Including People Who Use Drugs in the Development and Delivery of Harm Reduction Programs, Services, and Drug Policy: A Scoping Review of the Literature

by

Sarah Anne Wojcik

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We acknowledge with respect the Lekwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

Supervisory Committee

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Supervisory Committee

Dr. Bernie Pauly
School of Nursing, University of Victoria
Supervisor

Dr. Eric Roth
Department of Anthropology, University of Victoria
Co-Supervisor

Abstract

Background: People who use drugs (PWUD) are disproportionately burdened by rates of HIV and Hepatitis C, more likely to experience stigma, social exclusion, and as a result, have poorer health outcomes. To mitigate these inequities in health, people with lived experience of drug use are, and should be, included in decisions that affect them. There is evidence that including PWUD in the development and delivery of harm reduction programs, services, and drug policy ensures such initiatives addresses their needs most effectively. As such, the purpose of this thesis is to present the findings of a scoping review of the peer-reviewed literature examining the involvement of people who use drugs (PWUD) in the development and delivery of harm reduction programs, services, and drug policy.

Methods: Scoping reviews represent an increasingly popular method used to review the literature of a particular topic. It is a process of summarizing, or 'mapping', a range of evidence in order to convey the breadth and depth of a particular field. This scoping review implemented a search strategy focused on three categories: search terms that describe 'peer engagement', search terms that describe 'substance use' and finally search terms that describe 'harm reduction programs/services/policy'. Searches of five academic electronic databases were conducted. Peer-reviewed literature published between 2010 and 2020 that discussed the involvement of PWUD in the development and/or delivery of harm reduction programs, services, or drug policy was included in the scoping review.

Results: The search strategy produced a total of 1902 references. After duplicates were removed, thirty-two references met the inclusion criteria and were included for analysis. This scoping review identified five characteristics from each study: 1) type of study, 2) location of study, 3) year of publication, 4) type of engagement/participation, and 5) peer roles.

Conclusion: One critical finding of this scoping review is the highest level of participation among PWUD was achieved when drug-user organizations were involved.

Keywords: Scoping review, Peer engagement, People who use drugs, Harm reduction, Health equity, Social inclusion.

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Chapter 1: Introduction

In Canada and other countries around the world, illicit drug use is largely treated as an issue of criminal law, rather than as a major public health concern (Kerr, Tyndall, Li, Montaner, & Wood 2005; O'Shaughnessey, Hogg, Strathdee & Montaner, 2012). Marginalized because of their drug use, and discriminated against because of other factors such as poverty, homelessness, social exclusion, and mental illness, people who use drugs (PWUD) have historically been distanced from mainstream services and structures (Jurgens, 2008). As a result, PWUD are more likely to experience the negative health, economic, and social harms associated with illicit drug use (Des Jarlais, Freidman, & Ward, 1993; Marlatt, 1996). Such harms include acquiring Human Immunodeficiency Virus (HIV) and Hepatitis C Virus (HCV), experiencing stigma, having inadequate access to health care and social services, overdose, and incarceration (Des Jarlais, Freidman & Ward, 1993; Tyndall, Craib, Currie, O'Shaughnessy, & Schechter 2001; Kerr, Fairbairn, Tyndall, Marsh, Montaner, & Wood, 2007).

To address these health and social concerns, harm reduction approaches have been identified as integral to minimizing the harms associated with illicit drug use (Des Jarlais, Freidman, & Ward, 1993; Marlatt, 1996; Pauly, Reist, Schactman, & Belle-Isle, 2011). The philosophy underlying harm reduction moves the moral context away from 'fixing the individual' and shifts it towards 'reducing harms' (Marlatt, 1996; Friedman et al., 2007; Pauly, 2014). Harm reduction involves a pragmatic, multidisciplinary, non-judgmental health promoting approach that meets people where they are (Friedman, et al., 2007; Pauly, et al., 2011; Pauly, 2014). Harm reduction recognizes a continuum of appropriate responses with a range of beneficial outcomes, including limiting the spread of disease, improving environments, encouraging access to treatment and social services, lowering personal risk, promoting skills in

self-care, cutting down on expenses, and saving lives (Marlatt & Witkiewitz, 2009). However, as Pauly (2008) notes, although harm reduction interventions play an integral role in promoting the health of PWUD, these interventions do not necessarily address the root cause(s) of substance use or the structural inequities they face that negatively impact health (Pauly, 2008; Smye, et al., 2011).

Social inclusion is an approach to addressing health inequities of populations by ensuring that communities and populations who are most affected by a particular health or social condition are included in decisions that impact their lives (Solar & Irwin, 2010). Within recent decades, people with lived experience of many health and social issues have played increasingly integral roles in the development and delivery of programs, interventions, and services designed to meet their needs (Jurgens, 2008; Minkler & Wallerstein, 2004). On a global scale, community-based participation and social inclusion is recognized as an effective, life-saving health promotion intervention, where populations and communities have the ability to engage and participate in addressing concerns about their health (Jurgens, 2008; Minkler & Wallerstein, 2004). This is especially true for PWUD and the policies, programs, and services that affect them directly: their meaningful engagement is critical to the development of equitable and sustainable harm reduction initiatives (Ti, Tzemis, & Buxton, 2012; Marshall, Dechman, Minichiello, Alcock, & Harris, 2015). Using their lived experience, unique skills, and assets they each bring to the decision-making table, PWUD, or ‘peers’, are best positioned to make meaningful decisions that affect them directly (Jurgens, 2008). As such, participating and being involved in such decision-making processes is central to promoting the health equity of PWUD (Solar & Irwin, 2010; Jurgens, 2008).

While a considerable body of evidence acknowledges the importance of involving PWUD in decisions that affect them (Treloar, Fraser, & Valentine, 2007; Trujols et al., 2012; Trujols et al., 2015; Greer et al., 2016), little is known about the range, extent, and nature of including PWUD in the development and delivery of harm reduction programs, services, and drug policy (Ti, Tzemis, & Buxton, 2012; Marshall et al., 2015). To address this gap, I have undertaken a scoping review in fulfillment of my Masters thesis to harness an understanding of what is known about involving PWUD in the development and delivery of harm reduction programs, services, and drug policy, both globally and within Canada.

Research Objectives and Research Questions

The research objectives are:

- To explore and conceptually map the peer-reviewed literature (within the most recent ten years) to describe the involvement of peers in the development and/or delivery of harm reduction programs, services, and drug policy. Specifically, I will identify and conceptually map primary research articles (both quantitative and qualitative)
- To identify and describe, within each peer-reviewed article, how peers are being involved in the development and/or delivery of harm reduction programs, services, and drug policy. Where possible, identify how this description of peer engagement aligns to fit on Arnstein's Ladder of Citizen Participation (Arnstein, 1969).
- To determine and synthesize information that could help inform policy makers, service providers who work with peers in harm reduction initiatives, and others hoping to better and more meaningfully include people with lived experience in the development and delivery of harm reduction services, programs, and drug policies

These research objectives are guided by the research question:

What is known about the inclusion of PWUD in the development and delivery of harm reduction programs, services, and drug policies?

Chapter 2: Literature Review

Inequities in Health

According to Sir Michael Marmot (2007), all societies have social hierarchies where economic and social resources, including power and prestige, are distributed unequally (Marmot, 2007; WHO, 2008). This unequal distribution of resources has a powerful effect on health and its distribution in society, ultimately producing inequities in health (Marmot, 2007). Poor health disproportionately affects those who are disadvantaged due to factors such as socioeconomic status, geographic location, gender, and ethnicity (Braveman & Tarimo, 2002; Marmot, 2005). The World Health Organization defines health inequities as: "differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live work, and age. Health inequities are unfair and could be reduced by the right mix of government policies." (WHO, 2018). In Canada, PWUD are affected by health inequities in that they disproportionately experience inadequate access to health care, have poorer health outcomes, and decreased life expectancies in comparison to non-illicit drug-using populations (Tyndall et al., 2001; Braitstein et al., 2006; Lloyd-Smith et al., 2006; Kerr et al., 2007). I will now briefly examine two central drivers of health inequities affecting PWUD: stigma and criminalizing social policies.

Drug-Related Stigma

Stigma is a central driver of morbidity and mortality at a population health level (Hatzenbuehler, Phelan, & Link, 2013). Goffman (1963) defines stigma as a social attribute that is discrediting for an individual or group. Stigma is often regarded as having a detrimental impact on self-concept and identify, resulting in degrees of social exclusion (Goffman, 1963, Link & Phelan, 2001; Scambler, 2004, Phillips, Benoit, Hallgrimsdottir, & Vallance, 2012). Not

only does stigma impact identity formation and social interaction, but it intersects with other social and structural determinants of health to produce multiple disadvantages (Link & Phelan, 2006; Phillips et al., 2012). As such, due to the many psychological and structural pathways through which stigma operates to influence health, Hatzenbuehler, Phelan, & Link (2013) argue that stigma should be considered a fundamental social cause of health inequalities (Link & Phelan, 1996; Hatzenbuehler, Phelan, & Link, 2013).

PWUD are more likely to experience the structural manifestations of stigma (Jurgens, 2008). According to Ahern, Stuber, & Galea (2007), the stigmatization of illicit drug use adversely affects the health of PWUD in at least two ways. First, it has a direct impact on their mental and physical wellbeing as a result of chronic stress exposure (Krieger, 1999; Link et al., 1997; Ahern, Stuber, & Galea, 2007) resulting from experiences of societal discrimination, rejection by others, and the expectation of experiencing rejection (Link et al., 1999; Ahern, Stuber, & Galea, 2007). The effects of long-term stress may in turn lead to coping mechanisms involving social isolation, which worsens mental health (Link et al., 1999). Chronic stress also adversely affects physical health through the activation of the hypothalamic-pituitary-adrenal (HPA), a neuroendocrine process that regulates cortisol, a stress hormone (Taylor, Repetti, & Seeman, 1997; Miller, Chen, & Zhou, 2007).

