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The Development of a Toolkit & Guidelines to Support Peer Engagement

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UISCE

EXECUTIVE SUMMARY

The report explores the importance of peer engagement in harm reduction and advocating for the active involvement of marginalized community members in decision-making processes. It emphasizes the need for moving beyond tokenism to meaningful engagement, where peers, particularly people who use drugs (PWUD) are given real power to influence policy and services. The findings from this report also inform the toolkit and guidelines which was co-produced by the peer network and the academic researchers in partnership.

Key Objectives:

- Conduct an evidence-based review of current peer engagement models.
- Organise a Knowledge Exchange Workshop to collaborate with UISCE, establishing the evidence on best practices and the lived/living experiences of PWUD.
- Develop guidelines and a toolkit to help increase PWUD participation in advocacy, research, service improvement, policy influencing and the education of stakeholders to the value of the lived/living experiences of PWUD.

Research Approach

The study utilises a Community-Based Participatory Research (CBPR) methodology, emphasizing social action and sustainable change. This includes:

- A systematic scoping review of literature on peer engagement.
- A qualitative investigation into the lived/living experiences of PWUD.
- A Knowledge Exchange Workshop that integrates findings from both literature and community input.

Findings

Several emerging themes were identified from the literature, including:

- Definitions and purposes of peer engagement.
- The distinction between meaningful engagement and tokenism.
- Frameworks such as the CBPR and other models for fostering peer engagement.
- The benefits of peer engagement, including trust-building and better service outcomes.
- Enablers and barriers to peer engagement, such as flexibility, trust, and systemic discrimination.

Workshop Findings

The Knowledge Exchange Workshop highlighted similar challenges and enablers:

- Social determinants, poverty and environmental factors of trauma
- Participants noted experiences of stigma and exploitation in interactions with service providers.
- Structural barriers like criminalisation and institutional discrimination were identified as key obstacles to meaningful participation.
- Peer networks were seen as a critical enabler of engagement.

Recommendations

- **Build Trust, Reduce Stigma;** Create additional safe spaces for peer dialogue and continue to engage in public awareness campaigns to reduce stigma and highlight the importance of including PWUD in civic process.
- **Reform Policy and Structure;** Advocate for a human rights-based approach to drugs policy by ensuring that PWUD inform all policies that affect them, including decriminalisation and legal reforms.
- **Build Capacity and Empower;** Develop capacity for PWUD through training, education and peer leadership programmes.

- **Create Inclusive Platforms;** Continue to advocate for inclusive, structured consultative processes including public community forums that relate to service planning, local government and impact on PWUD their families and communities.
- **Build Alliances and Advocate;** Partner with advocacy groups and NGOs to amplify PWUD voices and advocate for their inclusion in civic processes, focusing on substance use, treatment, family support services and community safety. This includes collaboration with diverse stakeholders, to achieve policy changes, leveraging UISCE's experience and strategic alignment with other organisations.
- **Monitor and Testify;** Implement feedback mechanisms via peer networks to facilitate communication, transparency, evaluation and adjustment, and to hold policymakers to account.
- **Promote Representation;** Promote the visibility of PWUD in public life by highlighting success and encouraging full civic participation, inclusive of running for public office.
- **Address Social Determinants;** Continue to implement a social determinant approach and advocate for the integration of services that impact on the capacity of PWUD to fully participate in society.

In conclusion, the report advocates for transformative change by centring the voices of PWUD in policy development and service delivery, thereby promoting health equity and social justice. The definitive output from this report is the accompanying Peer Engagement Toolkit & Guidelines (2024).

FOREWORD

I would like to start by thanking all of our peers involved in many of the activities and actions UISCE delivers on, organisations that support us in supporting our peers and TCD, and Dr Peter Kelly and Dr Debra O Neill for producing this important document in collaboration with people who are normally left behind, cut off and experience punishment, discrimination and a denial of their human rights, which leads to poorer outcomes for people who use drugs, families and our communities.

This results in a reinforcing of negative stereotypes, structural violence and environmental trauma which becomes intergenerational and unfortunately leads to a great deal of harm and a high number of preventable drug related deaths. The people UISCE is made up of come from the groups already most at risk of marginalisation. Groups who are exposed to or experience poverty, from lower socio-economic backgrounds, members of the Traveller community, members of the LGBTQ+ community, members of new communities, have care experience, experience of homelessness, ex-prisoners, sex workers, people with a disability, mental health issues and undiagnosed neurodiversity issues.

Many of our peer state they feel they are punished for being poor or their background, then for experiencing trauma, then for taking drugs to cope with the trauma. Their experience is one of not being heard, having no power or agency and being excluded. This can be evident in their engagements with services, state agencies and policy makers which see them as a 'problem' to be fixed. This results in a depowering of people which leads to an institutionalising of people into a top-down approach which delivers services, research and policies 'onto them' which can create more harm and lead to poorer outcomes.

We welcome the findings of the Citizen's Assembly on Drugs Use which unequivocally stated that the current approach is not working, is not good enough and needs to be informed by those who are the most impacted and with the most experience.

To do this we must look at the research and evidence as to *how* we do this. This report and the subsequent toolkit do this. People tell us they value the services and agencies, but do feel controlled within them, and have limited ability to have an independent space to explore the issues through their own living experience, develop their own analysis and be able to play a lead role in the design, delivery and evaluation of service provision and policy design.

To achieve the outcomes, we all want to see it will mean a genuine sharing of power and opening up of our spaces and a changing of mindset that shifts from seeing people as a problem, or simply the recipients of a service not decided or designed by them to seeing us as valued partners who have a key role to play in identifying emerging issues and developing collective responses. In fact, it cannot be done without us.

The good news is this work is happening, its evidence based and back up by research. UISCE started as a 'service user forum' in Ana Liffey in the 90's. It was quickly realised by people who used drugs, the services and the state for it to be effective it needed to be independent.

In 2024 it's still here, is solely made up of people with lived and living experience of drugs and this year it has worked in partnership with many organisations to develop and deliver peer-led training, workshops, research, campaigns, outreach, position papers and the supporting of setting up peer-led advisory boards and informing policy on a national level.

This report and toolkit are a response by people with living experience of drugs through UISCE to a need identified across the country by our peers, services, organisations and state agencies who tell us people who use drugs are not represented well in decision making and they want guidance and support on how to incorporate what we do in UISCE, in their work.

This is an evidence-based framework informed by the structured, peer-led approach implemented by UISCE and international research and best practice which seeks to close the gap between those that have power and the ability to change things, and those that normally don't, but who everyone now agrees need to be central to it.

It's clear, its practicable and we bring it to you as a potential partner for change.

We know how to achieve change, change has been achieved, but we must be ambitious. We have structures, policies and research opportunities but we need to ensure they provide genuine partnership and focus on a process that promotes participation and leadership which ensures the voices of those who are saying they feel cut off and left behind included and driving the implementation of actions which promotes the expert role PWUD have in driving the change we all want to see.

Andy O'Hara

Coordinator. UISCE

November 2024

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1.0 INTRODUCTION

Harm reduction strategies have increasingly recognised the importance of peer engagement as a vital component in addressing health inequities and achieving social justice. Peer engagement, involving the active participation of marginalised community members in decision-making processes, ensures that harm reduction services are not only designed with the affected populations in mind but also executed in a manner that is equitable, respectful, and fair (Greer et al., 2016). This approach aligns with broader public health practices where inclusive participation is paramount to effective and sustainable outcomes (Brown, 1991, Robertson & Minkler, 1994).

The concept of peer engagement mirrors participatory public health processes where inclusivity and equity at the decision-making table are critical (International Association for Public Participation, 2018). In harm reduction, peers—individuals with lived/living experiences of drug use—bring invaluable insights into the local risk environments, encompassing physical, social, and economic factors. Their involvement ranges from being informed and consulted to becoming active collaborators and decision-makers, as outlined by frameworks such as the International Association for Public Participation's (IAP2) Public Participation Spectrum and Aronstein's ladder of citizen participation (Arnstein, 1969; IAP2, 2018).

Despite the recognized value of peer engagement, efforts in many regions, including Canada, have often fallen short, limited to mere tokenism where peer contributions are acknowledged but not empowered (Greer et al., 2016). There is a pressing need to move beyond tokenism towards meaningful engagement, where peers are given real decision-making power, leading to more effective harm reduction interventions (Arnstein, 1969).

From a health equity perspective, peer engagement is essential to make harm reduction services accessible, accommodating, affordable, and acceptable

(Greer et al., 2016; Robertson & Minkler, 1994). By involving peers as experts in the design and implementation of these services, we can ensure that the solutions are tailored to meet the actual needs of the community, thereby addressing systemic marginalization and fostering empowerment (Brown, 1991; Minkler, 1989). This introduction sets the stage for a deeper exploration of peer engagement in harm reduction, advocacy and research in general, highlighting its theoretical underpinnings, current practices, and the imperative for more inclusive and empowered participation.

1.1 AIM AND OBJECTIVES

The aim of this participatory research project is to facilitate the identification of tools that will allow peer support groups and services to identify where they are on a spectrum of participation, this will be achieved by the development of a conceptual framework. The aim is also to develop guidance on how to progress along this spectrum with a view to creating the conditions for transformative change.

The objectives are:

1. To provide an evidence review of current peer engagement processes and evidence-based models.
2. To develop and deliver a knowledge exchange workshop on best practices for developing peer engagement in multiple settings.
3. To co-produce a set of guidelines based on the evidence review and knowledge exchange workshop which can help to increase the participation of PWUD in the design, delivery and evaluation of policy and services.

1.2 RESEARCH & DESIGN APPROACH

The overarching methodology of this study is grounded in the Community Based Participatory Research (CBPR) approach which is ideal for the proposed research as it has been characterised as a research approach for helping researchers develop genuine partnerships within the community to help ensure a study is locally relevant and is addressing real community challenges (Sharek, 2018; Charlie, 2008). It also emphasises the importance of social action and sustainable change (Coughlin et al. 2017).

This also mirrors the central facet of the transformative paradigm in which the establishment of relationships with community members enables the study to be more *"culturally responsive"* (Mertens 2012: p.808). By comparison, traditional research is often investigator-driven, with less community involvement. The CBPR is commonly used in this type of research and could help assuage the PWUD community's concerns and reduce any distrust in relation to the research. Reflecting the transformative paradigm, within a CBPR approach, the researchers work with, and for the community rather than doing research on or about them. Importantly, the approach also emphasises the participatory power and action of community members as agents not only in the research process, but also in their own lives and communities.

This selected research methodology and design had several phases including a systematic scoping literature review and a qualitative investigation into the lived/living experience of PWUD in relation to participating in research and being members of decision-making fora. The Knowledge Exchange Workshop provided a comprehensive comparison of best practices identified in the literature with the lived and living experiences of workshop participants. The final phase was the integration of the collective data which identified gaps and potential areas for improvement in the current model of PWUD engagement

with a variety of stakeholders via Uisce. This methodology provided an added value which would not have been discovered if only one methodology was applied. The qualitative phase provided a deeper insight into the lived/ living experiences, barriers and enablers experienced by PWUD through participation in the Knowledge Exchange Workshop.

