#### **QUALITATIVE RESEARCH**



# Peer engagement barriers and enablers: insights from people who use drugs in British Columbia, Canada

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#### **Abstract**

**Objectives** Globally, engaging people who have used drugs, or *peers*, in decision-making has been increasingly touted as a best practice approach to developing priorities, programs, and policies. Peer engagement ensures decisions are relevant, appropriate, and effective to the affected community. However, ensuring that inclusion is accessible and equitable for those involved remains a challenge. In this study, we examined the perspectives of people who use or have used illicit drugs (PWUD) on peer engagement in health and harm reduction settings across British Columbia (BC), Canada.

**Methods** The Peer Engagement and Evaluation Project used a participatory approach to conducting 13 peer-facilitated focus groups (n = 83) across BC. Focus group data were coded and analyzed with five peer research assistants. Themes about the nature of peer engagement were generated. From this analysis, peer engagement barriers and enablers were identified.

**Results** Barriers to peer engagement included individual, geographical, systemic, and social factors. Issues related to stigma, confidentiality, and mistrust were intensely discussed among participants. Being "outed" in one's community was a barrier to engagement, particularly in rural areas. Participants voiced that compensation, setting, and the *right people* help facilitate and motivate engagement. Peer networks are an essential ingredient to engagement by promoting support and advocacy.

**Conclusion** PWUD are important stakeholders in decisions that affect them. This cross-jurisdictional study investigated how PWUD have experienced engagement efforts in BC, identifying several factors that influence participation. Meaningful engagement can be facilitated by attention to communication, relationships, personal capacity, and compassion between peers and other professionals.

#### Résumé

Objectifs À l'échelle mondiale, le dialogue avec les personnes ayant consommé de la drogue (les « pairs ») à la prise de décisions est de plus en plus considéré comme une pratique exemplaire pour l'élaboration de priorités, de programmes et de politiques. Le dialogue avec les pairs mène à des décisions pertinentes, appropriées et efficaces dans la communauté touchée. Il demeure toutefois difficile d'assurer l'accessibilité et l'équité de l'intégration des personnes en cause. Dans cette étude, nous avons examiné les points de vue de personnes consommant ou ayant consommé de la drogue (PCACD) au sujet du dialogue avec les pairs dans les milieux de la santé et de la réduction des méfaits en Colombie-Britannique, au Canada.

**Méthode** Ce projet de participation des pairs et d'évaluation a fait appel à une démarche participative pour mener 13 groupes de discussion animés par des pairs (n = 83) en Colombie-Britannique. Les données des groupes de discussion ont été codées et analysées avec cinq pairs adjoints à la recherche. Des thèmes sur la nature du dialogue avec les pairs sont ressortis. L'analyse a permis de cerner les éléments qui entravent ou qui favorisent le dialogue avec les pairs.

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Résultats Les éléments qui entravent le dialogue avec les pairs étaient des facteurs individuels, géographiques, systémiques et sociaux. La stigmatisation, la confidentialité et la méfiance ont été des questions chaudement discutées entre les participants. Le fait d'être révélé dans son propre milieu comme étant consommatrice ou consommateur de drogue constituait un obstacle au dialogue, surtout en zone rurale. Les participants ont exprimé l'avis que la rémunération, le lieu et les « bonnes personnes » facilitent le dialogue et motivent les gens à s'impliquer. Les réseaux de pairs sont un ingrédient essentiel du dialogue, car ils favorisent l'entraide et la défense des intérêts.

Conclusion Les PCACD sont d'importants acteurs dans les décisions qui les concernent. Cette étude à l'échelle intergouvernementale a porté sur la perception par des PCACD vivant en Colombie-Britannique des démarches visant à les faire participer; plusieurs facteurs influant sur le dialogue ont été recensés. Un dialogue sérieux peut être favorisé par une attention à la communication, aux relations, aux capacités individuelles et à la compassion entre les pairs et les autres professionnels.

Keywords Community participation · Consumer participation · Drug users · Harm reduction · Rural health · Focus groups

**Mots-clés** Participation de la communauté · Participation des consommateurs · Usagers de drogues · Réduction des dommages · Santé en zone rurale · Groupes focalisés

## Introduction

The definition of peers varies across the literature, but in the context of harm reduction, it can be defined as people who have lived experience of substance use and who use that knowledge to inform their work. Building upon the "Nothing About Us Without Us" and Greater Involvement of People Living with HIV/AIDS (GIPA) movements (UNAIDS 2007; Canadian HIV/AIDS Legal Network 2006), peer engagement (PE) is an approach to decisionmaking that can be used across a variety of public health contexts, including programming, treatment support, patient navigation, and harm reduction (UNAIDS 2007; Canadian HIV/AIDS Legal Network 2006; Damon et al. 2017; Greer et al. 2016; 2018; Marshall et al. 2015). Evidence shows that PE has the potential to improve equity in the distribution of services by increasing marginalized groups' influence over decisions that affect them (Damon et al. 2017; Bryson et al. 2013; Feldman et al. 2013; Pauly 2008).