Second, stigma may discourage PWUD from accessing health care services due to fear of poor treatment by health care providers (Link et al., 1997; Ahern, Stuber, & Galea, 2007). When they do seek health care, it is reported that PWUD often experience discrimination in healthcare settings and receive poorer quality of care compared to non-illicit drug users (Miller & Kaiser, 2001; Van Boekel, Brouwers, Weeghel, & Garretsen, 2013). Evidence indicates that PWUD mistrust traditional healthcare providers, including public health workers, because of prior

experiences of stigma when receiving care (Van Boekel, Brouwers, Weeghel, & Garretsen, 2013). This suggests that traditional healthcare and health promotion approaches may be inadequate in addressing the unique health needs of PWUD, and as such, may act to further perpetuate the inequities this population experiences (White, 2009).

Drug policies

Health inequities within marginalized populations are often exacerbated by regressive social policies (Whitehead & Dahlgren, 2006). Pertaining to the health inequities of PWUD, current international drug policy aimed at eliminating the non-medical use of certain drugs negatively impacts the health and wellbeing of those who use drugs (Jürgens, Cesete, Amon, Baral, & Beyrer, 2010). Such drug policy leads to criminalization and incarceration, thwarted harm reduction and health promotion efforts, and added barriers to accessing health and social services for those most in need (Jürgens, et al., 2010; Stevenson, 2011; Boyd & NAOMI, 2013). According to the Canadian HIV/AIDS Legal Network, repressive drug laws and policies have failed to reduce crime, drug use and drug related harms but, instead, have contributed to the mounting human rights violations against PWUD, and have propelled the HIV/AIDS and HCV epidemics by undermining life-saving access to harm reduction services and treatment for PWUD (Canadian HIV/AIDS Legal Network, 2015). Where harms may be associated with drug use itself, these harms intersect with and are exacerbated (as well as directly produced) by the damaging effects of prohibition, criminalization, and by the 'war on drugs' (Jürgens, 2008; Boyd & Boyd, 2014; Levy, 2014, pp.4). Rather than reducing or ameliorating the harmful consequences of drug use, such punitive laws and policies only serve to compound and exacerbate such harms, including stigma. Such laws and policies force the activities of PWUD underground, and only reinforces the difficult circumstances that contribute to the drug-related

harms they experience. The evidence is clear that prohibition laws and the criminalization of drug use have worsened the health and well-being of PWUD, accounting for the many health inequities they experience (Jurgens, 2008; Boyd & Boyd, 2014).

Harm Reduction

Much of the harms associated with drug use results not from the drugs themselves, but from the conditions under which they are used, and the criminalizing policies that maintains these conditions (Global Commission on Drugs, 2012; HIV and the Law, 2012). Harm reduction, both as a philosophy and a set of strategies, aims to minimize the harms and unintended consequences associated with illicit drug use (Des Jarlais, Friedman, & Ward, 1993; Marlatt 1996; Pauly, Reist, Schactman, & Belle-Isle, 2011). The philosophy underlying harm reduction involves a shift in moral context (Pauly, 2008). Specifically, it shifts the moral context away from 'fixing the individual', and towards one of 'minimizing harms' (Marlatt, 1996, Friedman et al., 2007; Pauly, 2008; Pauly, 2014). A harm reduction philosophy recognizes that drug use is a complex, multifaceted phenomenon that includes a continuum of behaviours ranging from total abstinence to chronic dependence (BCCDC, 2011). It also recognizes and values the dignity of PWUD, where everyone is seen as deserving of care, irrespective of their substance use patterns and behaviours (Pauly, 2008; Pauly, 2014). As defined by Harm Reduction International, a key principle of harm reduction involves the inclusion of people with lived and living experience of drug use in the development of harm reduction policy, and service planning/implementation (Harm Reduction International, 2021). By working together, it allows for all members of the decision-making table to learn about each other, bring unique strengths to the table, and allows for biases and assumptions to be challenged, which ultimately acts to reduce stigma (Belle-Isle, 2014)

As a strategy, harm reduction involves a pragmatic, multidisciplinary, non-judgmental health promoting approach to the provision of services and healthcare that meets people where they are at in their lives (Friedman et al, 2009; Pauly et al., 2007; Pauly, 2014). It recognizes a continuum of appropriate responses with a range of beneficial outcomes, some of which include: limiting the spread of disease, improving environments and communities, encouraging access to treatment and social services, lowering personal risk, promoting skills in self-care, cutting down on expenses, and saving lives (Marlatt & Witkiewitz, 2009). Some harm reduction interventions include: supervised consumption sites, needle exchange programs, take home naloxone programs, oral substitution therapies (e.g. slow-release oral morphine), injectable opioid agonist therapy (iOAT), and managed alcohol programs, among others (HealthLink BC, 2020). As Pauly (2008) notes, although harm reduction interventions help to promote the health of PWUD, such interventions do not always address the root causes of substance use or structural inequities contributing to the health inequities experienced by PWUD (Pauly et al., 2008, Smye, et al., 2011).

In Chapter 1 of *Harm Reduction: Pragmatic Strategies for Managing High-Risk Behaviours, Second Edition*, Collins et al. (2012) explore the bottom-up, grassroots advocacy of PWUD that helped to shape today's harm reduction policies, principles, and approaches. One example worth noting is that drug user organizations became prominent worldwide after the establishment of The Junkiebond in 1981, in Rotterdam, Netherlands (Marlatt, Larimer, & Witkiewitz, 2012). The Junkiebond was the first drug-user led group that advocated for harm reduction services and drug policy reform at both the local and national levels (Friedman et al., 2007; Marlatt, Larimer, & Witkiewitz, 2012). They did this by creating an underground syringe exchange in response to an outbreak of Hepatitis B among people using injection drugs

(Friedman et al., 2007; Marlatt, Larimer, & Witkiewitz, 2012). It was this underground syringe exchange, in combination with The Junkiebond's leadership and advocacy, that gave rise to the world's first government-funded syringe exchange program in 1984 (Marlatt, Larimer, & Witkiewitz, 2012). In response to the increasing cases of HIV/AIDS among PWID, members of the Junkiebond mobilized efforts and persuaded local health services to provide them with sterile syringes in bulk every week, which they then distributed throughout the Junkiebond community (Marlatt, 1998; Marlatt, Larimer, & Witkiewitz, 2012). Following this, the National Ministry of Health provided additional funding to expand the program nationwide (Friedman et al., 2007; Marlatt, Larimer, & Witkiewitz, 2012).

Another prominent example of a community of PWUD using bottom-up, grassroots approaches to harm reduction was the response of PWUD living in New York City during the height of the HIV/AIDS epidemic in the early 1980s. The public health response to the epidemic was long-delayed and limited, and at the time, syringe exchanges were fiercely opposed by politicians (Friedman et al., 2007). Similar to the Junkiebond, PWUD became rapidly aware of the necessity for reliable access to sterile syringes as a life or death issue. To mitigate the paucity of available sterile needles, PWUD in New York City implemented a massive city-wide, semi-public street market in sterile syringes (Rockwell et al., 2006; Friedman et al., 2007). As a result, HIV prevalence rates among PWUD in New York City did not reach above 50 percent, while HIV prevalence rates among other PWUD across the United States were on average around 70 percent (Friedman et al., 2007). This is a prime example of the grassroots, micro-social actions of PWUD having a profound impact on the overall health outcomes of their peers.

Social Inclusion and Participation to Address Health Inequities

When making decisions and developing policies aimed at improving the health outcomes of a community or population burdened by unjust health inequities, the specific needs of that population must be taken into account (Minkler & Wallerstein, 2004; Treloar & Rhodes, 2009). Community participation and social inclusion have been identified as effective avenues for engaging individuals in addressing health issues and inequities that affect them directly (Jurgens, 2008; Ti, Tzemis, & Buxton, 2012). Social inclusion involves community members bringing their knowledge, unique perspectives, and lived experience to decision-making tables, so that decisions are being made to reflect the wants and needs of that community (Minkler & Wallerstein, 2004; Rhodes, Malow, & Jolly, 2010; Belle-Isle, Benoit, & Pauly, 2014).

The World Health Organization (WHO) defines health promotion as the "process of enabling people and communities to take control over their health and its determinants" (WHO, 1984). According to Mooney (1998), community participation initiatives should be the foundation for identifying priorities and the allocation of health resources to ensure social justice and the promotion of health equity (Mooney, 1998; Mooney, 2000). As such, health initiatives and interventions should be promoted and enhanced through a bottom-up, user-led approach, driven by citizen control and partnership (Mooney, 1998; Rootman, Goodstadt, Potvin & Springett, 2001).

Belle-Isle, Benoit, & Pauly (2014) emphasize the importance of addressing health inequities through social inclusion. Health outcomes can be improved by the enhanced participation and involvement of socially excluded groups, including peers (Ti, Tzemis, & Buxton, 2012; Marshall et al., 2015; Trujols et al., 2015). Blankenship, Friedman, Dworkin, & Mantell (2006) identify community mobilization as a structural intervention for the prevention of

HIV. They define structural interventions as "a public health intervention that promotes health by altering the structural contexts within which health is produced and reproduced" (Blankenship et al., 2006). Community mobilization can act as a structural intervention by raising awareness among socially excluded groups about their rights, as well as providing strategies for demanding these rights, and by engaging in advocacy with stakeholders and other 'power brokers' who exercise varying degrees of control over that socially excluded group (Blankenship et al., 2006; Ti & Kerr, 2013).