Qualitative Phase: During the qualitative phase, the Knowledge Exchange Workshop established the convergence/divergence between the literature review and the current practices adopted by the PWUD network. A thematic analysis was used to map the findings from the exchange. A purposive sample of PWUD was recruited by UISCE from their membership to participate in the knowledge exchange workshop, reducing the ethical requirement of professional researchers engaging directly with PWUD. In this study, 'adults' are defined as individuals over the age of 18 years.

Quantitative Phase: A brief quantitative questionnaire also provided data on the main characteristics of participating PWUD and summarised their views on current engagement experiences, their satisfaction with the process and their views on sustainability.

As previously detailed the analysis of both data sets was integrated in a Joint Display. This provided a comprehensive understand of both quantitative and qualitative findings and their congruency. Adhering to CBPR best practice, UISCE team members participated in all aspects of the funding submission, qualitative and quantitative data collection and the production of this report.

1.3 SYSTEMATISED SCOPING REVIEW

The chosen scoping literature review applied a systematic format. This method combined the flexibility and exploratory approach of a scoping review with the pre-specific eligibility criteria of a systematic literature review (SLR). This combination allowed the research team to assess the extent of the available evidence and practices and to organise this evidence into groups. This facilitated the presenting of the findings in a narrative rather than a numerical format. In this format, the available publications, both empirical and grey, are screened to provide an evaluation of what is known about the topic of PWUD peer participation in decision making fora and interagency engagement, and addressed the research aims and objectives.

The initial stage of the process, a literature review, identified common practices, barriers and enablers in the research of peer engagement with PWUD. Common search strings and universal internationally applied terminology ensured the widest possible scope was applied during the literature search. In addition to the empirical evidence, "grey literature" was included to increase the breadth of the reviewed documentation. The grey literature included, but was not limited to, NGO and PWUD reports, PWUD Network Organisation websites, cited publications and surveys/ studies which advocate for the rights of PWUD. Other supporting documentation and reports produced by international organisations, educational institutes and advocacy groups were also included.

The review process commenced with a search of MEDLINE (PubMed) and CINAHL (The Joanna Briggs Institute 2015). This initial scoping established the search strings, including the key concepts outlined in the research tender objectives and subsequent meetings with UISCE. The key terms identified formed the basic concepts of the review and informed the basis of the scoping

literature review search. Once the search strings were refined, and the key terms identified, the key concepts and index terms were searched across the following databases – PubMed (MEDLINE), CINAHL (Cinahl Headings), PsychINFO (PsycINFO Descriptors) and Health Source. The outcome of the database search strategy formed the basis of the literature review analysis.

The search strategy and eligibility criteria focused on the three key concepts of People Who Use Drugs (PWUD), 'contribution,' and 'participation,' and 'guides / frameworks and best practices' (Appendix 1). The screening process was led by the Principal Investigator (PI) who identified the MeSH terms and parameters of the initial search in line with the research objectives. The Senior Researcher then conducted the Title and Abstract screening before full-text screening was completed. Finally, the PI approved extractions. Other non-database publications were identified by the team through websites, polices, organisations, frameworks, and citation searches. Following retrieval, this literature was also screened for eligibility, before being included in the review. The included PRISMA Flow Chart (Appendix 2) outlines how many articles were screened by title and abstract, full text, and finally included in the final review for narrative analysis.

Each of the four database search results were imported into unique corresponding folders in the citation management software, Endnote X9, Clarivate Analysis (US) LLC. These discovered publications were then imported into Covident V1388. The screening process of Covident V1388 is a four-step process as outlined in Table 1.

Table 1 Screen Process for Study Selection

Stages	Covident V1388 Review Process
Stage 1	Importation of publications from Endnote Library
Stage 2	Title and abstract screening
Stage 3	Full Text Screening
Stage 4	Extraction of relevant publications

A narrative synthesis and thematic analysis guided the analysis stage of the literature review (Mayes et al., 2005, Coughlan et al., 2013). The review also identified the most relevant emerging themes, including barriers and enablers of stakeholder engagement by PWUD.

1.3.1 INCLUSION CRITERIA FOR PUBLICATIONS INCLUDED

- Articles on adult PWUD engagement with stakeholders and service providers
- Articles focusing on PWUD's meaningful participation in policy and decision-making fora.

1.3.2 EXCLUSION CRITERIA FOR PUBLICATIONS INCLUDED

- Articles reporting on treatment, interventions or recovery practices for PWUD.
- Articles focusing on PWUD and other health, well-being or other measurements.

1.3.3 ADDITIONAL CRITERIA FOR INCLUSION

Further eligibility criteria denoted by the scoping process also ensured that the content of the included studies was relevant to the research aims and objectives. Only articles where full texts in the English language was available were included. Only publications dated between 2000-2024 were included to ensure current and best evidence was used. The library of Trinity College Dublin was made available to access and enhanced this process.

1.3.4 THE DATA RECORDING PROCESS

In the analysis, the following data fields were recorded to provide a narrative synthesis of the selected publications as detailed in the PRISM diagram.

- Author(s) and Year of publication
- Publication Title & Country
- Type of Study
- Sample Size
- Intervention
- Outcomes

2.0 SYSTEMATIC SCOPING REVIEW

In total ten publications were discovered by the scoping review database search and an additional thirty-seven documents were discovered in other searches including google search, citation searches and organisation websites (Appendix 2). Appendix 3 provides a synthesis of the publications discovered and the narrative summary (Appendix 4) provides a full overview of all discovered publications including the peer reviewed literature not discovered in the database search.

Eighty percent of the publications identified in the database search were from Canada, with one publication from the United Kingdom and the USA, respectively. Additional non-database searches found seventeen peer reviewed publications through citation and google scholar searches. Ten publications were found through searching organisational websites and another ten were found directly through organisations themselves. A full detailed narrative synthesis of identified literature is available in Appendix 4.

3.0 THEMES FROM LITERATURE REVIEW

This exploration of emerging themes, within the field of PWUD in the literature review, presents a comprehensive overview of the latest developments and innovations shaping research and practice around peer engagement. This chapter reports on the findings from the iterative thematic analysis (Braun & Clark, 2024), discovering multifaceted trends that are driving change and producing new practices in the field. The discovered themes are not isolated phenomena; they interact and overlap, creating a dynamic landscape that is continuously evolving. This section aims to unpack these emerging themes, providing a detailed analysis of their implications for future research, policy, and practice, including informing the proposed Peer Engagement Toolkit.

Across the discovered publications in the database searches (n=10), additional peer reviewed publications found via google and citation searches (n=8), websites (n=10), and additional grey literature explored (n=19) the following central themes have emerged and will be reviewed in more detail.

- The benefits of peer participation
- Pathways for peer participation
- Roadblock for peer participation.
- Environmental/organisational barriers to peer participation

However, before these overarching themes are explored several clarifications and classifications were also discovered in the literature which need to be addressed. These include the definition and purposes of peer engagement, as well as the most frequently adopted frameworks, models, guidelines and principals. Finally, the limitations of peer engagement and this review in general are discussed.

3.1 THE DEFINITION OF PEER ENGAGEMENT

In general peer support involves individuals who have lived or living experiences of overcoming challenges, such as mental health issues, substance / alcohol use, or other significant life stressors providing support to others undergoing similar experiences. The type of support can include emotional support, sharing of knowledge and skills, practical assistance, and connecting individuals with resources and communities of support, including advocacy or supporting researcher and/or service providers. While Ti et al. (2012) suggested there was no established universally accepted definition of peer engagement, more recent research in the field defines peer engagement as the

"active participation of people with lived experience of substance use in research, programmes and policy decision making procedures.

(Geer et al., 2016).

Greer et al. (2016) also stated that peers were the experts in relation to illegal drug use and provided valuable insight about challenges and enablers in accessing harm reduction programmes in their communities, as well as providing empathy and support to PWUD based on their shared experiences. This form of assistance is rooted in mutual respect and empowerment, fostering an environment where individuals can feel understood and supported on their journey to recovery or simply making informed decision about their life.

While the literature recognises peer support as a vital component in many aspects of research, advocacy, clinical interventions and harm reduction programmes. The findings also suggest that peer engagement can differ greatly from programme to programme (Damon et al., 2017). The research suggests that peer engagement can operate on a continuum (Ti et al., 2016; Damon et al., 2017) anywhere from tokenism, where participation is simply *"for show",* creating a false impression of participation limited influence, with participants undertaking unnecessary and redundant tasks to full collaborative involvement in every stage of the process and decision making (Damon et al., 2017, Lazarus et al., 2014a). However, regardless of the growing body of research, some research still suggests that the concept of peer engagement and participation is unclear (Follevag & Seim, 2021; Ti et al., 2016; Welsh Government, 2014). Ultimately the nature of peer participation and contribution is greatly influenced by the purpose of the engagement.

3.2 PURPOSE OF PEER ENGAGAMENT

The practice of peer engagement is primarily influenced by the purpose of the programme or the nature of the activity. It is limited to a few key areas including harm reduction interventions, advocacy and the reduction of societal and institutional stigma through training and research itself (Baily et al., 2023; Comiskey et al., 2019, Barron et al., 2019; Ti et al., 2012).

In addition to these key areas, engagement is also centered around ensuring the service needs of PWUD are met (Greer et al., 2016). This involves service providers being trained by PWUD organisations, especially in the ongoing development of social workers and harm reduction (Duddington et al., 2023). Training programmes were also delivered to build awareness of stigma, reduce discrimination and build legitimacy of PWUD in the development of relevant policies and programmes (Welsh Government, 2014; Follevag & Seim, 2021, Comiskey et al., 2021; Partschke et al., 2022).

Research forms another key activity of PWUD engagement. The effectiveness of this engagement and the extent of participation depends on their adaptation to the specific population and context of the research. Researchers emphasise that tailoring the engagement approach, the activity involving peer participation, and the interactions among peers are crucial. These tailored strategies help build trust and acceptability, which are essential for fostering meaningful and sustainable relationships among stakeholders (Greer et al., 2019).

While peer engagement in health care and research has become increasingly popular in the last few decades, the literature would suggest that within the population of people who use drugs (PWUD) there remains long-standing stigma, when compared to other peer communities. This PWUD-specific stigma includes concerns about the reliability and quality of the work (Dunne & Brown, 2019), when the literature would provide evidence to the contrary (Greer et al., 2019).

Finally, the inclusion of PWUD in their care planning, building personal capacity and informing personal decisions is also considered a fundamental human right (Dunne & Brown, 2019; Asian Network of People Who Use Drugs, 2018). The research suggests that this basic human right is often absent from

care provision and is discussed in the findings (Section 4.0) from the Knowledge Exchange Workshop.

3.3 MEANINGFUL ENGAGAMENT & TOKENISM

In addition to fostering meaningful relationships, the engagement or participation itself must be meaningful. PWUD face a variety of logistical, lengthy and organisational barriers to meaningful engagement (Kneden et al., 2021). Nonetheless, meaningful engagement can be facilitated in many ways including paying attention to communication (Greer et al., 2019; Lazus et al., 2014; Damon et al., 2017), inclusion, and the dispensing with hierarchical structures between community members and those they engage with (Damon et al., 2017). To ensure meaningful contribution and capacity building extra support, training and an empathetic respectful environment is necessary (Bailey et al., 2023). Meaningful engagement is examined further in the Knowledge Exchange Workshop, where examples are given in the findings (Section 4.0). In addition, the topic of meaningful engagement forms the cornerstone of the subsequent Toolkit and Guidelines Manual which is a direct result of this literature review and research.