PE can be applied across multiple groups of people. The GIPA principle in health programs and research has been particularly robust in terms of PE (International HIV/AIDS Alliance 2010; Peer health navigation: GIPA, MEPA and your organization 2018; UN AIDS 2007). The field of mental health has also made strides in developing comprehensive practice guides and critically discussing issues with the engagement of these groups (Brosnan 2012; Cheung and Smith 2009; Griffiths and Hancock-Johnson 2017; Noorani 2013). Within the field of harm reduction, PE is strong in principle but in practice is still relatively new (Marshall et al. 2015; Ti et al. 2012). Specifically in British Columbia (BC), Canada, peers with experiential knowledge of substance use have been at the forefront of a range of health and harm reduction initiatives, including needle and syringe distribution services and overdose prevention messaging (UNAIDS 2007; Soukup-Baljak et al. 2015). Although theories and frameworks for PE are building (Canadian HIV/AIDS Legal Network 2006; Damon et al. 2017), attention to how people who use or have used illicit drugs (PWUD) have experienced PE in harm reduction is lacking (Marshall et al. 2015; Ti et al. 2012). And, without understanding how the affected community wants to be engaged, PE efforts may remain *tokenistic* (Arnstein 1969).

Tokenism in PE is particularly concerning due to the stigma and structural oppression that many PWUD face (Ahern et al. 2007; Room 2005). Within bureaucratic organizations where PE is initiated, overlapping stigma related to poverty, race, gender, and sexual orientation can compound and complicate stigma and inequities faced by peers (Mahajan et al. 2008). The GIPA literature points out that measuring, assessing, and reducing stigma requires a multifaceted and multilevel approach (Mahajan et al. 2008). Understanding the individual and structural levels of stigma, along with promoting PE and other community organizing, can enable resistance among those who are stigmatized (Damon et al. 2017; Mahajan et al. 2008; Link and Phelan 2014; Parker and Aggleton 2003).

Tokenism in PE has been an ongoing concern in Canada. In 2007, an increase in the uptake of PE public health in BC was noted (BC Centre for Disease Control 2008) with the release of the "Nothing About Us Without Us" guidelines—a report published by the Canadian HIV/AIDS Legal Network which makes a compelling case for meaningful PE from a human rights perspective (Centre for Addictions Research of BC: Canadian Association of People Who Use Drugs 2014). Following the release of this report, the BC Harm Reduction Services and Strategies committee agreed: "people who use illegal drugs should be engaged in all aspects of harm reduction supply distribution program development, implementation, and evaluation" (BC Centre for Disease Control 2008). However, in 2013, a national symposium of 14 peer-run



organizations across Canada concluded: "lack of representation is still common" (Greer et al. 2018). Despite efforts to develop and expand PE, the approach is most often designed on an ad hoc basis (UNAIDS 2007). Peers are still absent from many decision-making tables, or their participation lacks any decision-making power (Greer et al. 2018; Belle-Isle 2016).

"Engagement," "involvement," and "participation" are terms that have been used in the literature, but active, empowering, and transformative PE ultimately depends on the level of commitment and active participation in the decision-making process (Ocloo and Matthews 2016; Cornwall and Brock 2005; Leal 2007). In the current paper, engagement signifies a commitment to the PE process but is not necessarily action-based. In other words, PE may fall short in that individuals may be engaged but not enabled to actively participate. At the same time, PE that enables transformation and empowerment is more than merely participation but requires a robust commitment of resources, capacity building, and reflexivity (Canadian HIV/AIDS Legal Network 2006).

Barriers relating to PE in harm reduction are yet to be identified in great depth in the academic literature. The purpose of this study was to explore perspectives of PE among PWUD across BC to identify barriers and enablers to PE. This information has the important potential to promote greater and more meaningful PE in public health decisions that affect PWUD's lives both locally and internationally.

## **Methods**

This community-based participatory study aimed to develop, implement, and disseminate research across communities with PWUD—an approach that can redress power imbalances, enable mutual benefits, and facilitate reciprocal knowledge sharing (Wallerstein and Duran 2010). Five research assistants (RAs) who identified as PWUD from each of BC's five regional health authorities (HAs) were recruited. RAs were recruited through peer-based organizations (in regions where they existed), whose peer-based boards nominated and voted in a regional representative to work on the project. In two health regions where no peer-based organizations were established, RAs were recruited through local harm reduction agencies.