Although there have been efforts to more meaningfully involve PWUD in research, policy, and service delivery, research shows these individuals are rarely involved in every stage of the development, design and dissemination of such decision-making initiatives (Roche, Guta, & Flicker, 2010). Many PWUD remain largely unrepresented when decisions are made about how to respond to their health and other concerns (Jurgens, 2008; Roche, Guta, &Flicker, 2010; Marshall et al., 2015). "*Nothing About Us Without Us: Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative"* is a call for more authentic inclusion of PWUD in the development of decisions that affect them. It examines why the meaningful involvement of people who use (or have used) illicit drugs is necessary in the response to combatting HIV, HCV, and other drug-related harms, and explores how this can be done (Jurgens, 2008). The authors also include a Manifesto prepared by PWUD: a declaration affirming that PWUD have a say in the decisions that affect them and their lives. This declaration lists a set of demands, including recognition, funding, support, and involvement in efforts on behalf of PWUD (Jurgens, 2008). From their lived experiences, PWUD are able to identify what works within their social networks and within the broader community, benefiting multiple stakeholders (Jurgens, 2008; Treloar & Rhodes, 2009; Marshall et al., 2015).

There is evidence that once PWUD are meaningfully included at the research, policy and program decision-making tables, their involvement enhances the relevance, acceptability, and accessibility of such projects, policies, and services (Popay et al., 2010; Ti, Tzemis, & Buxton, 2012; Belle-Isle, Benoit, & Pauly, 2014; Greer et al., 2016). The inclusion of PWUD can lead to the reduction in drug use risk behaviours (i.e. sharing of needles and other drug equipment; unsafe sexual practices), improved living conditions, health and well-being, as well as an increase in social support and social inclusion, which is a vital determinant of health (Ti, Tzemis, & Buxton, 2012; Belle-Isle, Benoit, & Pauly, 2014). Furthermore, for some PWUD, user involvement is not only about improving service provision and delivery, but also about broader social and political empowerment (Mold & Berridge, 2008). PWUD, like users of other types of health and social services, are entitled to a say in how services are run and in the kind of care they receive (Mold & Berridge, 2008; Jurgens, 2008).

Theoretical Lenses

Engagement, Power, and Empowerment

As describe above, the advantages of user involvement are well documented. Whiteford (2011) describes the principles of "user involvement", or peer engagement, in health services as being based on inclusivity, co-operation, and mutual respect. Peer engagement is a process that aims to challenge the uneven power relations often pervasive in the service user/service provider relationships by "democratizing the structures through which services are designed and delivered" (Whiteford, 2011, pp. 47; Norman & Pauly, 2013). Proponents for peer engagement argue that it provides people with lived experience a legitimate presence and voice at the decision-making tables for policies, programs, and services that affect them directly (Whiteford, 2011; Norman & Pauly, 2013).

Furthermore, it is worth recognizing the implications of mobilizing marginalized communities through empowerment to address issues of health inequity. It is important to note that the definition of empowerment is complex and contested. Lutrell et al. (2007) conceptualizes empowerment as a political concept in nature that describes a collective struggle against oppressive social relations and the effort to gain power over resources (Luttrell, Quiroz, Scrutton, & Bird, 2007).

Arnstein's Ladder of Citizen Participation

Many conceptual frameworks have been developed to examine the level of citizen participation used when historically marginalized and excluded groups are invited to decision-making tables. Sherry Arnstein's seminal work, the Ladder of Citizen Participation (1969), is perhaps one of the most widely cited frameworks on Citizen Participation. This framework breaks down citizen participation into eight different levels (or 'rungs' on the ladder) and discusses how power is redistributed at each of these levels (or whether power redistribution is hindered through manipulation and tokenism, for example). See Figure 1 (below) which depicts these eight rungs on Arnstein's Ladder.

Manipulation and therapy are the bottom two rungs on Arnstein's Ladder of Citizen Participation, and these rungs are characterized by non-participation, where power redistribution does not occur. Informing, consultation, and placation are the next three rungs on the ladder, where these rungs are characterized by tokenism. The top three rungs on the ladder are partnership, delegated power, and citizen control. These rungs are characterized by citizen power, where genuine redistribution of power takes place. Please see the next section for a summary of Arnstein's Ladder of Citizen Participation, and a detailed description of each of the eight rungs.

A description of the eight rungs on Arnstein's Ladder

The first rung on Arnstein's Ladder is *manipulation*, which occurs when citizens are manipulated into thinking they are part of the decision-making process, but in actuality, they hold no legitimate power or function. Manipulation is seen as an "illusory form of participation" (pp. 218), where citizens are educated, persuaded, and advised by powerholders. This form of non-participation is used as a public relations vehicle by powerholders (Arnstein, 1969). Examples of manipulation include citizens being "placed on rubberstamp advisory committees or advisory boards for the express purpose of 'educating' them or engineering their support" (Arnstein, 1969, pp. 218).

The second rung on Arnstein's Ladder is *therapy*, which involves powerholders "curing" the citizens (Arnstein, 1969, pp. 218). This rung assumes that the citizens are incapable of decision-making, and as a result, they are subjected to participate in paternalistic education exercises or group therapy sessions as a form of enlightenment (Brooks & Harris, 2008). The goal of therapy is to modify citizens' attitudes or values.

The third rung on Arnstein's Ladder is *informing*. Arnstein (1969) states that informing citizens of their rights, responsibilities, and options is often a key first step in legitimate citizen participation (Arnstein, 1969, pp. 219). However, the most distinguishing characteristic of this rung is that the flow of information is strictly one-way (from powerholders to citizens), where citizens have no opportunity to provide feedback, criticism, or to participate in negotiations. Some common examples of tools used during the informing process includes disseminating news media, pamphlets, posters, and meetings that provide superficial information and discourages asking questions (Arnstein, 1969, pp. 219).

The fourth rung on Arnstein's Ladder is *consultation*, which allows for a two-way flow of information through neighbourhood meetings, public hearings, and attitude surveys. However, Arnstein states that this rung on the ladder is not meaningful participation because consultation "offers no assurance that citizen concerns and ideas will be taken into account" (Arnstein, 1969, pp. 219).

The fifth rung on Arnstein's Ladder is *placation*. Here, citizens begin to have some degree of influence over the powerholder's decisions, however tokenism is still present (Arnstein, 1969, pp. 220). At this stage, a few citizens may be hand-picked as 'worthies' by the powerholders to sit on a board (or other governing body that makes decisions). Arnstein cautions that at this rung, citizens sitting on boards or advisory committees may be outnumbered, outvoted, or overruled by powerholders, particularly if citizens' opinions differ or are unfavourable (Brooks & Harris, 2009).

The sixth rung on Arnstein's ladder is *partnership*. At this rung, citizens and powerholders agree to share decision-making by creating joint policy boards, planning committees, or other mechanisms for solving impasses (Arnstein, 1969, pp. 221). With proper resources (for example financial resources to pay citizens well for their time-consuming efforts), citizens have genuine influence over decision-making.

The seventh rung on Arnstein's ladder is *delegated power*. This stage involves negotiations between citizens and powerholders resulting in citizens achieving dominant decision-making authority over a plan or program (Arnstein, 1969, pp. 222). It is the citizens who hold significant power, where powerholders must initiate the negotiation process (rather than the other way around). Here, citizens are empowered to execute tasks autonomously, or to take control of parts of a program/project.

The eighth and final rung on Arnstein's ladder is *citizen control*. This is the highest rung on the ladder, and it is characterized by citizens having complete power and control to govern a program or institution. Citizens are fully in charge of all policy and managerial aspects, and they have the right to negotiate the conditions under which outsiders can make decisions (Arnstein, 1969, 223).

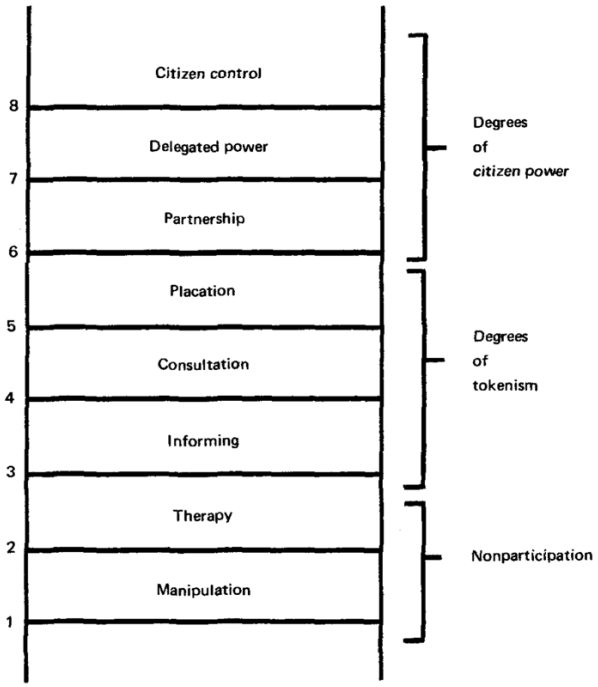


Figure 1: Eight Rungs on the Ladder of Citizen Participation (Arnstein, 1969, pp. 217).