3.4 FRAMEWORK AND MODELS USED IN PEER ENGAGEMENT

Another critical aspect of the developed Peer Engagement Toolkit and Guide Manual is to review aspects, frameworks and proven models of delivering peer engagement in the literature. Reviewing the themes, the most cited approach to research in marginalised communities including PWUD is the *Community-Based Participation Research (CBPR) model* (Damon et al., 2017; Greer et al., 2019; Lazarus et al., 2014a; Closson et al., 2016). Community-Based Participatory Research (CBPR) is an approach that emphasizes the inclusion and empowerment of affected communities in the research, service development or training process.

Its primary goals of CBPR are to strengthen community capacity and improve quality of life by placing community members and community-based organisations at the centre of activities (Damon et al., 2017). CBPR involves PWUD in all stages of the process, from the development of funding to the translation of knowledge into practice (Greer et al., 2019). This participatory approach ensures that research and projects address the real needs and priorities of the community, leading to more relevant and impactful outcomes.

Networks and coalitions of people living with HIV (PLHIV), people who use drugs (PWUD), community-based and international organisations are increasingly advocating for the meaningful engagement of affected populations in all aspects of the research and service development processes concerning their community (Greer et al., 2019). Considering the evidence, it can be concluded that there is a clear preference for this model by participants in the literature. However, the application of CBPR principals is not without its challenges, especially when the process is implemented in a tokenistic or inconsistent way (Damon et al., 2017).

Other discovered frameworks and theories worthy of a mention include *"The Ladder of Participation"* model (Welsh Government, 2014), which advocates for PWUD choosing their own level of participation which may fluctuate over time and is included in the very practical *"Substance Misuse Treatment Farmwork (SMTF), Service Users Involvement"* (2014). The Australian, "*What Works and Why (W3)"* framework also provides practical guidance albeit around peer support for HIV health interventions (Brown et al., 2019). In addition, the International Network of People Who Use Drugs (INPUD) have produced a significant publication on the use of language in their *"Words Matter "(*2020) guidelines, which could be included in any future Toolkits or Guidelines.

It is over twenty years since The Nordic Council for Alcohol and Drug Research (2003) (Denmark, Finland, Iceland, Norway and Sweden, Faroe

Islands, Greenland and Åland) reported on the introduction of *"participation"* in Danish social policy legislation in the early 1990s, paving the way for PWUD Networks, Peer outreach programmes and new ways of governing which is cited as best practice (Greer et al., 2019).

Ultimately regardless of the theory, framework or model adopted, it was the level of commitment and active participation in the decision-making process which was cited as distinguishing meaningful engagement from tokenism in PWUD peer engagement (Greer et al., 2019).

3.5 ELEMENTS OF GUIDELINES AND PRATICES

Overall, there is limited evidence of general good practices and operational guidelines. The literature tends to document project-specific guidelines and elements of good practices evidenced in peer programme. They could however be reframed as elements or enablers of meaningful peer engagement. Capacity building and empowerment for example focuses on enhancing the abilities of individuals and groups by improving access, mobilisation, networks, and literacy. This process involves community building, fostering social capital, and boosting participants' skills and confidence.

A key aspect of this process is the development of a robust peer network, supported by a combination of remote and in-person training across various mediums. Activities are designed with a strength-based approach, incorporating both collaborative and independent tasks. Over time, the complexity of these activities are increased to match the growing capacity of participants. Additionally, there is a continuous emphasis on building knowledge in research and various subjects, complemented by team-building exercises to strengthen group cohesion (Greer et al., 2018). The elements of best practice and guidelines include a balance between processes, structures and

flexibility as demonstrated in the code cloud from the thematic analysis in Figure 1.

Figure 1 Elements of Good Practice from Literature

3.6 BENEFITS OF PEER ENGAGEMENT

The examined literature also confirms that the benefits of peer engagement are multifold. Traditional researchers in the area struggled to understand the community experience and subsequently failed to ask the right questions to provide the most relevant findings (Damon et al., 2017). The research was subsequently cited as limited to stereotypes and lacking in credibility and often excluding hard- to-reach PWUD (Wilson et al., 2018,; Lennox et al., 2021).

Figure 2 Emerging Benefits of Peer Engagement

Nevertheless, peer support workers developed trust and relationships with healthcare providers (Damon et al., 2017), which enabled them to add valuable insight into service provision. Building rapport between peers and providing new insights into service development and harm reduction. Using thematic analysis across the eligible studies, the following benefits of peer engagement have emerged (Figure 2). The benefits of including peers in the research process improve their experience, improve the quality of the data collected and provide credibility to the research. This was particularly true while working with female drug users, as the degree of safety increased and there were more open and honest exchanges of lived/living experiences.

3.7 ENABLERS OF PEER ENGAGAEMENT

In addition to the multiple benefit of peer engagement, meaningful engagement was further enabled by the following elements of the process which was evident across the literature.

Led by peer networks, the importance of structures and processes were also cited as an enabler, as was the support offered by trusted allies. The enablers are outlined in the Word Cloud (Figure 3) and supported by the narrative in the supporting summary of enablers.

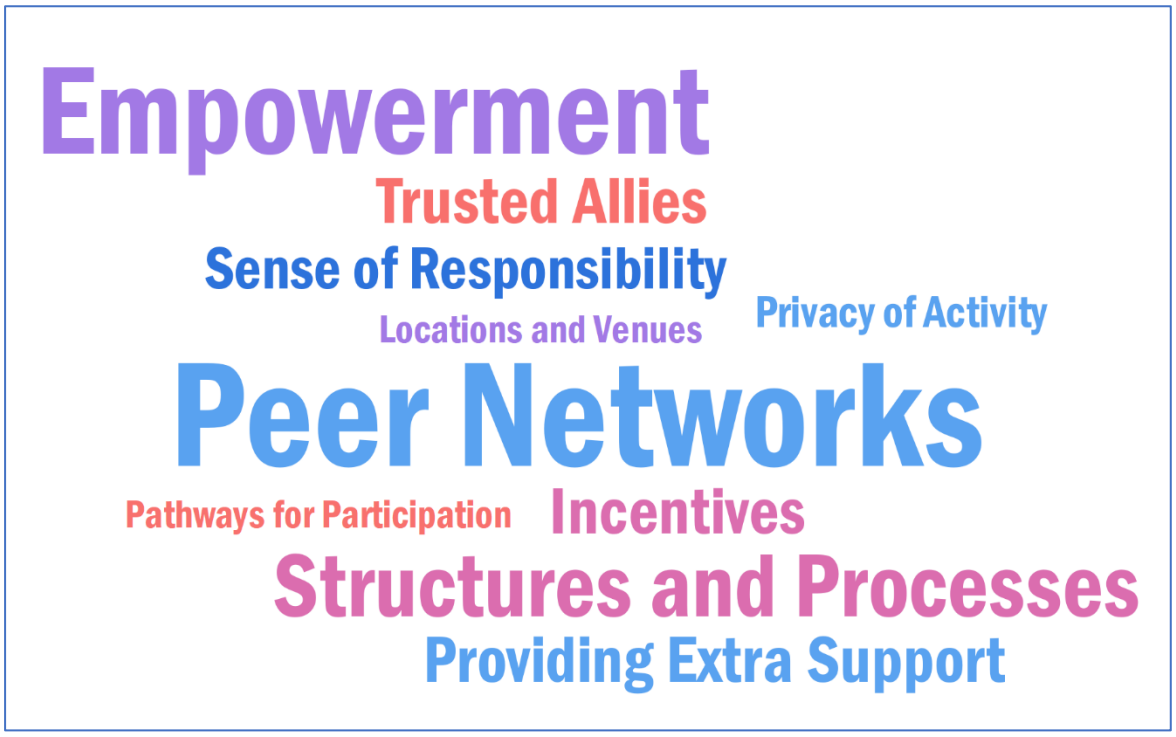


Figure 3 Enablers of Peer Engagement

Supporting summary of enablers.

- **Flexibility and Understanding**: Flexibility in the application of rules and a nonjudgmental approach were seen as crucial. This allowed for the adaptation to different capacities, making engagement more accessible (Wilson et al., 2018; Brown et al., 2019).
- **Meaningful Opportunities**: Designing projects that are worthwhile and engaging encouraged participation. Peer work was valued for providing a "safe space," mutual recognition, and a platform to share experiences (Charlie, 2008; Closson et al., 2016; Weeks et al., 2006).

- **Trust and Recognition**: Building trust and recognising the value that peers bring to discussions and decisions were important. Initiatives like naloxone training were highlighted as examples where peers could make a significant impact (Lennox et al., 2021; Brown et al., 2019).
- **Cultural Change**: Encouraging peer education for staff to foster cultural change within organisations was seen as fundamental. This included changing attitudes towards drug users and increasing empathy and understanding (Marshall et al., 2015; Follevag et al., 2022).
- **Support Systems**: Access to aftercare, housing, education, and employment support were crucial for enabling meaningful peer engagement. These supports helped peers integrate into society and contributed to their sense of purpose (Lennox et al., 2021; Damon et al., 2017; Lazarus et al., 2014b).
- **Independence**: Maintaining the independence of peer organisations like UISCE was considered vital. Independent funding and oversight ensured that peer involvement remained genuine and not merely a formality (Smith et al., 2016) .
- **Expansion of Peer Involvement**: Expanding peer involvement geographically and in different sectors, including advisory boards, was seen as a way to increase the impact and visibility of peer engagement (Lazarus et al., 2014; Marshall et al., 2015; Ti et al., 2012)
- **Empowerment**: Provided opportunities for upskilling , education, and learning empowered peers to take on more significant roles. This included involvement in service design, research and decision-making processes (Brown, 1991; Minkler, 1989).

These enablers emphasize the importance of a supportive, flexible, and inclusive approach to peer engagement, where peers are genuinely valued and empowered to contribute meaningfully to all aspects of the engagement from consultation to decision making.

3.8 BARRIERS FOR PEER EMGAGEMENT

The barriers identified which mitigated against peer engagement were varied and represented in the Word Cloud (Figure 4 and 5), where the frequency of the theme is represented by the size of the word in the cloud. Individuals in the literature recognised the environmental barriers posed by organisations and the systems in general which further stigmatised the individual who may already have been in an isolated and discriminatory environment (Figure 4). These environmental barriers stemmed from institutional stigma and discrimination which was embedded in the culture of the organisation.

Figure 4 Environmental Barriers to Peer Engagement

Some of the main barriers identified in the literature were of a personal nature, including the substance use of the individual and the risk of triggering behaviour specially when working in an outreach environment.

Figure 5 Barriers to Peer Engagement

Communication deficits including literacy also presented as a challenge, as did the cultural resistance experienced in several service provision organisations. Another barrier was the nature of the work and the conflicting identity it presented for the PWUD. This was especially the case when peer workers transitioned back into their community and were no longer engaged in advocating or assigned a role of responsibility.