In line with the participatory nature of the project, the team collaboratively determined the research protocol, data collection instrument, and recruitment strategy. The team decided to concentrate the research outside of Vancouver after an indepth team discussion about the state of PE in BC. Previous

research had also shown that PE was lacking in rural areas of BC (UNAIDS 2007). The recruitment was participatory in that peers were actively involved. RAs recruited PWUD in their respective regions primarily through word-of-mouth and, to a lesser degree, posters at harm reduction agencies. Focus group eligibility included being over 18 years old, used illicit drugs excluding marijuana in the past 30 days, and able to provide verbal informed consent.

The focus groups were held at sites familiar to the RAs, which included harm reduction agencies, food banks, and libraries. Once informed consent was established, participants completed a one-page questionnaire of demographic and drug use characteristics. The focus groups, lasting approximately 1 h, were moderated by the regional RA, with support from the harm reduction coordinator or academic research team members. A third team member took field notes. The groups were audio-recorded and later transcribed verbatim. Participants were given \$20 CAD in cash and food was provided.

The original question guide was developed with peers. The content areas for the focus group discussions were as follows: "access to harm reduction," "access to peer engagement," "experiences of peer engagement," and "peer networks/ organizations." However, after the guide was piloted in two groups, it was revised with the RAs so the language and content (but not the content areas) were more accessible to PWUD. After each focus group, general impressions about its process and content were discussed among the team members. Also, notes from group observations and team discussions were written about emerging themes. This iterative approach allowed gaps in the questioning to be identified and also salient or absent topics for subsequent groups.

The transcriptions and field notes were reviewed and thematically analyzed using a participatory coding process developed by the academic and peer researchers. The thematic approach was chosen as a method that could comprehensively identify, analyze, organize, and report themes with an applied focus (Braun and Clarke 2006; Nowell et al. 2017), which was appropriate for the aims of this study. This approach is also "a more accessible form of data analysis, particularly for those early in their research career" (Nowell et al. 2017), which worked well with our team.

The steps used in the analysis were similar to those outlined by Nowell et al. (2017), aimed to establish rigour and trust-worthiness in a thematic analysis. First, three broad themes which emerged through team debriefing, notes, and meetings served as initial codes. These codes were then synthesized and expanded on by the RAs and academic researchers to create hierarchies of concepts and themes. From this process, an exhaustive list of subthemes and codes was created and reviewed collaboratively, which was then used to code and sort the data in NVivo. The final themes and respective quotes were validated using the *cutting-and-sorting* method (Bogdan



<sup>&</sup>lt;sup>1</sup> After discussing the term "peer," the team decided to remove it from the RA job title (and this paper) as the team felt it may result in being treated differently than those identified as non-using members of the team. Rather, the word "peer" is only used in the context of highlighting the experiential knowledge that is contributed through this role.

and Biklen 1982) and discussed among all team members to confirm the quotes were dependable and accurate. Throughout this process, the team debriefed often, reflecting on interpretations and reactions to the data (Nowell et al. 2017; Lincoln and Guba 1985). The main set of themes which speaks to the barriers and enablers of peer engagement is presented herein. In line with the participatory research approach, several RAs on the Peer Engagement and Evaluation Project (PEEP) team importantly co-authored this paper.

## **Results**

# **Descriptives**

Of 13 focus groups, three were conducted in each of Northern, Interior, Fraser, and Island HAs, while only one was conducted in Vancouver Coastal HA. There was a range in the size of town or city the groups were held in, although where they were held was not necessarily participant's location of residence. Although 83 people participated in the focus groups, participants in two did not complete the demographic form (due to researcher oversight); therefore, the demographics presented are from 70 participants. The demographics are provided in Table 1. In terms of substance use, most participants reported using more than one drug in the past week. Stimulants were used mostly, with crack and methamphetamine being most reported, while almost half had used opioids in the past week (Table 2).

# **Focus group findings**

Several subthemes of barriers and enablers to PE were identified. These themes and subthemes are summarized in Table 3 and presented in more detail below.

#### **PE** barriers

## **Personal barriers**

Access to and knowledge of PE varied across BC. In rural areas, PE was a new concept to some participants. Challenges to seeking or reaching PE events were expressed, as was an unfamiliarity of acting on opportunities. A lack of self-efficacy, instability, and competing priorities made engagement challenging. Many discussed being "too busy, doing what you gotta do" or being caught up in either using or dealing drugs. One woman said: "I lead a double life, so it's a bit tricky for me" (Quesnel). Participants suggested that it was hard to engage because it meant altering their routine, which they were unwilling to do without consistent and sustainable PE opportunities. A lack of phone, computer, and transportation were also identified as barriers to engage.