I categorize the articles included in my scoping review using the eight rungs on Arnstein's Ladder of Citizen Participation. I have chosen to use Arnstein's framework to help me identify and conceptualize the different types of citizen participation employed in each study, where possible. My rationale for using Arnstein's Ladder of Citizen Participation is such that her definition of citizen participation centres on the redistribution of power that enables the 'have-not' citizens (who are traditionally excluded from the political and decision-making processes) to be deliberately included in planning for the future (Arnstein, 1969). The meaningful inclusion of historically marginalized groups is a strategy by which the have-not citizens join in (or take

control of) how information is shared, goals and policies are set, resources are allocated, and programs are implemented (Arnstein, 1969). Therefore, Arnstein's Ladder is a reminder that participation is about power and how it is redistributed in decision-making spaces.

Chapter 3: Methods

Scoping reviews have emerged as an effective method for mapping the literature of a particular topic, and the production of evidence-informed policies and practices (Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014). It is a process of summarizing, or 'mapping', a range of evidence in order to convey the breadth and depth of a topic (Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014). In fields where there may be a plethora of evidence, scoping reviews can act to provide an overview of the 'lay of the land' (Colquhoun et al., 2014). This type of review is a form of knowledge synthesis that aims to comprehensively summarize and synthesize evidence with the ultimate aim of informing policy, programs, and practices, as well as providing direction to future research priorities (Colquhoun et al., 2014).

Scoping reviews differ from systematic reviews in that the author(s) do not assess the quality of studies included in the review (Levac, Colquhoun, & O'Brien, 2010). According to Arksey & O'Malley (2005), a scoping study seeks to present an overview of all material reviewed, whereas in a systematic review, evidence or findings from studies not included in the final review may consequently be hidden from publication (Arksey & O'Malley, 2005). Furthermore, they differ from narrative reviews and literature reviews because the scoping process involves analytical reinterpretation of the literature (Levac, Colquhoun, & O'Brien, 2010).

However, scoping reviews are not without their limitations. It has been noted by Colquhoun et al (2014) that the scoping review is a relatively new type of methodology, and as such, there is a lack of consensus on terminology, definition, methodological context, and methods for reporting (Colquhoun et al., 2014). To address these shortcomings, Levac, Colquhoun, & O'Brien (2010) put forward key recommendations to advance and maintain

methodological rigor when conducting scoping reviews. These recommendations include: clarifying and linking the purpose and research question; balancing feasibility with breadth and comprehensiveness of the scoping process; using an iterative process when selecting studies and extracting data; incorporating a numerical summary and qualitative thematic analysis, reporting results, and considering the implications of study findings to policy, practice or research; and incorporating consultation with stakeholders as a required knowledge translation component of scoping study methodology (Levac, Colquhoun, & O'Brien, 2010).

Arksey & O'Malley (2005) describe four common reasons why a scoping study might be undertaken. These are:

(1) To examine the range, extent, and nature of research activity;

(2) To determine the value of undertaking a full systematic review (and to identify whether a full systematic review would be feasible or relevant);

(3) To summarize and disseminate research findings to policymakers, practitioners, and other stakeholders who might otherwise lack the time or resources to undertake such work themselves;

(4) To identify research gaps in the existing literature, and to identify gaps in the evidence base where no research has been conducted previously (Arksey & O'Malley, 2005).

For the purpose of this Masters thesis, this scoping review is concerned mainly with the first and fourth reasons put forward by Arksey & O'Malley. Specifically, this scoping review seeks to examine and conceptually map the peer-reviewed literature about the inclusion of PWUD in the development and delivery of harm reduction programs, services, and drug policy.

In an effort to provide direction to researchers and authors undertaking a scoping review, Arksey & O'Malley (2005) created a six-stage methodological framework for conducting such

reviews in a rigorous and transparent way. I will discuss these six stages below, as I use them to guide me throughout my thesis research. Furthermore, it is important to remember that the scoping review process, is not linear, but iterative. Many researchers who have experience conducting scoping reviews have reported on the importance of engaging with each of the six stages in a reflexive way, and when necessary, have repeated stages in order to ensure that the literature is covered in a comprehensive way (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010). Furthermore, Levac et al (2015) identified recommendations to clarify and enhance the scoping review methodology brought forward by Arksey & O'Maley. I use the updated stages by Levec et al to inform my scoping review process. A description of these six stages and how I incorporated them into my scoping review are:

Stage 1: Identifying the research question(s)

According to Arksey & O'Malley, identifying the research question(s) to be addressed within the scoping review guides the way the search strategies are built. It is important to consider what aspects of the research question are particularly important. Is it the study population, the intervention, or the outcomes? Defining these kinds of parameters and considering the implications of adopting particular positions is important at the outset of a scoping study (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010).

How I implemented Stage 1 in my scoping review

To conceptually map the range, extent, and nature of the peer-reviewed literature that focuses on the inclusion of PWUD in the development and delivery of harm reduction programs, services, and drug policy, the following scoping review questions have been identified: What is known about the inclusion of peers in the development and delivery of harm reduction programs,

services, and drug policies in the peer-reviewed literature? How are peers being involved and included at the decision-making table?

Stage 2: Identifying Relevant Studies

This stage involves searching for research evidence from different sources, such as: electronic databases, reference lists, hand-searching of key journals, existing networks, relevant organizations, and conference abstracts. From a practical point of view, it is recommended that decisions be made at the outset of the review about the coverage or scope that the review will cover in terms of time span and language (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010).

How I implemented Stage 2 in my scoping review

I conducted a scoping review of empirical studies published between the years 2010 and 2020 to identify peer-reviewed articles published within the last ten years focusing on peer engagement in harm reduction initiatives. I chose to limit my window to a ten-year period in order to maintain an appropriate and manageable scope for my Masters thesis. The following electronic databases were searched for peer-reviewed literature: Academic Search Premier, MEDLINE, CINAHL, PsychInfo, and Social Work abstracts.

There are multiple terms used to describe peer engagement in relation to harm reduction, as well as multiple ways of describing harm reduction programs and services. In order to capture a comprehensive scope of the peer engagement literature, I devised a list of search terms that are broken down into three categories, which I devised in consultation with Dr. Carol Gordon, the University of Victoria health sciences librarian. The first category pertains to the many terms used to describe 'peer engagement'. The second category involves 'substance use' search terms, and the third category involves 'harm reduction programs, harm reduction service provision, and

drug policy' search terms. I performed a Boolean search of the above databases, with the following search terms: ((Peer engagement search terms) AND (drug use search terms) AND (policy/program search terms)). Please see Table 1 for a breakdown of each of the three categories, and the search terms used within each category.

TABLE 1: Breakdown of scoping review search terms

Peer engagement search terms:	**Drug use search terms:**	**Harm reduction program/service provision/policy search terms:**
Engagement	Drug use	Drug policy
Participation	Opioid use	Harm reduction polic*
Social inclusion	Injection drug use	Drug law
Capacity building	Crack use	Drug law reform
User Involvement	Meth use	Drug policy reform
Community Participation	Heroin use	Service provision
Peer educat*	Illicit drug use	Service provider
Peer work*	Cocaine use	Harm reduction servic*
Peer support	Substance misuse	Harm reduction approach*
Peer support worker	Substance use	Harm reduction strateg*
Peer staff	Crystal meth use	Harm reduction therap*
Peer involvement	Crack cocaine use	Harm reduction program*
Peer outreach	People who use drugs	Harm reduction interventions
Peer run organization	People who inject drugs	Harm reduction model
Drug user organization		Supervised consumption
People with lived experience		Supervised consumption site
Empowerment		Supervised injection
Community mobilization		Supervised injection site
Community based approaches		Supervised injection facility
Peer network		Methadone
		Methadone maintenance therapy
		Needle Exchange
		Needle Exchange program
		Syringe Exchange
		Syringe Exchange program
		Overdose prevention
		Substitution treatment

		Substitution therapy
		Opioid substitution therapy
		Minimization of harms
		Harm minimization
		Safer smoking supplies
		Safer crack supplies
		Safer meth supplies
		Safer meth use
		Safer crystal meth use
		Naloxone
		Take-home naloxone
		Drug consumption room

Stage 3: Study Selection

Systematic review methods typically develop inclusion and exclusion criteria based on a specific research question to ensure consistency in decision-making. However, in a scoping review, study selection involves inclusion and exclusion criteria which are devised *post hoc*. These criteria are still based on the specifics of the research question, but also on the increased familiarity with the subject matter and literature. It is especially imperative to treat this stage iteratively, rather than linearly: the author should be continuously searching the literature, refining the search strategy, and reviewing articles for study inclusion (Arksey & O'Malley, 2005; Levac Colquhoun, & O'Brien, 2010; Colquhoun et al., 2014). In order to devise inclusion and exclusion criteria post hoc, Levac et al (2014) recommends the scoping review team refines their search strategy based on abstracts reviewed from the search.

How I implemented Stage 3 in my scoping review

The final inclusion and exclusion criteria are discussed in table 2 (see below).

TABLE 2: Scoping review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Published between the years 2010 and 2020	• Studies involving people who use alcohol or marijuana

• Published in English • Empirical studies of original research (both qualitative and quantitative) • Literature reviews, commentaries • Discusses the involvement of people who use or have used illicit drugs (illicit drugs include those currently considered illegal, such as: heroin, cocaine, fentanyl, and crystal meth among others, that may be ingested, snorted, injected, or absorbed) • A clear description of the involvement of PWUD in the development and/or delivery of harm reduction programs, service provision, or drug policy • Case studies and program evaluations that described their methods were also included	• Community-based Participatory research and Participatory Action Research studies that did not discuss any peer engagement efforts in harm reduction programs, services, or drug policy • Summary reports, grey literature, and news items

Stage 4: Charting the Data

This fourth stage involves extracting data from the included studies using a data-charting tool. A data-charting tool is used to determine which variables are important and relevant to extract that will help to answer the research question(s) (Levac, Colquhoun & O'Brien, 2010). Arksey & O'Malley indicate that the synthesis of material is critical, as scoping reviews are more than a short summary of collected articles (Levac, Colquhoun & O'Brien, 2010; Arksey & O'Malley, 2005).