3.9 LIMITATIONS OF PEER ENGAGEMENT

The literature suggests that peer engagement evolved progressively, improving over time due to reflective learning. However, the absence of adequate support, coordination, and formal guidelines hindered these efforts, highlighting the need for a deeper understanding of effective practices (Greer et al., 2016). While the practice of peer engagement is now widespread especially in mental health services, the concept and understanding of meaningful peer engagement remains unfamiliar for many service providers.

There is evidence that service providers lack understanding of the basic concept of peer engagement (Greer et al., 2019), and how the role and level of engagement vary on a continuum from information to empowerment. This is demonstrated in Arnstein's (1969) *Ladder of Citizen Participation*, which is still the most frequently used example of the various levels of peer engagement, although it has been adapted in several publications (Pratschke et al.,2022; Follevag & Seim, 2021).

The research has also indicated that the excessive research of some marginalised communities or geographical areas has led to research fatigue, with PWUD exposed to additional risks and ethical dilemmas (Damon et al., 2017). On a very practical level, the meaningful engagement of peers requires a robust, well-resourced network organisation that is continually building capacity and reviewing operations. The engagement must also ensure that the PWUD has power and influences the decision-making aspect of the process and is not simply *"consulted"* or *"informed" (*Follevag & Seim, 2021; Arnstein, 1969)

4.0 KNOWLEDGE EXCHANGE WORKSHOP FINDINGS

The knowledge Exchange workshop took place in August 2024 and was attended by twelve peer network members (including one UISCE researcher) and two researchers from Trinity College Dublin (n=13). In total the participants were five female and eight males. The average age of the participants was 42 years and all except one identified as white Irish. Excluding the researchers' participants were mainly single (n=7), followed by those who were married or cohabitating (n=3), one participant was in a relationship, and one was recently separated or divorced. The housing status is displayed in Figure 6, most of the peer participants (n=6) were in sable accommodation.

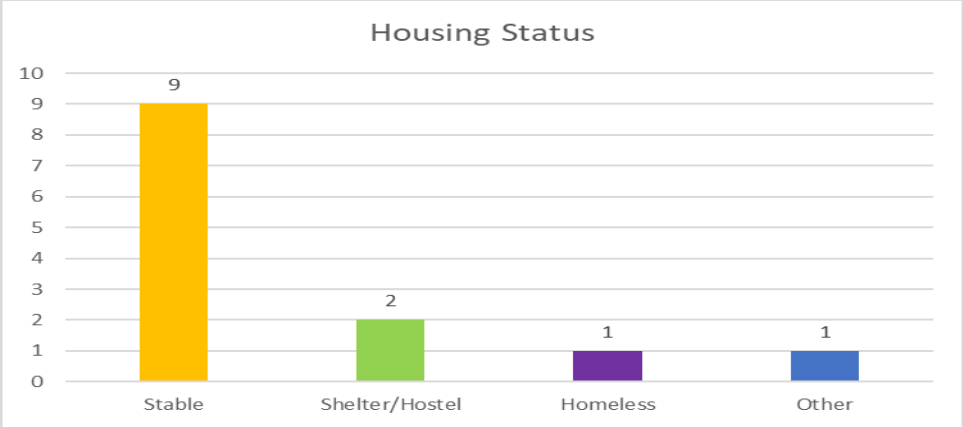


Figure 6 Housing Status of Workshop Participants

Excluding the academic researchers and the two UISCE employees two peer participants had a third-level education. The majority had completed lower secondary school (n=3). One participant had no formal schooling. The educational attainment of all peer participants is displayed in Figure 7. In general, most peer participants had a negative educational experience and had attained poor educational outcomes. Apart from the two UISCE employees, none of the peer participants had ever been employed prior to their engagement with the peer network. All peer participants reported being criminalised or had been through the Criminal Justice System.

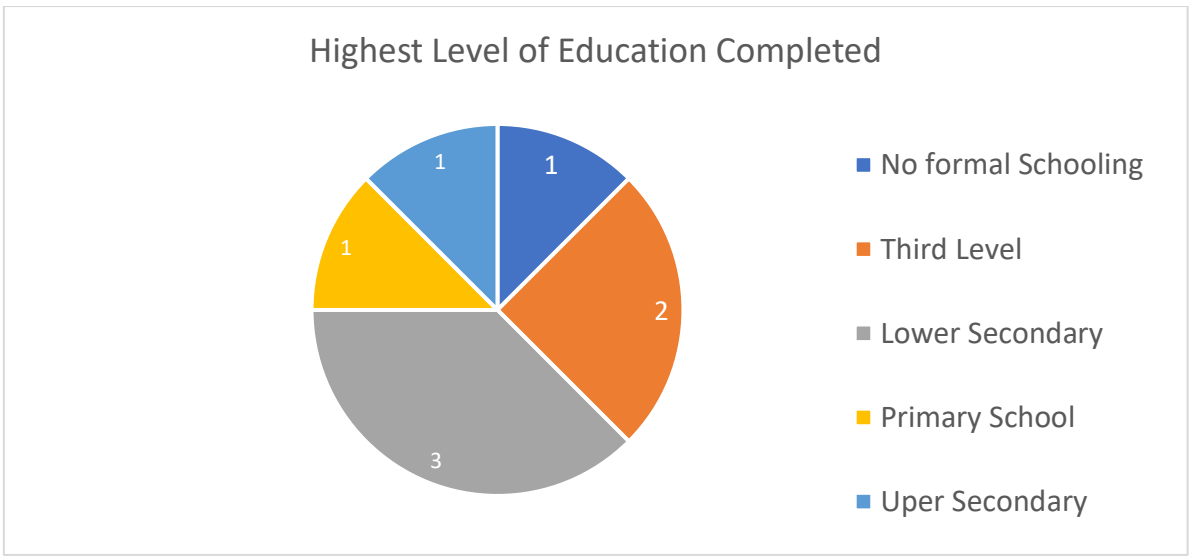


Figure 7 Highest Level of Education Completed by Peer Participants

All participants, including researchers, had lived / living experience of drug use, with one participant detailing their use of intravenous heroin and cocaine from the very young age of 12 years. One participant had lived experience as both a PWUD and a service provider, while another spoke of the significant hidden harms of their drug use as a teenager. All the peer participants had lost loved ones or close friends through drug use, and most had experienced multiple overdoses themselves. Excluding the UISCE employees and researchers approx. six of the peer participants currently used street drugs or various medication. In addition, all have reported a decrease in their drug use and harm reduction since their involvement with UISCE. This is in line with the internation evidence, which provides value, opportunity and a sense of worth for PWUD.

In relation to the groups experiences as peer support workers (n=9), participants stated that the experience through UISCE had been very positive however their experiences when engaging with external organisations had been less than satisfactory. Participants indicated that their engagement had not been positive and would not encourage them to engage with some service providers again. Unfortunately, a percentage of these organisations where providing addiction services and supports.

The word cloud below summarises participant's personal experience with peer working (Figure 8), it represents the discriptiones used in the Knowledge Exchange Workshop survey. Of those who had received peer support (n=10) all rated their experience as 10/10 with one participant scoring 9/10.

Figure 8 Peer Support Experience of Participants

While participants discribed their mental health as "OK or alright" (n=8), two participants deemed their mental health poor or very poor and three participants reported their mental health as being good or very good. The sources of income for the participants varied with three in full-time employment. Figure 9 below shows the sources of income from all workshop participants.

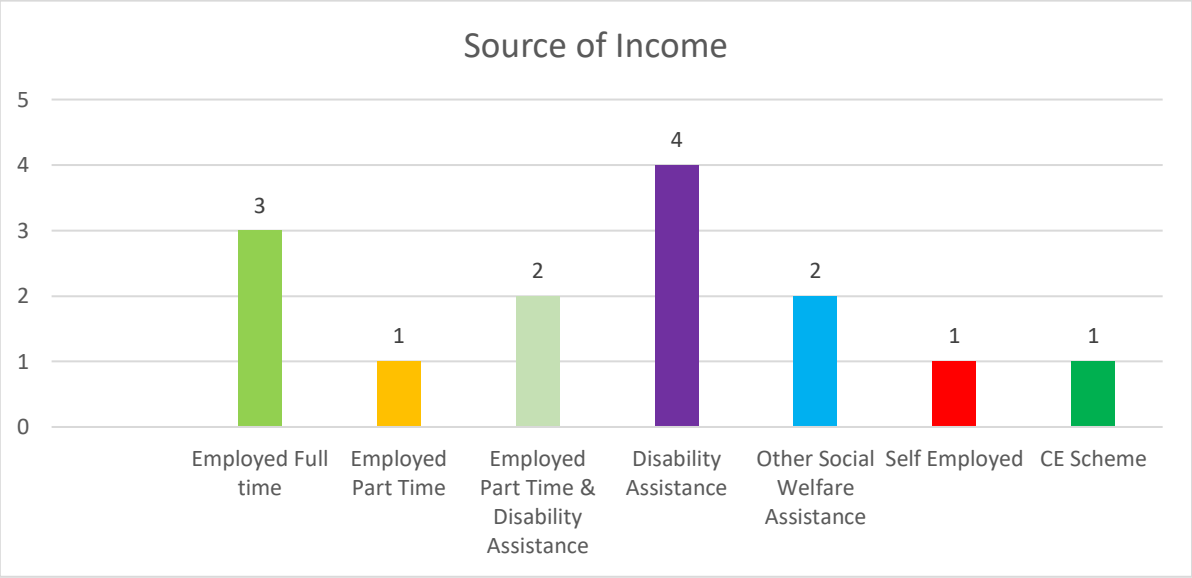


Figure 9 Sources of Income of Workshop Participants

4.1 PEER ENABLERS IDENTIFIED AT WORKSHOP

The single greatest enable for peer engagement was identified by the participants as the peer network itself. The network understood the workshop participants and met them *"where they are"* offering a nonjudgmental environment with flexibility and understanding. This concurs with the findings in the literature review where peer networks were highlighted as the single most important enabler of meaningful structured peer engagement. UISCE was described as a strong and supportive critical enabler by all workshop participants.

> *"UISCE is the best thing that ever happened to me, we are focused on change and peer-led engagement, it gives me a purpose in life and a reason to get up in the morning."* (Workshop Participant)

Within the peer network, participants felt heard and appreciated. The lived and living experiences of the workshop participants were highly valued, though respondents noted that readiness to participate was crucial as well as an interest in the project topic. To succeed in the peer environment, participants felt they needed to be good listeners and willing to invest their personal time. The main motivation for involvement was a desire to help and feel part of something meaningful. For many, participation provided a sense of purpose and a reason to get up in the morning. UISCE's reputation was well-known within the community, and most new members who joined the organisation were recruited by other members through word of mouth.

It was also considered important that the tasks assigned matched the skills of the peer, as many participants had unique abilities. Despite training efforts, some service providers lacked empathy and the ability to form human

connections, leading to ongoing stigma even within organisations providing services to the drug-using community. The criminalisation of drug users was also seen as a significant barrier that needed addressing, with many advocating for a health-focused model instead. For some service providers, peer engagement was merely a box-ticking exercise, driven by funding requirements rather than genuine interest in collaboration. In these cases, peers were included in service planning and training merely as a formality, reinforcing a divide between "them" and "us" with no real involvement in the decision-making process. One participant described how everything starts with stigma.