**Table 1** Demographic characteristics of clients (n = 70)

	n	Percent
Gender		
Female	30	42.9
Male	38	54.3
Trans or other	2	2.8
Age, years		
All clients, mean (range 18-24)	43.7	
Female, mean (range 18-60)	41.4	
Male, mean (range 20-64)	45.2	
Ethnicity		
Aboriginal	25	35.7
Non-Aboriginal	45	64.3
Income source <sup>†</sup>		
Part-time employment	6	8.6
Self-employed	7	10.0
Disability assistance	42	60.0
Social assistance	20	28.6
Other	13	18.6
Housing status		
Owned unit	3	4.3
Rental unit	38	54.3
Shelter	10	14.3
No fixed address	16	22.9
Other	3	4.3
Duration of drug use, years		
Mean (range 18–64)	43.7	

Thirteen participants who did not receive the demographic survey were excluded

**Table 2** Drugs used in the last week (individuals could give more than one answer) (N = 70)

	n	Percent
Heroin	30	42.9
Methadone	19	27.1
Morphine	28	40.0
Dilaudid	15	21.4
Oxycodone	12	17.1
Fentanyl	15	21.4
Benzodiazepine	15	21.4
Cocaine	27	38.6
Crack	37	52.9
Crystal meth	36	51.4
Stimulant	12	17.1
Marijuana	10	14.3

Thirteen participants who did not receive the demographic survey were excluded



<sup>†</sup> Individuals were able to answer more than one income source

**Table 3** Barriers and enablers to PE (N = 83)

	Examples
Barriers	
Personal	<ul><li>Access to and knowledge of PE</li><li>Self-efficacy and other commitments</li><li>Access to phone and computer</li></ul>
Geographic	<ul><li>Distance, particularly in rural areas</li><li>Access to transportation</li></ul>
Financial	• Lack of resources, including time, space, and money (for programs and peers)
Gatekeepers	Support from leadership     Blocking from police, city council, and government
Stigma	• Stigmatization of PWUD locally and in society • Lack of community acceptance for PE
Fear of being outed	Being "outed" via setting and relationships     Breaches of confidentiality in healthcare settings
Enablers	
Incentives	<ul><li>Recognition and value for peers' expertise</li><li>Cash, food, and activities</li></ul>
Consistency	• Stable, consistent, and sustainable opportunities • Consistent people involved
Location	<ul><li>Inconspicuous location or entrance</li><li>A "safe space" identified by PWUD</li><li>Close to or access to transportation</li></ul>
The right people	<ul> <li>Committed, compassionate, and knowledgeable staff</li> <li>Staff with lived experience</li> <li>Build trust through relationships over time</li> </ul>
Peer networks	<ul><li>Access to information and opportunities</li><li>Support and capacity building</li><li>Advocacy/organizing</li></ul>

#### **Geographic barriers**

Geography was identified as a barrier, particularly for those in rural areas. Some participants felt disconnected to health services and needed to travel long distances (sometimes days) to participate: "it's too far to come in" (female, Victoria). Part of the difficulty traveling was due to transportation availability, as well as distance to locations:

It's hard to start something when it's so far across, like people are so spread out and there's really not one big meeting or just a spot where people can go... (female, Nanaimo)

### **Financial barriers**

Participants expressed a lack of organizational support for PE. Funding for PE initiatives seemed to be a main concern, both regarding paying peers but also the resources needed to support inclusion. Some participants experiencing poverty had faced economic barriers to engagement. Participants identified that "space and money" and "staff full-time" were challenges, alluding to a lack of organizational capacity. In regions lacking PE, secured funding was suggested as a starting point: "Anyone starting anything, you need money" (male, Quesnel). Others explained that funding would also support their participation; most participants faced poverty, unemployment, and homelessness, so economic support was paramount for engagement. One woman from Vancouver said:

...to help take the load off of like the time we're spending because we have to take away the time from our survival or our everyday...

Financial support went beyond monetary purposes. Remuneration for peers' time and effort was important "to have like the government or whoever recognize that our time is valuable too" (female, Vancouver), reinforcing the notion that incentives were important as a sign of respect and value of their expertise. They mentioned that other professionals were paid for their time and efforts; therefore, compensation was a symbol of respect and inclusion.