How I implemented Stage 4 in my scoping review

All studies that met the inclusion criteria were entered into an Excel spreadsheet (my data-charting tool of choice). I analyzed and extracted key characteristics from each included study, and entered it onto the Excel spreadsheet.

Stage 5: Collating, Summarizing, and Reporting the Results

It is important that the scoping review findings are reported on in a consistent and rigorous manner. To adequately achieve this, Levac, Colquhoun & O'Brien recommend that the authors consider and plan out the best approaches to articulating the findings of the scoping review. These approaches could include developing a table to map out the strengths and gaps in evidence, or reporting through themes or a specified framework, etc. (Levac, Colquhoun & O'Brien, 2010). It is important to consider the implications of the findings within the broader context of policy, practice, and future research directions (Levac, Colquhoun & O'Brien, 2010). Levec et al also describe the need to provide a quantitative or descriptive numerical summary of the studies, where "researchers should describe the characteristics of included studies, including: the overall number of included studies, types of study design, years of publication, types of interventions, characteristics of the study population, and countries where studies were conducted" (Levac, Colquhoun & O'Brien, 2010, pp. 6)

How I implemented Stage 5 in my scoping review

From the data I extracted in step 4 of my scoping review, I summarize and report my findings according to the following characteristics, which align with my scoping review objectives and research questions:

- Author(s) of study
- Material reviewed (quantitative, qualitative, case study, or program evaluation)
- Geographic location of study
- Description study aims
- Description of study outcomes
- Description of peer roles within study
- Form of participation identified according to Arnstein's Ladder of Citizen Participation

My completed and filled in data extraction tool is located in Table 3 and is titled "Data Extraction Tool - Key Characteristics of Studies that Met Scoping Review Inclusion Criteria", which can be found at the end of the next chapter, on page 43 of the Results section.

Results

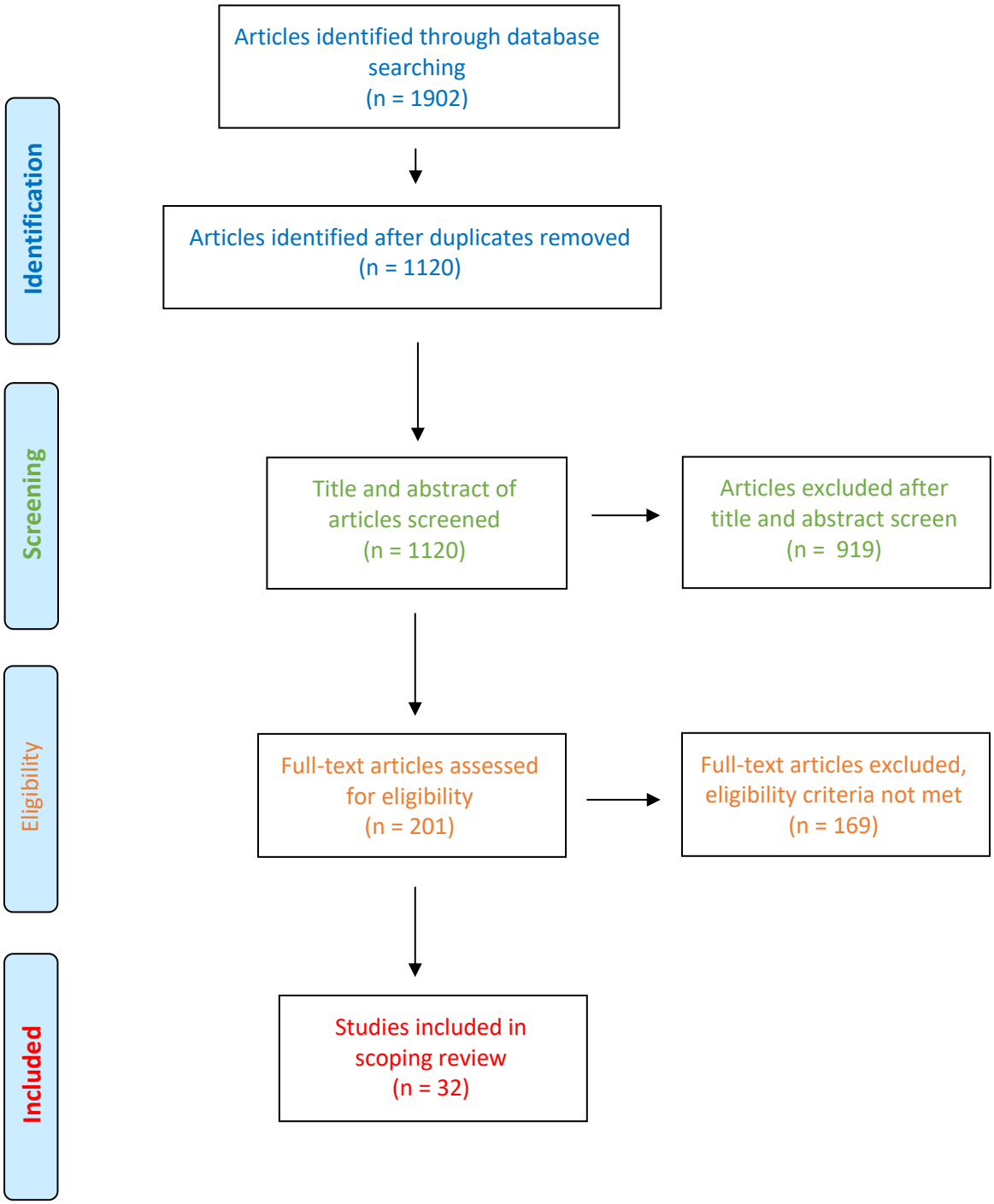
Search results

Using the search strategy outlined in Stages 2 and 3 of my Methods section, I conducted initial searches of electronic databases, which yielded 1902 peer-reviewed references. After removing duplicates and non-English language references, the titles and abstracts of 1120 references were screened. During this initial screening stage, 919 references were excluded either because the population of study was not PWUD, or because the title/abstract did not mention the involvement of PWUD in harm reduction initiatives. Of these 1120 references, 201 full-text documents were examined. After reading the full text of the 201 articles, 169 references were excluded. Articles that did not meet the search criteria were typically excluded for two reasons. First, because the population of study was not PWUD. Second, references were excluded if they did not have a clear description of the involvement of PWUD in the development and/or delivery of harm reduction services, and/or drug policy. In total, my search strategy yielded 32 peer-reviewed articles that met the inclusion criteria for this scoping review. See Figure 1 on the following page for a breakdown of the search process, using the PRISMA flow diagram.

Description of included studies

I will describe the 32 studies included in the scoping review based on the following five characteristics: 1) type of peer-reviewed study, 2) location of the published peer-reviewed study by country, 3) year of publication, 4) form of participation identified in each study according to Arnstein's Ladder of Citizen Participation, and 4) categories of peer roles.

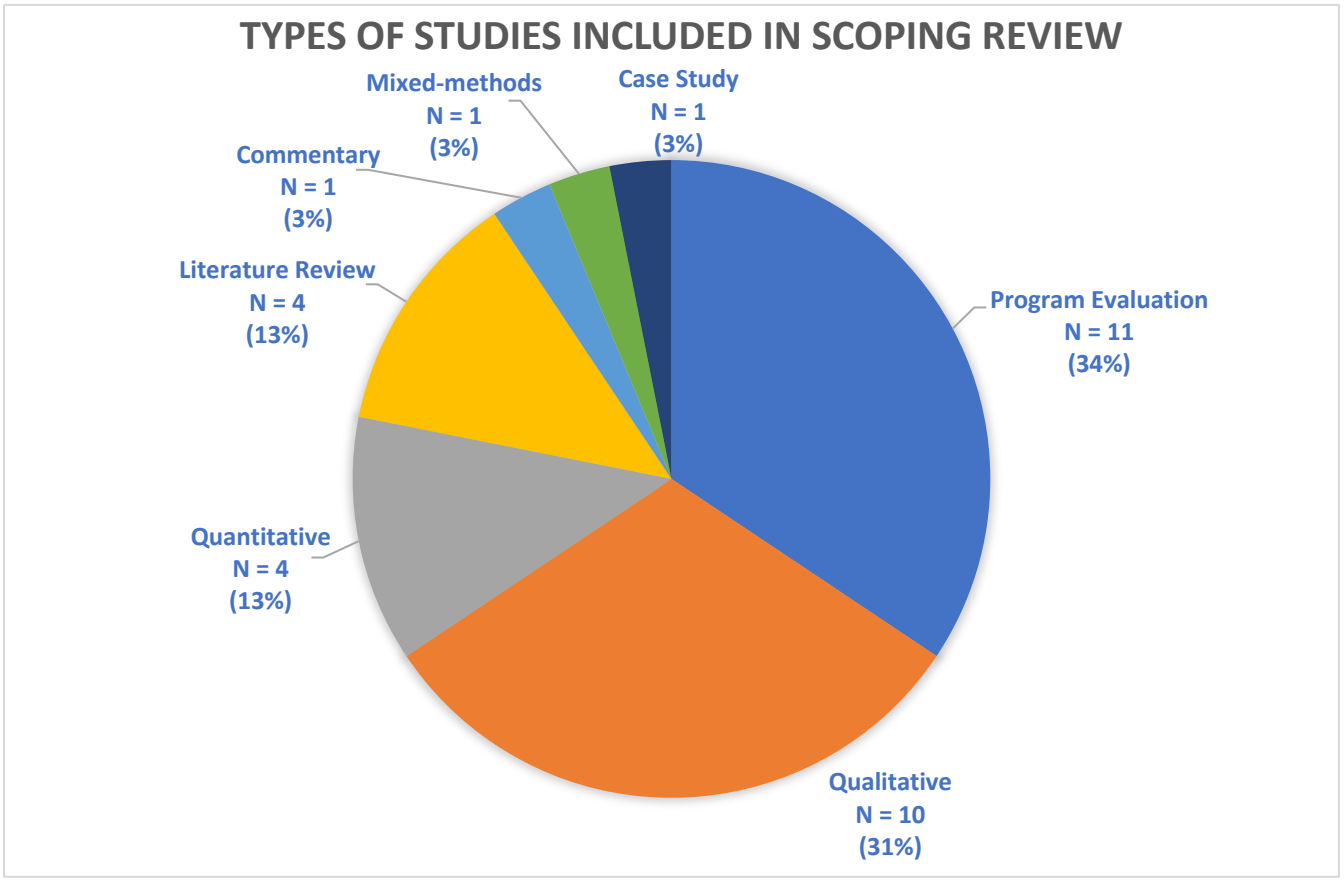
Figure 2: PRISMA flow diagram for my peer-reviewed search process