> *"We are normally seen as THE problem; it starts with stigma and that underpins everything and informs everything."*

Participants in the Knowledge Exchange Workshop spoke of feeling *"less than"* or *"stupid"* and of not being treated as equals. Participants described how they wanted to be part of the solution with knowledge, overdose prevention, sharing and gathering information and increasing safety for PWUD. Participants wanted to be part of the change process, but felt the system was always against them. This was evident from an early age, in schools, in employment, in the legal system, the focus was on punishment and blame, and making things worse. Overall participants felt the system had failed them.

When challenged and support by the peer network, participants felt they had the lived and living experience to contribute significantly to policy development. This was recently evident when given the opportunity to present at the Citizens Assembly and meeting with the Minister for Drugs.

4.2 CHALLANGES IDENTIFIED AT WORKSHOP

While the benefits of peer participation and community engagement are well known, substantial barriers can exist for conducting this work among PWUD. Stigma, discrimination, and disciplinary drug policies were identified as barriers for PWUD from engaging in policy and programme development (Ti et al., 2012). During the Knowledge Exchange Workshop (KEW) participants identified several barriers. Participants felt disempowered when they were not listened to or when they felt their contributions were exploited. When service providers or collaborators failed to deliver on promises, or simple offered no feedback or further involvement, this was considered highly inappropriate.

"One day I'm a nobody, the next day I'm in there helping to train them, then I come to the counter a few days later, and I'm totally ignored by the lads I was training."

(Workshop Participants explain his experience of training service providers)

The training provided to service providers and others seeking peer input was often criticized for being tokenistic and piecemeal. Participants felt that individuals did not truly understand the community or the risks and often assumed they knew more than they did. This issue was exacerbated by power imbalances, making collaboration and inclusion difficult, particularly given the criminalization of drug users. The challenges from the Knowledge Exchange workshop can be summarised as follows.

1. **Power Imbalances and Exploitation**: Participants often felt disempowered when they were not listened to or when their contributions were used without recognition. The perceived power

imbalance between service providers and peers exacerbated feelings of exclusion and exploitation.

2. **Inadequate Training**: Training provided to service providers was often seen as insufficient by PWUD. This lack of understanding and empathy from those who were supposed to support peer engagement, led to continued stigma and a lack of genuine collaboration. Participants suggested that the purpose of the engagement was often driven by funding and was mere tokenism.
3. **Structural Barriers**: Criminal records and personal histories created significant obstacles for individuals wishing to engage in peer work. The stigma tied to their backgrounds made it difficult for them to navigate the system and be heard. It was communicated that this was born from the criminalisation of drug users which was not the medical model espoused by the current government policy.
4. **Systemic and Bureaucratic Challenges**: Disconnected services, a lack of consistency with key workers, and bureaucratic hurdles were identified as major barriers. These systemic issues made it hard for peers to contribute meaningfully and consistently.
5. **Tokenism**: In some cases, peer engagement was reduced to a box-ticking exercise rather than a genuine effort to include peer perspectives. This superficial involvement reinforced the divide between service providers and peers.
6. **Lack of Flexibility**: The rigid application of rules and authority without considering individual circumstances was seen as a barrier to effective peer engagement. There was a call for greater flexibility and understanding.

These challenges point to the need for a more inclusive, empathetic, and genuinely collaborative approach to peer engagement, with a focus on addressing power imbalances, structural and organisational cultural barriers.

4.3 ENVIRONMENTAL IMPACTS IDENTIFIED AT WORKSHOP

While the workshop attendees identified numerous environmental barriers, one of the key structural factors identified as a barrier was the National Drug Strategy, which emphasized a health-led approach, but did not deliver this.

Access to aftercare was also seen by PWUD as crucial for enabling meaningful contributions. Participants expressed that aftercare support was essential. However, many felt they were simply left to return to the same environments, they had come from, without adequate assistance. To truly support individuals, there should be a focus on providing housing, education, employment support, and community services to keep them connected. Aftercare services, along with other supports like counselling, health care, and financial assistance, were viewed as necessary to help peer workers reintegrate into society and contribute to a meaningful life. In some cases where participants had accessed a detox or a treatment programme, they were discharged back to the streets and the same situation from which they had come. The lived/living experience of these individuals was seen as invaluable in shaping service development.

However, personal histories and criminal records, regardless of how minor, often followed participants for years, creating significant structural barriers within an already fragmented system. These barriers frequently prevented people from engaging in peer work. The culture of stigma they experienced was often tied to their background, including factors like education, housing, and poverty.

For many, no matter how hard they tried, navigating the system was incredibly difficult. Services were often detached, there was no consistency with key workers, and bureaucratic obstacles related to things like home addresses and

residential areas proved insurmountable, especially with elevated levels of literacy challenges. When it came to providing peer support, participants frequently felt unheard and believed that changes in the law were necessary. It was particularly frustrating for them when they were ignored in matters related to their own care plans. However, when advocated for by a professional, even a peer support professional, their voices were suddenly taken seriously in housing, legal affairs and healthcare.

> *"They think we're ignorant and can't speak up for ourselves or understand what's going on, so they don't listen. Drug use needs to be decriminalized and we need more peer workers"* (Workshop Participant)

The workshop also highlighted the many challenges relating to peer engagement, particularly in the context of collaborating with people who use drugs in other organisations that do not have any peer engagement training.

5.0 CONCLUSION & RECOMMENDATIONS

The development and promotion of an autonomous network organisations for PWUD is critical. In relation to UISCE, this may require closer considering, of its funding model and how it impacts on its independence and autonomy. The autonomy of the peer network provides a platform, a safe space and an organisation on which to build a solid, consistent, comparable peer engagement network. This will the lead to full inclusion of PWUD in civic participation which is the only way to influence policy development and adoption.

Including people who use drugs (PWUD) in civic participation involves creating an environment where their voices are heard and their experiences

are valued in the decision-making processes that affect their lives. The following strategies and actions are born from a combination of the evidence in the literature and the lived/living experience presented in the Knowledge Exchange Workshop which advocated for the inclusion of PWUD in civic participation:

5.01 BUILD TRUST AND REDUCE STIGMA

1. **Anti-Stigma Campaigns**: Launch public awareness campaigns to reduce stigma associated with drug use and highlight the importance of including PWUD in civic processes. This should also include the production of a Toolkit and Guideline to cover the high-level elements of meaningful positive peer engagement.
2. **Safe Spaces for Dialogue**: Create safe spaces where PWUD can openly share their experiences and opinions without fear of judgment or repercussions. This can be delivered through the current UISCE network which should be independent and sustainable.

5.02 POLICY AND STRUCTURAL REFORMS

1. **Inclusive Policy Development**: Ensure that PWUD are actively involved in the development of policies that affect them. This can be done by including them in policy-making bodies, advisory boards, and working groups, as part of the UISCE advisors and national structure proposal.
2. **Decriminalisation and Legal Reforms**: Advocate for the decriminalisation of drug use and other legal reforms that remove barriers to civic participation for PWUD. This is in keeping with the national drug policy on harm reduction and the adoption of best practice in line with European directives and practices, which includes a more medical approach to substance use.
3. **Human Rights Framework**: Advocate for a human rights-based approach to drug policy that recognizes the dignity and rights of PWUD.

5.03 BUILD CAPACITY AND EMPOWER

1. **Training and Education Programs**: Provide training and educational opportunities for PWUD to build their capacity for civic engagement and leadership. Training and capacity building in the network is critical and should be part of core funding to make the organisation more sustainable.
2. **Peer Leadership Programs**: Establish peer leadership programs where PWUD can take on leadership roles within their communities and advocate for their rights and the rights and needs of their peers. Those who have the capacity and wish to progress their involvement should be facilitated to do so in order to ensure succession and futureproofing of the network activities.

5.04 CREATE INCLUSIVE PLATFORMS

1. **Consultative Processes**: Advocate for a structured consultative processes that actively seek the input of PWUD in community service planning and decision-making. This process should form part of all UISCE strategy plans which impact PWUD, their families and their community.
2. **Community Forums and Assemblies**: Organise community forums and assemblies specifically designed to include and engage PWUD, ensuring their voices are heard in public discussions. It is critical that the network is represented in the current local government decision making structures to ensure inclusion and representation.

5.05 SUPPORT SERVICES AND RESOURCES

1. **Access to Services**: Advocate for access to essential services such as healthcare, housing, and legal assistance, which can enable PWUD to participate more fully in civic life. It is imperative that there services are

connected under one banner to reduce complexity and administrative barriers which disenfranchise PWUD.

2. **Resource Centres**: Advocate for the creating of a resource centres that provide information, support, and tools for full participation tailored to the needs of PWUD. This can be delivered directly through the network of PWUD mainly UISCE.

5.06 BUILD ALLIANCES AND ADVOCATE

1. **Partnerships with Advocacy Groups**: Partner with advocacy groups and NGOs that work with PWUD to amplify their voices and the voice of the network, advocating for their inclusion in civic processes. Particular attention should be paid to Substance Use and Treatment services, Family Support Services and other community-based services who work with families and those PWUD.
2. **Coalitions and Networks**: Continue to collaborate and build relationships that include diverse stakeholders, including PWUD, to work on common goals and policy changes. UISCE is ideally placed to continue this journey, formalising their experience and strategic thinking to alight to other organisation.

5.07 MONITOR AND TESTIFY

1. **Regular Feedback Mechanisms**: Implement regular feedback mechanisms via the network that allow PWUD to provide input on initiatives and hold policymakers accountable. To this end UISCE must develop a robust communication strategy to ensure transparency and independent as the network develops.
2. **Evaluation and Adjustment**: Continuously evaluate the effectiveness of inclusion initiatives and make necessary adjustments based on feedback from PWUD. The network should continue to gather case studies and document key performance indicators to ensure

accountability to funding streams that does not compromise independence.

5.08 PROMOTE REPRESENTATION

1. **Encouraging Civic Roles**: Encourage and support PWUD to run for public office or take on civic roles within their communities.
2. **Visibility of PWUD in Civic Life**: Promote the visibility of PWUD in civic life by highlighting their contributions and successes in public forums and media. This should form a critical element of a comprehensive communication strategy to promote the work and impact of the network.

5.09 ADDRESS SOCIAL DETERMINANTS

1. **Holistic Approaches**: Continue to highlight the social determinants of health and well-being, such as poverty, homelessness, and lack of education, which can impact the ability of PWUD to participate fully in society.
2. **Integrated Services**: Advocate for integrated services that address multiple needs of PWUD, making it easier for them to engage in civic activities.

By implementing these strategies, communities can create a more inclusive environment where PWUD are empowered to participate in civic life and contribute to the decision-making processes that affect their lives. This approach not only benefits PWUD but also enhances the overall health, safety, and cohesion of the community.