## Gatekeepers

When asked about the opportunity to expand PE, some participants thought "no way" and openly discussed "gatekeepers" to PE—like city council, police, and government. Participants discussed the notion of police as gatekeepers, operating within the context of drug criminalization. One woman said: "I know the policing and that would be a big part of it, having their support…" (Smithers). Participants voiced skepticism of these gatekeepers' intentions and whether they would further marginalize peers. Part of this distrust was based on historical accounts of various gatekeepers exerting power over participants:

[Government agency] comes in, they take your kids for example[...] Like you're setting me up for failure.... What do you want me to do? You've done this to me (female, Langley)

These oppressive experiences added to the distrust of figures of authority and privilege.

## Stigma

The stigmatization of PWUD, in addition to other intersecting identities, was a topic that weaved through every discussion. Participants perceived the acceptability of substance use influenced people's understanding of and commitment to PE. Harm reduction was not widely accepted in rural areas, so



expanding PE in these areas was perceived as unrealistic due to the pervasive stigma of PWUD. Participants also discussed their fear of further marginalization and harm if they did engage. One woman recalled what happened when the public discovered PWUD were organizing in a local office space, describing the repercussions they faced by bringing PWUD together:

...it's just certain community members...we've had like people trying to break the windows, vandalize it, like that kind of stuff to try and keep it away from that, those type of people [PWUD] (female, Smithers)

In some communities, drug use was viewed as a *moral choice*. These descriptions were often met with internalized stigma.

Others shared that their neighbours, community, and society at large were unfamiliar and uncomfortable with drug use and PWUD: "They're scared 'cause they don't know us and they don't know what we're like" (male, Smithers). Participants noted the stigmatization of PWUD within the context of criminalization and often compared it to regulated substances like alcohol.

...drug addiction is still viewed as a moral choice so there's something morally wrong with us...we *choose* to be addicts.... I can't remember as a little girl sitting there and saying, 'I just wanna be a crack addict that works on the street selling my ass so that I can buy dope'.... Nobody chooses it (female, Quesnel)

Participants were quick to compare the acceptability of drug use in their regions to other areas, noting vast differences across BC.

# Fear of being outed

The impact of stigma became clear as participants described their reluctance to engage. Some would avoid engaging with particular people or locations because it would "out" them. One group discussed a "wall of shame" in a small town where PWUD frequently stood. One man stated: "My wife constantly gets asked why [I am] down there...why is he around the wall of shame?" (Courtenay). Being "outed" due to visibility in public spaces was particularly problematic for people facing homelessness.

Participants had also been outed in healthcare settings and voiced their fear of "being punished" as a result. One of the main impacts of "outing" was losing access to medical care or pain management. Being "flagged" as a PWUD in the medical system was one consequence: "there's a big red check mark that's put on your record for the rest of your life" (female, Nelson). There were several examples of healthcare providers

sharing PWUD's HIV or methadone status with others in the community. Examples of breaches in confidentiality were common and important as they contributed to the distrust participants had towards figures of authority and the healthcare system, which stood as a main barrier to PE.

#### PE enablers

#### **Incentives**

Incentives were important as they showed respect and value for time and knowledge; examples given were food, money, cigarettes, and activities. Some suggested incentives could make them *feel normal*. Social benefits were also seen as incentivizing. For some, PE contributed to a sense of social inclusion.

## Consistency

Examples of PE varied widely across BC. Often, people had engaged once or twice, or not at all. Consistency across PE processes was important, although not the norm. Participants suggested ways to mitigate these gaps: "How about a meeting, monthly meetings or something, start there" (male, Quesnel). Consistent opportunities also showed organizational commitment to PE. Furthermore, consistency promoted trust and capacity building.

#### Location

The place where peers participated was important, in terms of both the space and location. People suggested making sure locations were convenient and could promote confidentiality or "not draw unwanted attention" to people. One man said: "it needs to be confidential or it needs to be in a safe place" (Courtenay). Participants offered examples of spaces and storefronts in their regions that were inviting for *them* (i.e., libraries) that they described as "safe." One example of a location participants liked was an agency with a backdoor entrance, which promoted confidentiality.

## The right people

Participants talked about the commitment from PWUD and providers required to support meaningful PE. Part of this idea was "finding the right people." The concept of the *right people* was based on trust and compassion, like staff who worked from a harm reduction approach. Participants thought "an educated leader" or "somebody who wants to help empower and move people forward," like those working specifically in harm reduction because "they wanna be there" or "they actually like people." However, participants emphasized the need for people with a history of substance use to



be involved (i.e., peers), who could lead by example and offer experiential knowledge:

Users. People that use who have been there, people who have walked the walk (male, Vancouver)

Many participants discussed that "book smarts" was not enough to be equipped to work with PWUD. Some views stemmed from interactions with doctors who were uneducated on matters about peers' lives:

They haven't lived it, they live it every day with the people that they're in contact with but if they haven't really lived it...you guys [need to be] educating doctors (male, Courtenay)

A drug use history was described as a unique expertise—a lived knowledge—that they saw as highly valued and necessary in PE.