Type of Study

I first looked at the included peer-reviewed studies according to what type of study they are. Of the 32 included studies, the most common type were program evaluations, where 11 studies (or 34% of included studies) were described as program evaluations in their respective methodology sections. The next most common type of study was qualitative in nature, where ten (31%) of studies fit these criteria. Following this, I identified four (13%) quantitative studies, and four (13%) literature reviews. I also identified one commentary, one mixed-methods study, and one case study, where each comprise 3% of the included studies. Please see Figure 2, which describes the types of studies included in the scoping review in pie chart form.

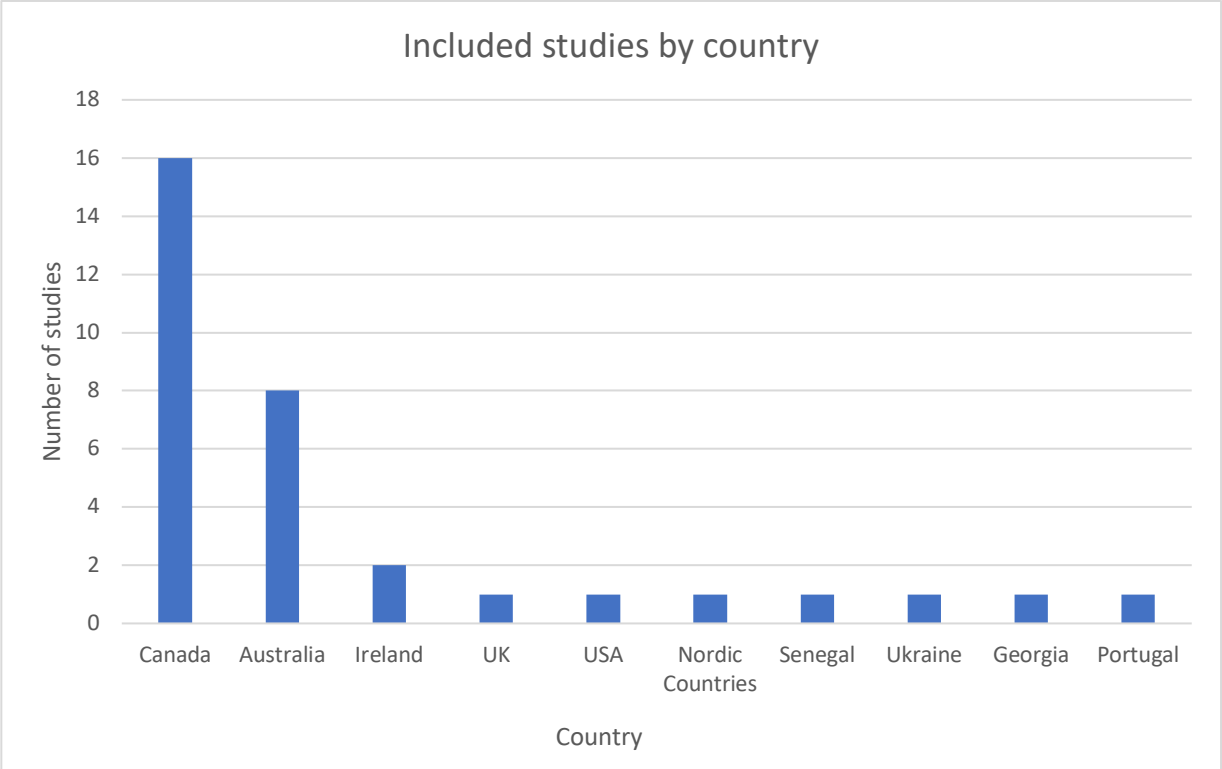
Figure 3: Type of study included in scoping review



Location of Study by Country

Next, I describe the included studies based on where each study was published, by country. Most studies were published in Canada (16 of 32 studies). The next most popular location was Australia, with eight studies. Following this, there were two studies in published in Ireland. The scoping review yielded one study published in each of: The United Kingdom, the United States, the Nordic Countries, Senegal, the Ukraine, Georgia, and Portugal. Please see Figure 3, a bar graph which provides a description of study breakdown by country of publication.

Figure 4: Included studies as described by country where study was conducted

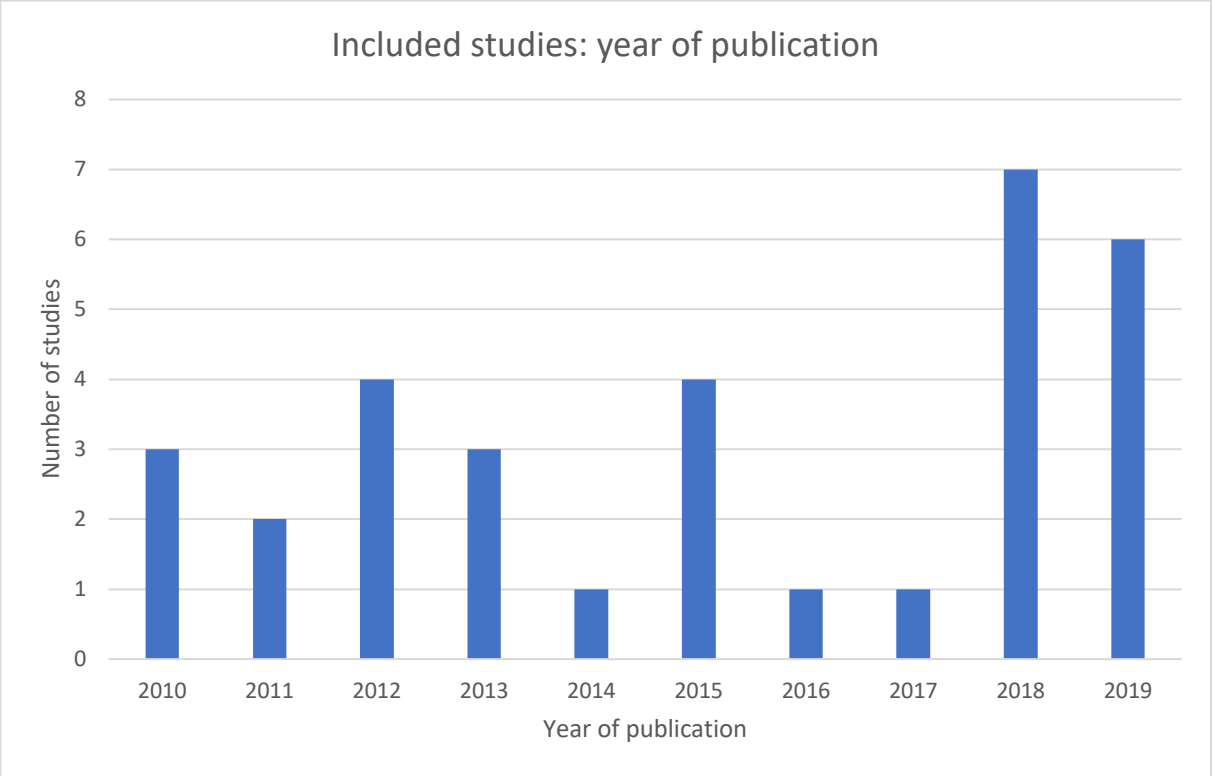


Year of Publication

Next, I describe studies based on what year they were published. The year with most publications was 2018 (seven studies), followed by 2019 (six studies). There was a relatively even split between the rest of the studies and when they were published. I identified four studies that were published in each of 2012 and 2015, and three studies that were published in 2010 and

2013. Two studies were published in 2011, while only one study was published in each of 2014, 2016, and 2017. It is worth noting that this scoping review only captured studies published up to March 1st, 2020. As such, I did not find any studies published in the year 2020 that met my inclusion criteria. Please see Figure 4, which demonstrates the breakdown of included studies according to their year of publication.