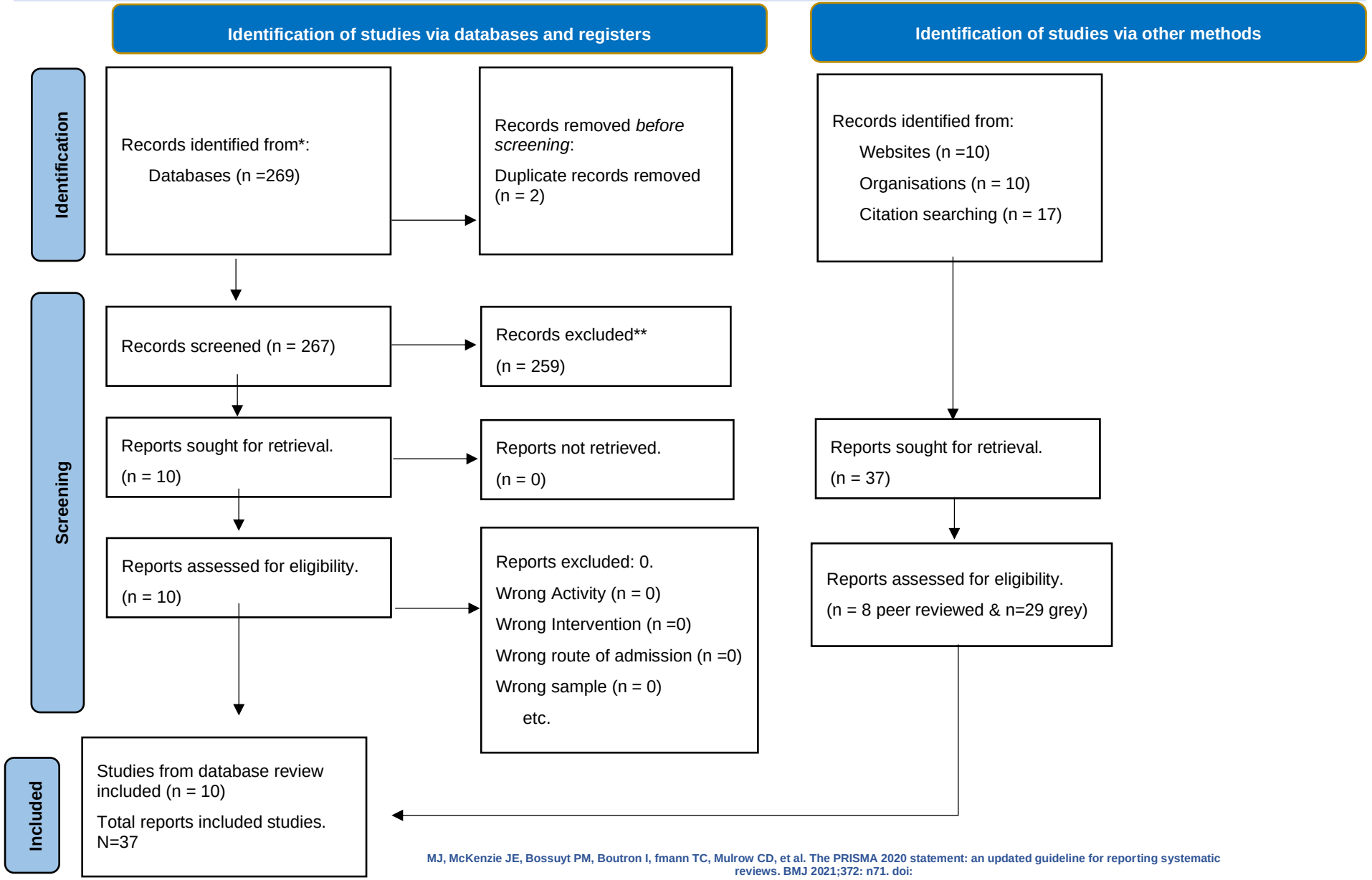
6.0 Appendix

APPENDIX 1 LITERATURE REVIEW- SEARCH STRATEGY

Table 1: Sample table for documenting search terms

Search dates	Databases	Concepts	Search terms	No. studies retrieved	
13/12/2021	PUBMED	People who use drugs	AB (substance user OR substance abuser OR drug user OR drug abuser OR dependency on drugs OR addicted person OR drug addict OR person who uses drugs OR people who use drugs)	30,878	
		Peer advocate	AB (peer support workers OR experts by experience OR lived experience OR peer partnership OR peer engagement OR peer led participation OR participation partnership OR peer advocacy OR peer advocate OR peer advocating OR peer representation)	15,603	
		Best practice	best practices OR guidelines OR evidence-based practice OR toolkits OR guide* OR manual OR training	1,536,088	
			All keywords combined with AND + Date restrictions (2000 – 2024)	**27**	
	Health Source Nursing & Academic Edition	People who use drugs	AB (substance user OR substance abuser OR drug user OR drug abuser OR dependency on drugs OR addicted person OR drug addict OR person who uses drugs OR people who use drugs)	7,147	
		Peer advocate	AB (peer support workers OR experts by experience OR lived experience OR peer partnership OR peer engagement OR peer led participation OR participation partnership OR peer advocacy OR peer advocate OR peer advocating OR peer representation)	5,754	
		Best practice	best practices OR guidelines OR evidence-based practice OR toolkits OR guide* OR manual OR training	217,325	
		Combined	**All keywords combined with AND + Date restrictions (2000 – 2024)**	**3**	
	CINAHL	Person who uses drugs	AB (substance user OR substance abuser OR drug user OR drug abuser OR dependency on drugs OR addicted person OR drug addict OR person who uses drugs OR people who use drugs)	10,803	
		Peer advocate	AB (peer support workers OR experts by experience OR lived experience OR peer partnership OR peer engagement OR peer led participation OR participation partnership OR peer advocacy OR peer advocate OR peer advocating OR peer representation)	15,006	
		Best practice	best practices OR guidelines OR evidence-based practice OR toolkits OR guide* OR manual OR training	499,062	
		Combined	**All keywords combined with AND + Date restrictions 2000-2024**	14	
	PsychInfo	People who use drugs	(MM (substance user OR substance abuser OR drug user OR drug abuser OR dependency on drugs OR addicted person OR drug addict OR person who uses drugs OR people who use drugs))	293,869	
		Peer advocate	(Peer support workers OR experts by experience OR lived experience OR peer partnership OR peer engagement OR peer led participation OR participation partnership OR peer advocacy OR peer advocate OR peer advocating OR peer representation)	2,783	
		Best practice	(Best practices OR guidelines OR evidence-based practice OR toolkits OR guide* OR manual OR training)	813,117	
			All keywords combined with AND + Date restrictions 2000-2024	**225**	
		TOTAL		**269**	

APPENDIX 2 PRISMA SYSTEMATIC REVIEW



MJ, McKenzie JE, Bossuyt PM, Boutron I, fmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372: n71. doi:

APPENDIX 3 NARRATIVE SYNTHESIS OF QUALIFYING STUDIES

Authors	Title of Paper	Type of Study	Sample Size	Intervention	Outcome
Lindsay Wilson, Sarah Vannice, Catherine Hacksel & Lynne Leonard (2018)	Peer worker or client? conflicting identities among peer workers engaged in harm reduction service delivery (Canada)	Qualitative	17 interviewees (Six key informant interviews were held with program managers and 11 were held with peer worker. PWUD 18+with informed consent	Recruitment of peer support workers as harm reduction agents in service delivery.	Provided unique insights into current issue of peer engagement. Peer programming requires a balancing of the dual intertwined identities. If peer workers are not adequately supported by the agencies that employ them, peer workers may experience inadvertent harm. Offering peer workers jobs that are beyond the point at which they are ready to move on can risk causing harm to peer workers.
M. R. Weeks, J. Dickson-Gamez, K. E. Mosack, M. Convey, M. Martinez, S. Clair (2006)	The Risk Avoidance Partnership: Training Active Drug Users as Pere Health Advocates. (USA)	Qualitative Ethnographic Study	76 candidates received the intake interview, of whom 130 (73.9%) initiated the training program. 18 + years using drugs in the last 30 days.	Train active drug users as peer/public health advocates (PHAs) to bring a structured, peer-led intervention.	The training content was acceptable to active drug users in duration, rules, and expectations, as well as in its goals, objectives, and activities. This was indicated by the high retention rate of those who initiated the training program at least through two staff-partnered sessions in the field. Participants perceived it to be interesting and worthwhile enough to keep them active through the full in-office program, the partnered field sessions.
Ti, Lianping, Tzemis Despina, and Buxton, Jane (2012)	Engaging people who use drugs in policy and program development: A review of the literature. (Canada)	Narrative Literature Review	19 publications included	Investigating the form of engagement among PWUD who were engaged in policy and programme development.	PWUD face many challenges that restrict their ability to engage with public health professionals and policy makers, including the elevated levels of stigma and discrimination that persist among this population. Efforts to minimize stigmatizing barriers associated with illicit drug use are urgently needed to improve the engagement of PWUD in decision making processes.

Robin Lennox, Larkin Lamarche and Tim O'Shea (2021)	Peer support workers as a bridge: a qualitative study exploring the role of peer support workers in the care of people who use drugs during and after hospitalization (Canada)	Qualitative Study	14 (6 hospitalized PWUD, 5 members of the healthcare team (two family physicians, general internist, infectious diseases specialist, cardiologist), two peer support workers and one employer of peer support workers)	The integrating of peer support workers into hospital teams that could combat barriers for PWUD and help to rebuild trust in the healthcare system.	Identified the need for programs to ensure adequate training and mentorship, boundary setting, and the use of self-care practices to protect peer workers against distress.
Lisa Lazarus, Ashley Shaw, Sean LeBlanc, Alana Martin, Zack Marshall, Kristen Weersink, Dolly Lin, Kira Mandryk, and Mark W Tyndal (2014)	Establishing a community-based participatory research partnership among people who use drugs in Ottawa: the PROUD cohort study (Canada)	Community-based Participatory Research Prospective Cohort Study	858 (Male n=638, female n=220) 16 years plus, injected in the last 12	PWUD recruited street-based participants in a HIV risk environment study, design the survey and deliver the research using a community advisory committee structure of 8 people with lived experience with drug use.	The study meaningfully engaged the communities of people who use drugs in Ottawa through the formation of the CAC, the training of peers as community-based researchers. This project successfully supported skill development across the team and empowered people with drug use experience to take on leadership roles, ensuring that this research process will promote change at the local level.
A. M. Greer, A. Amlani, C. Burmeister, A. Scott, C. Newman, H. Lampkin, B. Pauly, A. Buxton (2019)	Peer engagement barriers and enablers: insights from people who use drugs in British Columbia, (Canada)	Community based Participatory Cross Jurisdictional Study	13 peer-facilitated focus groups, (n = 83) Female n=30, male n=38, trans n=2, 18 years + with informed consent	Perspectives of PWUD on peer engagement in health and harm reduction settings across British Columbia (BC), Canada.	PWUD are important stakeholders in decisions that affect them. PWUD identify several factors that influence their participation. Meaningful engagement can be facilitated by attention to communication, relationships, personal capacity, and compassion between peers and other professionals.