There were certain non-peer roles that were considered more trustworthy than others, such as street nurses. These *allies* often lacked a drug use history but tended to take a non-judgemental and inclusive approach. Given that stigma was such a predominant barrier, recognizing compassion and building trust in relationships were necessary. In terms of building trust, participants described fostering relationships over time.

#### Peer networks

The importance of peer networks was a main theme. Several benefits to peer-based organizations or peer networks were offered, including access to information, support, and looking out for each other. Participants described their peers as "family"—"brothers" and "sisters." There were strong feelings of helping and safety attributed to other PWUD:

Someone said the addicts down here and the people, the homeless have more heart and more compassion than most regular people.... We understand (female, Maple Ridge)

Many participants recognized that by looking out for others, capacity was built for the entire community: "getting the information first hand in front of your peers about what's bad, you know, what's not, what's happening, what's going on" (male, Vancouver). Networks also worked as an informal harm reduction system, getting information and supplies to PWUD who were less connected to services.

Participants saw the benefits and drew distinction to peer groups with a specific cause or issue. Many described how a formal peer group gave them a sense of purpose. Participants recognized the importance of banding together to overcome barriers and support each other, stating they were "stronger with numbers."

## **Discussion**

This study sought to qualitatively understand how PWUD experience PE, the barriers they face, as well as what could improve PE. This study is novel in that it is one of the first qualitative studies to investigate barriers and enablers to PE among PWUD. Using a participatory research approach, we spoke to 83 PWUD across BC, revealing a range of individual, interpersonal, organizational, and societal factors that influence PE experiences and motivations. This study approach allowed us to explore how PWUD experience the local context of PE and the realities of participation.

We revealed that a lack of confidence, stability, and capacity were personal barriers to engagement, which were met with geographic and logistical challenges, particularly in rural areas. These barriers added to the broader, interrelated themes of stigma, fear of being outed, and gatekeepers, which seemed to be reinforced through a history of marginalization and criminalization of PWUD. However, despite these experiences, several "terms of engagement" were suggested as a way to facilitate participation, including consistent opportunities with the right people, place, and incentives. GIPA research has shown similar barriers, including HIV-related stigma, healthrelated challenges, "credentialism," lack of capacity to engage, other priorities, and mistrust of researchers (Oliver 2014; Travers et al. 2008). In our study, PWUD and networks were described as a safe and supportive way to connect, as well as provide information about opportunities. These important insights from PWUD are vital to expand engagement that works for peers.

This study adds to a small but growing body of research and theoretical stances on the uptake of inclusive and participatory approaches with affected communities (Damon et al. 2017; Marshall et al. 2015; Cheung and Smith 2009; Ti et al. 2012; Mahajan et al. 2008; Attree et al. 2011; Barker and Maguire 2017; Guta et al. 2013). The current study provides an example of the importance of talking to PWUD: peers themselves provide important insights about the local context of PE, including why and how peers can be enabled to engage. However, the recognition of peers' lived experience as a valued form of knowledge is still lacking, although some organizations have started to develop critiques and resources to paying peers (Damon et al. 2017; Guta et al. 2013; Greer and Buxton 2018). One way to shift this privileged space and show recognition is to adequately compensate peers for the unique knowledge they bring to the table. As our findings suggest, peers view this knowledge as an expertise that needs to be recognized. In doing so, equitable pay may mitigate stigma and marginalization that PWUD face.



This study serves as a starting point to build processes and capacity for PE in health and harm reduction settings. However, the effectiveness of engagement and the extent of participation relies on how and how much it is adapted to the population and context. Researchers stress that both the approach to engagement, the activities involved in peers' participation, and the interactions with peers all build trust and legitimacy, thus promoting meaningful and sustainable relationships between stakeholders (Marshall et al. 2015). Our findings support this notion that the right people are needed, especially to build trust and relationships that support inclusion. Further, we must examine (and re-examine) the ways in which professionals develop trust, redress power imbalances, and improve relationships. From a critical perspective, this work may identify and address structural barriers that peers may face across multiple, overlapping inequities (Pauly 2008; Mahajan et al. 2008; Parker and Aggleton 2003).

Despite well-intentioned efforts to overcome barriers and build meaningful relationships with PWUD, we found that without adequate leadership, support, and resources, PE may continue to be tokenistic. One outcome of the PEEP research has been developing PE best practice guidelines for BC health authorities (Canadian HIV/AIDS Legal Network 2006). Similar to our results, Marshall et al. (2015) found that inadequate training, lack of support, and availability of roles remain as challenges for PE—this paper and the guidelines serve as a starting point to address these shortcomings. However, the range of factors that inform PE may be undermined by the systemic, taken-for-granted social arrangements that PWUD face. Other researchers have noted that while PE is supported in theory, practice often lags far behind (Travers et al. 2008). Therefore, gaining leadership support for PE, as well as sufficient resources (financial and human) required to do meaningful work, may be the first step in ensuring PE is not tokenistic.