Figure 5: Included studies as described by year of publication



Participation type: Arnstein's Ladder

In order to provide additional information about peer engagement, all studies that included sufficient details (28 of the 32 studies), were then categorized using Arnstein's Ladder of Citizen Participation (see Table 3: Data Extraction Tool). The remaining four studies were literature reviews; these did not discuss first-hand efforts of peer engagement, and so, were not categorized according to Arnstein's Ladder. To recall, Arnstein's Ladder of Citizen Participation

contains eight levels of participation, from non-participation (manipulation and therapy), through moderate participation or tokenism (consultation, informing, placation), to high participation (including partnership, delegated power, and citizen control). Please see Table 4, which discusses the rationale for assigning each study to a particular 'rung' or category on Arnstein's Ladder. These rationales take into consideration the definition of each 'rung' on the ladder, and how a particular study's use of citizen participation reflected that definition.

When using Arnstein's Ladder as a classification scheme, engagement efforts in harm reduction programs, services, and drug policy among PWUD tended to be concentrated within the moderate to high levels of participation. In particular, this scoping review found eight studies described engagement in the form of partnerships, two studies identified delegated power, and eight studies described engagement that aligned with Arnstein's highest level of participation: citizen control. Please see Figure 5, a bar graph demonstrating the breakdown of included studies according to the type of engagement each study used. Examples of peer engagement that reflect the different levels of participation are highlighted below.

Non-Participation

No studies in this scoping review described peer engagement in the form of *manipulation*, and only one study described peer engagement in the form of *therapy*. This study, Kikvidze et al. (2018), described their peer-support intervention as consisting of three *mandatory* face-to-face sessions for people who use injection drugs living with HCV. The authors did not disclose or specify whether the mandatory face-to-face sessions were designed by staff at the treatment centres or by the peer workers. While the intervention was deemed a success by the authors (98% of participants completed HCV treatment), mandatory sessions provide PWUD with little to no opportunity for autonomy or influence in their decision-making.

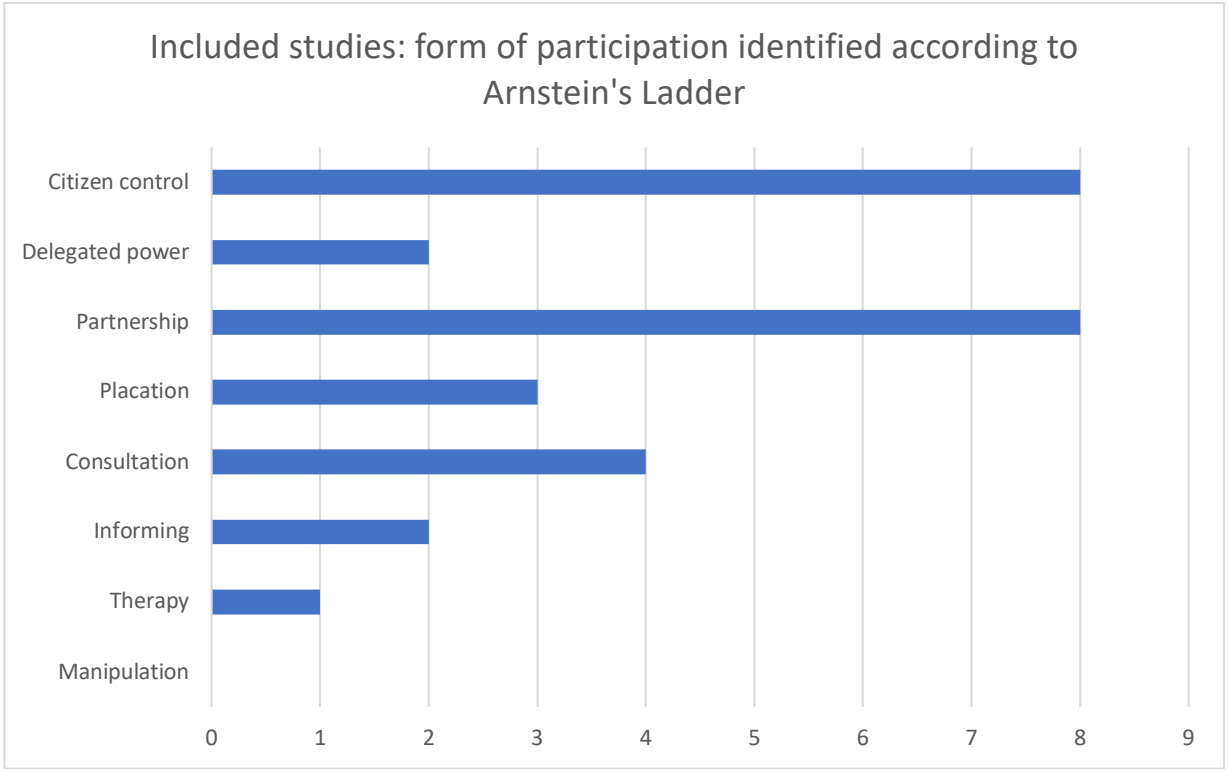
Tokenism

Two studies described peer engagement in the form of *informing*, three studies described peer engagement in the form of *consultation,* and four studies described peer engagement in the form of *placation.* At these mid-level forms of engagement, power remains in the hands of professionals, where peers are asked to answer questions from policy makers or program managers with little to no opportunity to participate in decision-making (informing), or are recruited by outsiders to act as peers and contribute to pre-defined objectives (consultation and placation). An example of 'informing' was the study by King et al. (2011), who explored Irish methadone maintenance treatment (MMT) user perspectives by establishing whether collaboration existed between the users and providers of MMT. The MMT service users and providers both agreed that service users could and should actively participate in determining their own care, but at the end of the day they had little influence over the treatment which they received and had no representative role at decision-making tables (King et al., 2011). Another study, Darke & Torok (2013) showed an example of Arnstein's 'consultation', where the opinions of PWUD were consulted to determine their attitudes towards certain forms of drug policy, including drug prohibition, decriminalization, and legalization of major illicit drugs. For 'placation', Treloar, et al. (2015) administered peer support services at two opioid substitution (OST) clinics in Australia, where two peer support workers were employed by the New South Wales users and AIDS Association (NUAA, a drug-user organization). At one of the clinics, two peer support workers (who were also clients of the clinic) were able to engage with clients and build relationships. However, they were only permitted to engage with clients in the waiting room and were not allowed access to 'staff only' areas.

Citizen Power

The majority (18 of 32) of studies included in this scoping review used high levels of engagement that aligned with the top third of Arnstein's ladder of citizen participation. Eight studies described peer engagement in the form of *partnership*, and two studies described peer engagement in the form of *delegated power*. Drug user organizations embody the highest level of participation on Arnstein's ladder: *citizen control*. Eight studies described peer engagement in the form of citizen control. Drug user organizations seek to empower people with lived experience through collectively organizing, which allows peers to have more autonomy and control. The drug user organizations identified by this scoping review include: VANDU (Vancouver), drug user organizations of the Nordic countries (Denmark, Sweden, Norway, and Finland), Meta D'Ame (Montreal), as well as an unnamed DUO in New South Wales, Australia.

Figure 6: Bar graph displaying the forms of participation identified in each study using Arnstein's Ladder of Citizen Participation



Peer roles

Several different peer roles were identified during data extraction, and were subsequently grouped into six categories of peer roles: delivering harm reduction and health services, peer-delivered education, peer support work, drug user organizing, PWUD sharing their perspectives on drug policy, and learning from peers: PWUD sitting on Advisory committees, participating in focus groups and surveys. Each of these six peer roles are summarized below.

Delivering harm reduction and health services

Peers participating in the delivery of harm reduction and health services was the most commonly identified role in the scoping review, with seven references being identified. Specific activities of delivering harm reduction programs and health services include: peers distributing needles/syringes and other harm reduction supplies (Dechman, 2015, Hayashi et al., 2010), peers participating in a user-run witness injection program (Bardwell et al, 2018), peers implementing and operating an Overdose Prevention Site (Kennedy et al, 2019), peers delivering harm reduction services in Ottawa (Wilson et al., 2018), involving peers in the planning and delivery of five drug treatment services in Australia (Treloar et al, 2011), and peers providing manual assistance with injections and education on injecting techniques (Small et al., 2012).

Peer-delivered Education

Peer-delivered harm reduction education was the second most common peer-based activity, with five references identified. These activities include: delivering a Take-Home Naloxone education program among their peers (Marshall et al., 2017), delivering a user-led safer injecting education campaign (Callon et al., 2013), providing Hepatitis C prevention education (Newland & Treloar, 2013), harm reduction education to PWID (Stengel et al., 2018), and delivering education on reducing HIV-related risk behaviours (Colon et al., 2010).

Drug-user Organizing

Five references were identified that described peers participating in drug-user organizing of some form. These activities include: the use of volunteer stipends at VANDU provided to PWUD in order to provide symbolic and material recognition of their time, effort, and expertise (Bardwell et al, 2018), the organizing of service users in the UK to enhance the delivery of drug treatment services (Patterson, Weaver, & Crawford, 2010), the organizing efforts of different drug-user groups in Denmark, Sweden, Norway, and Finland (Frank, Anker, & Tammi, 2012), and the introduction of consumer participation initiatives by the New South Wales Users and AIDS Association (NUAA) within three OST clinics to promote engagement between service users and staff at two OST clinics (Rance & Treloar, 2015). Lastly, Brown et al (2019) looked at how peer-based drug user organizations can contribute to HCV elimination by examining the broader policy and community systems within which they operate (Brown et al, 2019).