Duddington, A., Gowar, D, Wall, K. (2023)	Nothing about Us without Us: The Voices of People with Lived Experience in Practice Education and post-Qualifying Social Work (UK)	Literature Review	PWUD	Review of the Inclusion of the "person with lived experience " in formal training and development of qualified social workers, post training period.	The inclusion of PWLE is very challenging. The nature of post qualification social work is complex and PWLE can become marginalised within the managerialist structure. The learning period extends beyond 2-3 years and the continued voice of PWLE is a vital and integral part of this development.
Will Damon, Cody Callon, Lee Wiebe, Will Small, Thomas Kerr, Ryan McNeil (2017)	Community-based participatory research in a heavily researched inner city neighborhood: Perspectives of people who use drugs on their experience as peer researchers (Canada)	Qualitative Community based Participatory Research	14 in depth interviews (PWUD female, n=6, Male, n=7, transgender n=1)	Sought seeks to understand the impact of CBPR on PWUD, particularly those living in heavily researched and stigmatized neighborhoods where CBPR projects are often located.	Participants reported positive personal gains from participation in CBPR projects. However, many participants had negative experiences with CBPR projects, especially when CBPR principles were implemented in a superficial or incomplete manner. Participants emphasized the importance of inclusiveness and active deconstruction of hierarchy between researchers and community members to successful CBPR among drug using populations.
K. Closson1, R. McNeil, P. McDougall, S. Fernando, A. B. Collins, R. Baltzer Turje, T. Howard S. Parashar 2016)	Meaningful engagement of people living with HIV who use drugs: methodology for the design of a Peer Research Associate PRA) hiring model (Canada)	Mixed Method Community-based participatory research (CBPR	49 applications for 2 positions in year one and 17 in year 2 (PWUD)	Evaluation of effectiveness of integrated care facility in Vancouver and the impact of low-barrier peer research associates (PRA) hiring process to meaningfully engage PWUD communities.	The hiring model was successful at engaging five PRAs over a 2-year period and fostered opportunities for future paid employment and meaningful collaboration.
Fern, Charlie (2008)	Women Care in Vancouver's Downtown Eastside (Canada)	Participatory Action Research Case Study	N=50 women who use drugs	Provided training, remuneration and support to 13 WWUD in Vancouver to interview 50 women.	Shows the value of peer driven research by, with and for women who use drugs.

Bailey, A. Graham, B. Harps, M. Sedore, G (2023)	Vancouver's Alcohol Knowledge Exchange: lessons learned from creating a peer-involved alcohol harm reduction strategy in Vancouver's Downtown Eastside (Canada)	Community-Engaged Research Practice	Vancouver Area Network of Drug Users, and other stakeholders' collaborative policy development.	Explores the experiences of producing this community-led alcohol policy with those who face criminalization due to housing precarity and visible poverty.	The authors emphasizing the importance of respecting and creating space for the lived experiences of people who use illicit alcohol in the development of alcohol-related policies and the need for governmental public health institutions to provide resources to meaningfully prevent and reduce alcohol-related and policy-induced harms.
Brown, G. Crawford, S. Perry G. Byrne, J. Dunne, J. Reeders, D. Corry, A. Dicka, J. Morgan, H, Jones, S. (2019)	Achieving meaningful participation of people who use drugs and their peer organisations in a strategic research partnership	Community-Engaged Research Practice	5-year collaborative study with peer organisations	Study to demonstrate the role of peer organisations within their community and policy systems.	Recognizing peer organisations as active participants and drivers within community and policy systems can help clarify their unique and critical role in research. Achieving meaningful collaboration with PWUD peer organisations requires looking beyond good practice methods to the system-level factors with attention to the system-level benefits, barriers, and enablers
Follevag, B. Seim, S. (2021)	Bridge over Troubled Water: Patients' Opportunities for Collective Participation in Substance Use Institutions through Research Circles	Participatory Action Research	A total of 16 people participated in the research circle	Introduced research circles in substance use treatment institution to foster change.	The findings showed that research circle activities led to institutional changes, promoting a culture of participation and equality. Challenges however included a lack of individual participation, power hierarchies, and insufficient preparation for life after treatment. This study underscores the importance of collective participation and empowerment in substance use treatment and highlights the need for institutions to adapt structurally and culturally to support these practices.
Greer, A Amlani, A Pauly, B. Burmeister, C. Buxton, J. (2019)	Participant, peer and PEEP: considerations and strategies for involving people who have used illicit substances as assistants and advisors in research	Community Based Participatory Research	Peer Engagement and Evaluation Project N=83 PWUD 13 Focus Groups	The study critically analyzes the methods and outcomes of this engagement around recruitment of peer participants.	The project demonstrates that peer involvement enhances the relevance, capacity, and quality of research, and provides valuable insights for future community-based participatory research involving marginalized groups.

Marshall, Z. Dechman, M.K. Minichie; o, A. Alcock, L. Harris, G.E. (2016)	Peering into the literature: A systematic review of the roles of people who inject drugs in harm reduction initiatives. (Canada)	Systematic Literature Review	The review included 164 documents, with 127 peer-reviewed and 37 gray literature references		Key findings include the identification of 36 distinct peer roles grouped into five categories: harm reduction education, direct harm reduction and health services, support/counselling/referrals, research assistance, and advisory committee participation plus programme characteristics.
O Gorman, A. Quigley, E. Zoble, F. Moore, K. (2014)	Peer, professional, and public: An analysis of the drugs policy advocacy community in Europe	Systematic Internet search	profile of civil society advocacy as a policy community in the drugs field in Europe	It identifies over 200 EU-based advocacy organisations, including civil society associations, NGOs, and large-scale alliances and coalitions, operating at local, national and European levels	The study highlights the diverse strategies and tools used by advocacy groups, including awareness raising, lobbying, education and training, and research, to influence policy at national, European and international levels
Smith, C. (2016)	About Nothing Without Us": A Comparative Analysis of Autonomous Organizing Among People Who Use Drugs and Psychiatrized Groups in Canada	A critique of how PUD are positioned in Canadian drug policy	autonomous organizing among people who use drugs (PUD) and psychiatrized groups	It reviews the literature on the significant role of directly engaging PUD in policies and programs affecting their lives and presents ethnographic vignettes to identify persistent structural barriers to activism among these communities in Canada	The paper concludes by unpacking the notion of "collaborative autonomy" and the fundamental value of users' experiential knowledge, asserting that research neglecting the perspectives of PUD risks becoming worthless.
Van der Sterren, A. Nathan, S. Rawstone.P. Yarbakhsh, E. Gough, G (2023)	Involvement of people who use alcohol and other drug services in the development of patient-reported measures of experience: A scoping review (Australian)	Scoping Literature Review		aims to identify how and to what extent people accessing alcohol and other drug (AOD) services have been involved in developing measures of patient-reported satisfaction and experience	The review highlights the importance of involving service users in developing patient-reported measures to ensure these tools accurately reflect their experiences and needs.

APPENDIX 4 NARRATIVE SYNTHESES OF IDENTIFIED LITERATURE

Closson et al. (2016)

This article describes the development and implementation of a low-barrier hiring process to engage people living with HIV (PLHIV) who use drugs as Peer Research Associates (PRAs) in a community-based participatory research (CBPR) project evaluating the effectiveness of an integrative HIV care facility in Vancouver, Canada. The hiring process involved establishing a hiring team with diverse stakeholders, developing and disseminating a job posting, interviewing applicants, and selecting participants. The process aimed to address gaps in paid employment opportunities for PLHIV who use drugs within research, and to meaningfully involve affected communities in all stages of the research. Over a 2-year period, five PRAs were successfully hired using this low-barrier approach, which demonstrates the benefits of engaging vulnerable PLHIV who use drugs as paid members of the research team. The article highlights the importance of harnessing the expertise of affected communities, addressing power imbalances, and providing meaningful employment opportunities to promote the meaningful involvement of PLHIV and people who use drugs in research.

Duddington et al (2023)

This publication from Duddington and colleagues recently published in the Oxford Press on behalf of the British Association of Social Workers emphasizes the importance of incorporating the voices and perspectives of People With Lived Experience (PWLE) in social work practice, education, and post-qualifying training. It highlights the pivotal role PWLE can play in enhancing student learning and challenging inadequate practices, but notes that this involvement often diminishes after qualification as service delivery and resource management take priority.

The article discusses various attempts to capture PWLE feedback, including through mobile apps, but cautions that these methods can overlook power dynamics. It advocates for longitudinal feedback from the beginning to the end of social work involvement. While pre-qualifying research generally points to students developing empathy and new perspectives through PWLE involvement, qualified staff have sometimes resisted power-sharing and seen PWLE trainers as a dilution of professional standards.

The authors, as members of the IMPACT service user and carer group, were involved in the Practice Educator Professional Standards (PEPS) program at the University of Worcester. They aimed to extend the value of PWLE input into practice education and beyond, modelling a co-production approach. Their involvement in the PEPS program led to positive feedback

from trainee practice educators, who reported increased awareness of the challenges and importance of obtaining meaningful PWLE feedback.

The article concludes that continuous professional development is mandatory for qualified social workers, and the voice of PWLE should be seen as a vital and integral part of this process, despite the challenges of embedding it within the complex, managerialist structure of post-qualifying social work practice.

Damon et al. (2017)

This study, again from Canada, explores the perspectives of people who use drugs (PWUD) and their experiences as peer researchers in Community-based Participatory Research (CBPR) projects conducted in Vancouver's heavily researched Downtown Eastside neighbourhood. Participants were generally supportive of CBPR, viewing it as necessary to contest stigmatizing assumptions and researcher bias. Peer researchers were seen as able to build better rapport with participants and collect more accurate data. However, many participants had negative experiences when CBPR principles were implemented superficially, feeling tokenized or judged by academic researchers. Participants emphasized the importance of inclusiveness and actively deconstructing hierarchies between researchers and community members for successful CBPR. While CBPR was seen as empowering and providing personal benefits, projects that failed to meaningfully engage community members were criticized as exploitative and disconnected from community needs. The findings suggest a need for capacity building within affected communities to develop independent support, training, and grievance processes for peer researchers, as well as stronger commitments from universities to ensure the social and economic benefits of research are captured by marginalized communities.

Ti et al. (2012)

A review of this publication identified several key themes related to the engagement of people who use drugs (PWUD) in policy and program development. It highlighted the significant challenges and barriers that PWUD face, such as elevated levels of stigma and discrimination, which restrict their ability to engage with public health professionals and policymakers. Despite these barriers, the literature showed that many international organisations are recommending the involvement of PWUD in policy and program development. The review also discussed the success of peer-run services and interventions in achieving positive health outcomes for PWUD, such as reducing HIV-related risk behaviours. However, the review found a lack of published data on the implementation of efforts to engage PWUD in policy and program decisions. The paper emphasized the need for additional research to explore and

document the engagement of PWUD in these areas, as well as the urgent need to minimize stigmatizing barriers associated with illicit drug use to improve their engagement in decision-making processes. The review highlighted examples of progress in engaging PWUD in policy and program development in countries like Canada and Australia but noted that these efforts are often poorly documented in the literature. Overall, the publication underscored the importance of meaningfully involving PWUD in consultative processes, decision-making bodies, and advisory structures dealing with issues related to their health and well-being.