There are some limitations to our study that should be acknowledged. First, many communities were unfamiliar with or not ready to talk about PE. Although this is a finding in itself and the focus group guide was peer-informed (and peerfacilitated), some groups had difficulty understanding the concept of PE. Future research would benefit by creating a discussion early on of what level of commitment is needed and what engagement means to the group, thereby using language and concepts that are generated by participants. We also noted the potential influence of recruitment among RAs and harm reduction agencies. While the aim of qualitative research is not to be representative, research with harder-to-reach PWUD or those in communities without harm reduction services may elicit other findings. Moreover, our analysis did not use an intersectional lens, although we attempted to be critical of the positionality of participants and implications of our findings. Finally, since collecting these data, BC has declared a public health crisis from the proliferation of opioid poisonings, placing peers at the forefront of the response. As such, the findings of this study may be augmented in light of current policy and program changes across Canada. Nonetheless, findings here reveal a nuanced picture of how PWUD experience PE that can be applied to designing future initiatives.

In conclusion, people who have used illicit drugs are important stakeholders in decisions that affect them. As participatory processes are increasingly recognized as a best practice approach in health and harm reduction settings, this study provides insights into several factors that influence PE. By addressing or leveraging these considerations, future efforts, both locally and internationally, may begin to promote more meaningful PE by fostering communication, relationships, personal capacity, and compassion between peers and other professionals.

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# References

- Ahern, J., Stuber, J., & Galea, S. (2007). Stigma, discrimination and the health of illicit drug users. *Drug and Alcohol Dependence*, 88(2–3), 188–196.
- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35(4), 216–224.
- Attree, P., French, B., Milton, B., et al. (2011). The experience of community engagement for individuals: a rapid review of evidence. Health & Social Care in the Community, 19(3), 250–260.
- Barker, S. L., & Maguire, N. (2017). Experts by experience: peer support and its use with the homeless. *Community Mental Health Journal*, 53(5), 598–612.
- BC Centre for Disease Control. (2008). Best practices for British Columbia's harm reduction supply distribution program. Vancouver, BC: BC Centre for Disease Control. Available at: http://www.bccdc.ca/resource-gallery/Documents/Guidelines% 20and%20Forms/Guidelines%20and%20Manuals/Epid/Other/BestPractices.pdf. Accessed April 3, 2017.
- Belle-Isle, L. (2016). At the table with people who use drugs: transforming power inequities. Available at: https://dspace.library.uvic.ca//handle/1828/7199.
- Bogdan, R., & Biklen, S. (1982). *Qualitative research for education: an introduction to theory and methods.* Boston: Allyn & Bacon, Inc.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.
- Brosnan, L. (2012). Power and participation: an examination of the dynamics of mental health service-user involvement in Ireland. *Studies in Social Justice*, 6(1), 45–66.
- Bryson, J. M., Quick, K. S., Slotterback, C. S., et al. (2013). Designing public participation processes. *Public Administration Review*, 73(1), 23–34.
- Canadian HIV/AIDS Legal Network. (2006) "Nothing About Us Without Us" greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative. (Accessed June 25, 2015). Available at: http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf.



