224 (10.9%) showing reactive results and 70.1% of those (157) accepted referrals to HCV services. People with past or current drug use constituted 47.3% of the tested population, with 17.7% showing reactive results and 71.7% of those accepting referrals. People with past or current injecting drug use, accounting for 13.1% of the tested population, had the highest reactivity rate (55.5%) but maintained a 71.5% acceptance rate for referrals. Migrant people made up 49.9%, with a 4.7% reactivity rate and a 69% acceptance of referrals. People with a history of imprisonment had a higher reactivity rate (29.6%), and 71.9% accepted referrals.

Throughout 2022, 414 registered clients used the centre regularly, averaging 51 daily client visits. During this period, 450 screening sessions were conducted, and 126 peer accompaniments to services were carried out. The centre also facilitated 197 referrals to other health services, contributing to a total of 3,070 health interventions. Additionally, clients actively engaged with social workers, participating in 2,441 appointments to address their diverse needs. GAT IN-Mouraria’s close partnership with stakeholders and individuals across the local community is considered a key component in achieving such positive results.

Beyond the numbers, the qualitative impact is evident in the centre’s contributions to debates on drug policy, community research, national and international visibility, awareness-raising activities, and the participation of peer workers in research and scientific events.

While the GAT IN-Mouraria project has been successful in its community-led approach to HCV testing and treatment, challenges persist, particularly in securing funding and a larger physical space. Peer professionalisation is another important aspect that needs attention and support from the government and relevant organisations.

While the project has, in the past, received partial funding from the municipality and the local government and the testing offer is funded by the regional health administration, the project has never been funded by the national HIV programme. Despite facing financial obstacles, the project remains resilient, and recently, grants from SICAD and the Social Security Institute were secured.

The sustained commitment of peer workers, coupled with political and community support, positions GAT IN-Mouraria as an important actor in Portugal’s ongoing battle against HCV. Peer workers and community-led services have proven to be essential in promoting testing, treatment and care for HCV, HIV and other blood-borne infections among people who use drugs. The sense of understanding, trust and empathy created by peer workers has led to improved engagement, adherence to treatment and overall well-being of clients in these vulnerable populations. GAT IN-Mouraria has tackled immediate health concerns and contributed to broader societal discussions and interventions, showcasing the power of community-led responses in transforming lives and shaping public health outcomes.

“From my own experience, I had Hep C before working here, and if it wasn’t for peers, I wouldn’t have got tested. I have never been in a hospital for treatment. Everything was through GAT. If it wasn’t for peers, it would have never happened. Drug users don’t want to go to hospitals.”

— GAT IN-Mouraria service user
Similarities and Differences between Norway and Portugal

Both Norway and Portugal have successfully integrated peer workers into their initiatives. Peer-led interventions have played a crucial role in establishing trust, fostering connections with marginalised populations, and providing support throughout the HCV testing and treatment processes.

Both initiatives recognise the importance of reaching out to vulnerable populations facing barriers to traditional healthcare access. Norway’s Hepatitis Bus travels to various locations, including institutions and shelters, while Portugal’s IN-Mouraria focuses on low-threshold, peer-led services for people who inject drugs, migrants, homeless people and sex workers.

Community engagement and collaboration with local stakeholders have been instrumental in the success of both initiatives. Establishing partnerships with local service providers and leveraging community networks have enhanced the reach and impact of the HCV testing and treatment programmes in both countries.

Norway and Portugal initiatives differ in the type of venue where HCV testing is provided. Norway’s approach with the Hepatitis Bus involves a mobile testing unit that travels to different locations, including institutions and shelters. This dynamic strategy allows the service to reach diverse populations, especially those who may avoid conventional healthcare. On the other hand, Portugal’s IN-Mouraria relies on a fixed drop-in centre in Lisbon. While this provides a consistent location for services, it may present challenges in reaching populations in more remote or underserved areas.

The countries also differ in the level of financial support from national government health programmes. Portugal’s IN-Mouraria has not received any funding from the national HIV programme. In contrast, the Hepatitis Bus project in Norway secured a grant from the Ministry of Health. The varying degrees of government recognition may impact the sustainability and integration of these community-led initiatives into broader health systems.
Conclusion

The community-led approaches to HCV testing, treatment and care presented in this technical briefing show a transformative paradigm in public health. The significance of these approaches lies not only in their effectiveness but also in their capacity to address the complex challenges posed by HCV. The important role played by peer workers and drug user activists, as shown by the case studies, highlights the importance of lived experience in reshaping HCV healthcare.

The success of community-led initiatives in Portugal is a testament to the power of peer engagement. Drawing on their personal experiences, peer workers have increased awareness and fostered an environment conducive to HCV testing and treatment. The positive outcomes from Portugal show how community-led strategies can effectively address both the medical aspects of HCV and the social and cultural dimensions, contributing to a more holistic approach to healthcare.

Likewise, the case study from Norway shows the effectiveness of collaborative efforts in HCV testing and treatment accessibility. The engagement of peer workers and drug user activists has played a key role in demystifying HCV, making testing and treatment more approachable to a broader audience. The Hepatitis Bus has played a key role in dismantling barriers and reducing stigma, promoting a more inclusive and accessible healthcare experience.

The community-led approaches presented in this briefing align with strategic objectives aimed at saturating peer networks with resources and knowledge. By doing so, these initiatives ensure widespread access to HCV testing and comprehensive care, ultimately enhancing healthcare outcomes for affected populations. The success stories from Portugal and Norway serve as compelling evidence that integrating lived experience into healthcare strategies is essential for the success of HCV interventions. The lessons learned from these case studies provide a roadmap for policymakers, healthcare providers and communities to collaboratively forge a more inclusive and accessible healthcare landscape for people who inject drugs.
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Lana Durjava from Altlier (altlier.com) developed and edited the briefing based on information collated by Lynn Jefferys and John Melhus.

Anda Theodorakaki designed the briefing in a smart approach that reflects the technical quality and community spirit of the resource.

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The Peer-Led Harm Reduction project is a showcase of global and European best practices that are accessible, non-judgemental resources that drug user groups use to power the quality of their local training and advocacy.

EuroNPUD Peer-led Harm Reduction Team produces Technical Briefings that describe good practice principles and case studies and one-day capacity-strengthening courses. To date, the focus has been on naloxone and opioid overdose prevention and management, safer injecting and needle and syringe programmes, and HCV testing, treatment and care.

"When peers and practitioners train together, there is an exchange of lived and learned expertise that helps bust stigma among practitioners and boost the motivation of the peers."
— Mat Southwell, EuroNPUD Project Executive

"The design approach of the Peer-Led Harm Reduction courses aims for a balance of short text passages and vivid images that emphasise the material. The design champions inclusivity and demonstrates the diversity of the drug-using community, with a special focus on destigmatising people who use drugs."
— Mali Alicia Nieto Brotons, graphic designer

EuroNPUD’s peer-led harm reduction resources are designed to be tailored and translated to different national contexts. The design and presentation are mindful of the fact that the target audience are drug user activists or harm reduction practitioners. The courses will normally be delivered by a training team including those with lived or living experience. Drug user trainers are able to use their personal testimonies and examples from the work of drug user groups as teaching aids within the course.

Peer-Led Harm Reduction Resources
EuroNPUD’s peer-led harm reduction resources are available to use and download on our website, www.euronpud.net.