Weeks et al. (2006)

The Risk Avoidance Partnership (RAP) project trained active drug users as peer/public health advocates (PHAs) to bring a structured, peer-led intervention into the sites where they and their drug-using social networks use illicit drugs. The RAP peer health advocacy training curriculum and peer-led intervention promoted harm reduction among drug users and supported drug-user organisation to reduce infectious disease and other harm in the context of injection drug use, crack cocaine use, and sexual activity. The training program was designed to build a team of health advocates who could work independently, in partnership with staff, or jointly with each other for HIV, sexually transmitted infection (STI), hepatitis, and other disease prevention, as well as for general health advocacy for drug users, their networks, and their community. The RAP peer-led intervention included standard harm reduction approaches, such as condom promotion and distribution of bleach for sterilizing syringes, as well as locally novel components, such as RAP prevention slogans and promotion of rubber tips for crack pipes. The RAP Community Advocacy Group (CAG) provided trained PHAs an ongoing opportunity to get together to plan and implement community advocacy action, share their experiences conducting harm reduction and health advocacy with other PHAs, and socialize in a safe environment. The process evaluation found that the training program was effective in preparing active drug users to become educators and health advocates, and that the peer-led intervention was feasible for active drug users to implement and appropriate for them and their contacts. The findings also suggested a significant transformation in many project participants, both in their self-assessment and in their peers' assessment of them, as they took on the role of peer health advocates and made positive contributions to their communities despite their ongoing struggles with addiction and poverty.

Wilson et al (2017)

This study explored the challenges faced by peer workers engaged in harm reduction service delivery in Ottawa, Canada. The researchers conducted qualitative interviews with peer workers and program managers to understand the key issues. A central theme that emerged was the difficulty peer workers faced in balancing their identities as people who use drugs and

require harm reduction services, and their identities as peer workers providing those services to others. This manifested in several ways: peer workers struggled with triggering events during their shifts that put them at risk of relapse, they were reluctant to use the agency's own harm reduction services due to concerns about being perceived as unable to perform their role, and they felt 'stuck' in positions that were overly dependent on their 'drug user' identity rather than being able to develop new skills and identities. The researchers analyzed these findings through a symbolic interactionist lens, noting that peer workers' self-worth was often tied to their ability to successfully perform the idealized 'peer worker' identity, which conflicted with their experiences as clients of harm reduction services. The study provides recommendations for agencies to better support peer workers, such as ensuring flexibility around drug use, providing training opportunities to develop skills beyond harm reduction, and facilitating peer workers' transitions out of these roles when they are ready. Overall, the study highlights the need to carefully consider the implications of peer programming on the identities and wellbeing of the peer workers themselves.

Peer Reviewed Publications Discovered in Citation Searches (n=8)

Bailey et al. (2023)

The paper describes the development of the Vancouver Alcohol Strategy (VAS), a comprehensive harm reduction-oriented policy framework for addressing alcohol-related harms in Vancouver's Downtown Eastside (DTES). The VAS was created through a community-led process involving the Eastside Illicit Drinkers Group for Education (EIDGE), an affiliate group of the Vancouver Area Network of Drug Users, and other stakeholders. The article highlights the experiences of producing this community-led alcohol policy, with a focus on cantering the perspectives of people who use alcohol, particularly those who consume non-beverage alcohol and face criminalization due to housing precarity and visible poverty. The historical context of the DTES, including the legacy of settler colonialism, legislated poverty, and the financialization of housing, is provided to understand the VAS's place within the community. The text outlines the six thematic areas of the VAS and provides examples of the 47 unique recommendations, which address issues such as the decriminalization of public drinking, the creation of safe indoor and outdoor spaces for drinkers, the expansion of managed alcohol programs and addiction treatment services, peer-led education, and long-term partnerships with governmental partners. The authors conclude by emphasizing the importance of respecting and creating space for the lived experiences of people who use illicit alcohol in the development of alcohol-related policies and the need for governmental public health institutions to provide resources to meaningfully prevent and reduce alcohol-related and policy-induced harms.

Brown et al.(2019)

The paper discusses the experiences and findings of the What Works and Why (W3) Project, a 5-year collaborative study with peer organisations that aimed to develop a framework to demonstrate the role of peer organisations within their community and policy systems. The study required peer staff and researchers to undertake the simultaneous role of drivers, participants, and analysts in the research. The paper provides insights into the nuances of community-engaged research practice and the ongoing benefits, barriers, and enablers to the meaningful participation of people who use drugs (PWUD) and their peer organisations in research. Key benefits include strengthening the relationship between peer organisations and researchers, enhancing the credibility and authenticity of the research centre, and ensuring the research outcomes are directly relevant to the work of peer organisations. Barriers include misalignment between the funding of peer organization services and their role in collaborating and advocating in research, the emotional and resource costs for peer staff and volunteers already under pressure, and the political nature of peer programs with PWUD. Enablers include flexibility in research funding and project management, ongoing demonstration of two-way trust and commitment, and visible valuing of peer participation and leadership to counter system-level stigma. The paper concludes that achieving meaningful collaboration with PWUD peer organisations requires looking beyond good practice methods to the system-level factors with attention to the system-level benefits, barriers, and enablers.

Follevag at al., (2021)

The study examines how patients in a substance use treatment institution can participate collectively through research circles. Patients and staff collaborated with researchers to implement changes in treatment practices. The focus was on how milieu therapy could bridge treatment in the institution to life post-treatment. The findings showed that research circle activities led to institutional changes, promoting a culture of participation and equality. Challenges were faced, particularly with structural and cultural barriers within the institution. User involvement was essential for improving services for people with substance use problems. The challenges however included a lack of individual participation, power hierarchies, and insufficient preparation for life after treatment. Efforts to strengthen milieu therapy through user participation led to changes like regular meetings, weekly quizzes, and reduced controlling procedures. In the institutional culture there was a shift towards more participation and equality. However, structural and cultural barriers limited some changes. Patients felt empowered and recognized through participation. Mutual recognition. This study underscores the importance of collective participation and empowerment in substance use treatment and highlights the need for institutions to adapt structurally and culturally to support these practices.

Greer et al., (2019)

This document details the Peer Engagement and Evaluation Project (PEEP), which aimed to include people who use or have used illicit substances as active members of the research team. The study applies the Peer Engagement Process Evaluation Framework to critically analyse the methods and outcomes of this engagement. Key elements of the process include recruiting and hiring peers, ensuring fair compensation, setting clear role expectations, and fostering communication and collaboration. The project demonstrates that peer involvement enhances the relevance, capacity, and quality of research, and provides valuable insights for future community-based participatory research involving marginalized groups.

Marshall et al, (2015)

This systematic review examines the roles of people who inject drugs in harm reduction initiatives, how programs are organized, and the obstacles and facilitators to engaging people with lived experience in harm reduction programs. The review included 164 documents, with 127 peer-reviewed and 37 grey literature references. Key findings include the identification of 36 distinct peer roles grouped into five categories: harm reduction education, direct harm reduction and health services, support/counselling/referrals, research assistance, and advisory committee participation. The review also describes program characteristics such as organization, setting, and population focus. Obstacles to peer involvement were identified at systemic (criminalization, stigmatization, abstinence-based policies), organizational (exclusionary attitudes/policies, insufficient training and support, decision-making removed from lived experiences), and individual (availability, drug use, competing interests, fear of relapse) levels. Facilitators were found at systemic (positive community relationships, political/police support), organizational (meaningful involvement, flexible programming, recognizing peer influence, providing training and support, developing supportive cultures), and individual (transforming risk norms, leveraging social networks) levels. The authors propose ten strategies to improve peer involvement in harm reduction initiatives, including addressing criminalization, initiating anti-stigma campaigns, fostering organizational cultures that support peer leadership, and developing consensus frameworks for describing peer roles and participation.

O'Gorman et al. (2014)

This study provides a nuanced profile of civil society advocacy as a policy community in the drugs field in Europe. It identifies over 200 EU-based advocacy organisations, including civil society associations, NGOs, and large-scale alliances and coalitions, operating at local, national and European levels. Three forms of advocacy emerged from the data analysis - peer, professional and public policy advocacy. Peer advocacy groups engage in representing the interests of, or defending the rights of, themselves and/or their peers, while professional

advocacy groups help professions represent and speak out on behalf of a specific person or group. Public policy advocacy organisations represent the interests of, or defend the rights of, the general public, and are mainly concerned with establishing rights or entitlements to services and resources through the legislative system.

The advocacy organisations focused their campaigns on either practice development (harm reduction or abstinence) or legislative reform (reducing or strengthening drug controls). Over two-thirds of the groups campaigned on issues related to professional practice and service provision, with the majority promoting a public health and harm reduction approach. The remaining one-third focused on changing or maintaining drug control legislation, with the majority campaigning for reforms such as decriminalisation, regulation of consumption, and legalisation. This indicates a level of convergence and divergence in Europe in relation to policy positions on service provision ethos and drug control regulation. The study also highlights the diverse strategies and tools used by these advocacy groups, including awareness raising, lobbying, education and training, and research, to influence policy at national, European and international levels.

Smith, C. (2016)

This paper provides a comparative analysis of autonomous organizing among people who use drugs (PUD) and psychiatry groups in Canada. It traces the history of Canadian drug/service user organizing, highlighting the structural barriers they face and suggesting that the psychiatric survivor and mad movements have served as critical organizing models. The paper examines the parallels between various forms of self-identification and organizing among people with lived experience of psychiatrist and substance use, including "consumers," psychiatric survivors, and the mad constituency on one hand, and drug/service user clients, recovery/support groups, and politicized organisations of PUD on the other. It reviews the literature on the significant role of directly engaging PUD in policies and programs affecting their lives and presents ethnographic vignettes to identify persistent structural barriers to activism among these communities in Canada. The paper argues that despite the increasing emphasis on user involvement, Canada represents an uneven, contested landscape where PUD face significant barriers to meaningful participation, in contrast to the Australian experience where user-driven organisations have been institutionally supported. The paper concludes by unpacking the notion of "collaborative autonomy" and the fundamental value of users' experiential knowledge, asserting that research neglecting the perspectives of PUD risks becoming worthless.

Van der Sterren at al. (2023)

The scoping review aims to identify how and to what extent people accessing alcohol and other drug (AOD) services have been involved in developing measures of patient-reported satisfaction and experience. Database searches included PubMed, EMBASE, CINAHL, Scopus, ProQuest, Google, and Google Scholar. The inclusion criteria was publications that described the development and/or implementation of a multi-item measure of patient-reported experience or satisfaction specifically for people accessing AOD treatment and/or harm reduction programs. A framework was generated to assess service user involvement in measure development. The findings identified 30 measures -23 focusing on satisfaction and 7 on experience. Sixteen measures reported some level of involvement by AOD service users in their development, although typically at a low level. The extent of involvement has increased over time. Only four measures were specific to harm reduction settings, with fewer than half of the measures reported analysis of underlying scale structure and constructs. The paper suggested that there is a need to develop experience measures for use in harm reduction settings and across various AOD settings. Improved reporting of the psychometric properties of these measures is also needed. Increasing the meaningful involvement of AOD service users in the development of these measures is crucial for enhancing patient-centered care. The review highlights the importance of involving service users in developing patient-reported measures to ensure these tools accurately reflect their experiences and needs. This involvement is critical for advancing person-centered care in the AOD sector.

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