- Centre for Addictions Research of BC: Canadian Association of People Who Use Drugs. (2014). Collective voices effective change: a final report of National meeting of peer-run organizations of people who use drugs. Victoria, BC: Centre for Addictions Research of BC: Canadian Association of People Who Use Drugs. Available at: static1.squarespace.com/static/53015f40e4b0c6ad9e406a13/t/53972833e4b0240065925810/1402415155682/CollectiveVoices+Report+FINAL+30May14.pdf.
- Cheung, R., Smith, C. (2009). Engaging people with lived experience for better health outcomes: collaboration with mental health and addiction service users in research, Policy and Treatment. Ministers Advisory Group. Available at: http://canadianharmreduction.com/sites/default/files/Engaging%20PWLE%20-%20July%207%202009.pdf.
- Cornwall, A., & Brock, K. (2005). What do buzzwords do for development policy? A critical look at 'participation', 'empowerment' and 'poverty reduction'. *Third World Quarterly*, 26(7), 1043–1060.
- Damon, W., Callon, C., Wiebe, L., et al. (2017). Community-based participatory research in a heavily researched inner city neighbourhood: perspectives of people who use drugs on their experiences as peer researchers. Social Science & Medicine, 176, 85–92.
- Feldman, M., Quick, K., Guillermo, N. (2013). The emergence of coproduction: learning from history. In Madison, Wisconsin. Available at: http://www.union.wisc.edu/pmra2013/Paper%20Submissions/ Renamed/The%20Emergence%20of%20Co-Production% 20Learning%20from%20History.pdf.
- Greer, A., Buxton, J. (2018). A guide for paying peer research assistants: challenges and opportunities (version 2). Vancouver, BC: BC Centre for Disease Control. Available at: http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer PEEP payment 2018.pdf.
- Greer, A., Luchenski, S. A., Amlani, A. A. et al. (2016). Peer engagement in harm reduction strategies and services: a critical case study and evaluation framework from British Columbia, Canada. *BMC Public Health*. (Accessed July 8, 2016);16(1). Available at: http:// bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-016-3136-4.
- Greer, A., Amlani, A., Burgess, H., et al. (2018). Peer engagement principles and best practices for BC health authorities and other providers. BC Centre for Disease Control. Available at: http://www.bccdc.ca/health-professionals/clinical-resources/harm-reduction/peer-engagement-evaluation
- Griffiths, C. A., & Hancock-Johnson, E. (2017). The experiences of paid formal lived experience workers within a secure mental health service. *Journal of Mental Health Training, Education and Practice*, 12(5), 313–322.
- Guta, A., Flicker, S., & Roche, B. (2013). Governing through community allegiance: a qualitative examination of peer research in communitybased participatory research. *Critical Public Health*, 23(4), 432– 451.
- International HIV/AIDS Alliance. (2010). Greater Involvement of People Living with HIV (GIPA) good practice guide. Available at: http://www.aidsalliance.org/assets/000/000/411/464-Good-practice-guide-Greater-involvement-of-people-living-with-HIV-(GIPA)\_original.pdf?1405586730.

- Leal, P. A. (2007). Participation: the ascendancy of a buzzword in the neo-liberal era. *Development in Practice*, 17(4–5), 539–548.
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newcastle upon Tyne: SAGE.
- Link, B. G., & Phelan, J. (2014). Stigma power. Social Science & Medicine, 103, 24–32.
- Mahajan, A. P., Sayles, J. N., Patel, V. A., et al. (2008). Stigma in the HIV/ AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS, 22(Suppl 2), S67–S79.
- Marshall, Z., Dechman, M. K., Minichiello, A., et al. (2015). Peering into the literature: a systematic review of the roles of people who inject drugs in harm reduction initiatives. *Drug and Alcohol Dependence*, 151(0), 1–14.
- Noorani, T. (2013). Service user involvement, authority and the 'expertby-experience' in mental health. *Journal of Political Power, 6*(1), 49–68.
- Nowell, L. S., Norris, J. M., White, D. E., et al. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods.*, 16(1), 1609406917733847.
- Ocloo, J., Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qualitative Safety*. bmjqs-2015-004839.
- Oliver, B. W.. (2014). Work in progress: a conceptual framework for understanding the successful vocational experiences of people living with HIV in Canada. University of Calgary. Available at: http://theses.ucalgary.ca/handle/11023/1448.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine, 57(1), 13–24.
- Pauly, B. (2008). Harm reduction through a social justice lens. *International Journal of Drug Policy*, 19(1), 4–10.
- Peer health navigation: GIPA, MEPA and your organization. (2018). Available at: http://www.catie.ca/en/webinars/peer-health-navigation-gipa-mepa-and-your-organization.
- Room, R. (2005). Stigma, social inequality and alcohol and drug use. Drug and Alcohol Review, 24(2), 143–155.
- Soukup-Baljak, Y., Greer, A. M., Amlani, A., et al. (2015). Drug quality assessment practices and communication of drug alerts among people who use drugs. *The International Journal on Drug Policy*.
- Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: a review of the literature. Substance Abuse Treatment, Prevention, and Policy, 7(1), 47.
- Travers, R., Wilson, M. G., Flicker, S., et al. (2008). The greater involvement of people living with AIDS principle: theory versus practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care*, 20(6), 615–624.
- UN AIDS. (2007). The Greater Involvement of People Living with HIV (GIPA). Available at: http://data.unaids.org/pub/BriefingNote/2007/jc1299\_policy\_brief\_gipa.pdf.
- UNAIDS. (2007). Greater Involvement of People Living with HIV (GIPA). (Accessed June 25, 2015). Available at: http://data.unaids.org/pub/BriefingNote/2007/jc1299\_policy\_brief\_gipa.pdf.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American Journal of Public Health*, 100(S1), S40–S46.