Learning from peers: PWUD sitting on Advisory committees, participating in focus groups and surveys

Five references identified the participation of people who use drugs in focus groups, surveys, or sitting on advisory committees for the purpose of sharing their perspectives on the delivery of services (i.e., in drug treatment centres) and how these services can be improved upon. In three of these studies, PWUD provided input on various topics by way of focus groups to discuss how to improve service provision. For example, in King (2011)'s study, service users provided input on how to improve service provision in a methadone maintenance program. In Van Hout & McElrath (2012), peers provided input on how to improve service user involvement in West Ireland drug treatment systems. In Greer et al (2016), peers shared their perspectives on and experiences with peer engagement practices. One study (Greer et al., 2019) discussed peers sitting on an Advisory Committee called the BC Harm Reduction Services and Strategies

committee, which helped to evaluate peer engagement efforts in British Columbia, Canada. Lastly, Taylor et al (2019) surveyed PWUD to learn about their needs and determine their willingness to access a mobile drug consumption room in Portugal (Taylor et al., 2019).

Peer Support Work

Peer support and counseling was another peer role identified in the literature, where three references discussed peer activities involving support work of some sort. Two reference discussed peer support workers providing support and counseling in a Hepatitis C program (Tookey et al., 2018; Kikvidze et al., 2018), and one study discussed peer support work within the context of an opioid substitution treatment (OST) program (Treloar et al., 2015).

Peers' perspectives on drug policy issues

Three references described people with lived experience of drug use providing their perspective on issues relating to current drug laws and drug policy. In one reference (Darke & Torok, 2013), PWUD were consulted on their attitudes and perspectives towards the prohibition, legalization, and decriminalization of drugs. Another reference (Lancaster, Sutherland & Ritter, 2014) examined the opinions of PWUD towards drug policy in Australia, while Greer & Ritter (2019) examined the attitudes of PWUD surrounding current drug laws in Australia.

Table 3: Data Extraction Tool - Key Characteristics of Studies that Met Scoping Review Inclusion Criteria

Authors	Material Reviewed	Geographic Location	Aim of Study	Study Outcomes	Description of peer role(s) in the harm reduction intervention (ie. program or service)	Form of Participation (Arnstein's Ladder)
Bardwell et al., 2018 (a)	Qualitative study	Canada	To explore the impact of 'volunteer stipends' provided to PWUD through a drug user organization (VANDU)	Volunteer stipends provided participants with symbolic and material recognition of their time, effort, and expertise; stipends functioned to facilitate participation, and further provided PWUD with social connection, a sense of purpose, and time structure. Low wages were noted as a main barrier to participation.	Peer-led program: Drug user organization (VANDU)	Citizen control
Bardwell et al, 2018 (b)	Qualitative study	Canada	To examine the role of peers in the implementation of a "peer witness injection program" within Vancouver emergency shelters, from the perspective of shelter residents	The shelter residents valued the contribution of peer-workers, as evidenced by four themes: support, safety, a preference for peer workers compared to non-peer staff (due to power imbalances and past negative experiences with non-peer staff), and the routinization of peer worker roles among all PWUD residing in the shelter.	Peer-led program: peer staff of the "peer witness injection program" implemented at two seasonal emergency shelters	Citizen control
Brown et al., 2019	Qualitative study	Australia	To better understand the role of peer-based drug user organizations in the Australian HCV response, as described by the W3 (What Works and Why)	System-level interactions enhance or constrain the quality and influence of policy advice from peer-based DUOs. Peer-based DUOs demonstrate their	Eighteen workshops conducted in partnership with 10 peer-based drug user organizations (who	Partnership

			Project, which drew on complex systems theory and methods	capacity and credibility through engagement, alignment, adaptation, and influence. Policy and service organizations must recognize their own system role to better support peer-based DUOs in achieving their potential.	invited peer staff and volunteers).	
Callon et al., 2013	Program evaluation	Canada	To describe a drug user-led safer injecting campaign, and to explore facilitators' experiences delivering a user-led safer injecting education campaign	Injection Support Team (IST) facilitators' injection drug-using identity enhanced their ability to connect to workshop participants; it allowed them to communicate in a language that is accessible to workshop participants.	Peer-led program: drug user organization (VANDU)	Citizen control
Colon et al., 2010	Quantitative study	USA	To describe the challenges encountered in conducting an intervention developed to train patients in methadone maintenance treatment programs (MMTPs) to work as peer outreach workers	Several challenges were identified in the following four phases of the intervention: recruitment, training, conducting outreach, and booster sessions/intervention completion. From these challenges, five recommendations are suggested to counter these challenges.	Patients enrolled in MMTP for six months or more were recruited as peer outreach workers, who then conducted 12 weeks of supervised peer outreach (supervised by MMTP staff)	Placation
Darke & Torok, 2013	Quantitative study	Australia	To determine PWUID's attitudes (and correlates of attitudes) towards drug prohibition, legalization, and decriminalization of major illicit drugs.	Methamphetamine was rated the most harmful illicit substance among PWUID. The highest level of support for legislative change was for cannabis (61.7 % support legislation), 41.7% supported the	300 PWUID were recruited from needle and syringe programs, through word of mouth, and in street press publications	Consultation

				decriminalization of heroin, and 63.3% supported the continued prohibition of methamphetamine.		
Dechman, 2015	Program evaluation	Canada	To illustrate the dilemmas and personal difficulties that can arise for peer/natural helpers when they are carrying out harm reduction practices	Three main themes emerged: (1) the othering and disenfranchisement experienced by PWUD from medical professionals, (2) the 'official' sanctioned practices performed by natural helpers in response to the disenfranchisement from medical professionals, and (3) the 'unofficial' practices performed by natural helpers.	17 "natural helpers" (individuals with lived experience of drug use) who act as secondary distributors for an Atlantic Canada needle exchange (The Sharp Advice Needle Exchange, or SANE)	Delegated power
Frank, Anker, & Tammi, 2012	Commentary	Nordic Countries	To expand on the knowledge of drug user organizations by comparing organizations in four different, but similar, Nordic countries	The authors discuss the emergence, history, and current context of four DUO's operating in Denmark, Sweden, Norway, and Finland. Challenges, opportunities, and ways forward as legitimate actors in the drug policy processes in the Nordic Welfare states is also discussed.	Drug user organizations	Citizen Control
Greer et al., 2016	Program evaluation	Canada	To describe and evaluate the peer engagement efforts undertaken with the BCHRSS from 2010-2014	Findings describe the cyclical and iterative nature of peer engagement. Providing clear expectations of both peer and committee roles at meetings and other engagement opportunities	Two peers who were part of the BCHRSS committee, as well as with other harm reduction initiatives throughout BC. Drug user organizations were asked to nominate	Partnership

				was paramount in increasing capacity and equity of the peer engagement process. There was an under-representation of peers from rural/remote regions at BCHRSS meetings.	participants as representatives from their region (where peer groups existed)	
Greer & Ritter, 2019	Qualitative study	Australia	To investigate the views of PWUD with regards to drug laws and how drug laws could be improved upon, as well as their opinions of campaigns for drug law reform in Australia	PWUD in this study showed support for 3 models: decriminalization, legalization, and a medical/prescription model; however, opinions were diverse and there was no consensus on a single model	37 individuals participated in three focus groups (participants included PWUD and their partners/friends/drug dealers)	Consultation
Greer et al., 2019 (a)	Qualitative study	Canada	To understand PWUD's experiences of peer engagement	Barriers to peer engagement identified by participants: personal, geographical, financial, stigma, gatekeepers (e.g. city council, police, government), and fear of being outed. Enablers of peer engagement: incentives (such as cash, food, activities), consistency, location (ease of access, as well as being a "safe space"), working with the right people, and the importance of peer networks.	Focus group participants were PWUD recruited by peer RAs from each of BC's five Health Authorities	Partnership
Greer et al., 2019 (b)	Literature review	Canada	To understand issues involved in paying people with lived experience of substance use in community-based work	25 peer-reviewed and grey literature documents were included in the final narrative review of the literature. Greer et al	N/A	N/A – literature review, thus no first hand engagement efforts with PWUD

				identified five central issues in compensating peer work: 1) perspectives of compensation, 2) the valuation of peer work, 3) the type of peer work, 4) mode of compensation, and 5) structural barriers impacting peer pay.		
Hayashi et al., 2010	Program evaluation	Canada	To evaluate a peer-run outreach-based syringe exchange program by VANDU (the Alley Patrol)	The Alley Patrol was successful in reaching a higher risk group of PWID and was significantly associated with lower levels of needle re-use.	Peer led - drug user organization (VANDU)	Citizen control
Kennedy et al., 2019	Qualitative research	Canada	To examine peer worker involvement in the implementation and operation of an overdose prevention site (OPS) in Vancouver.	Peer worker involvement at OPS fostered feelings of comfort and safety among OPS clients, and it facilitated engagement with OPS among PWUD. Peer workers were provided with small stipends amounting to less than minimum wage, and received few work-related benefits. Many peer workers experienced trauma and grief from the overdose epidemic and a lack of formalized supports, contributing to burnout.	Trained peer staff who offered supervision of drug consumption, THN training, naloxone administration, harm reduction supply distribution and education. OPS #1 was operated by peers, while OPS #2-4 was non-peer operated.	Partnership
King, 2011	Program evaluation	Ireland	To explore user involvement processes within Irish MMPs by establishing the degree to which partnership and collaboration exist between	Despite a general consensus among participants that drug service users could and should actively participate in determining their own care needs and directing	Eight service users from 12 different MMPs	Informing

			the users and providers of MMPs	their treatment, power was still retained by service providers, while service users continued to play a passive role. Service users had little influence over the treatment which they received, and played no representative role at decision-making levels.		
Kikvidze et al., 2018	Program evaluation	Georgia	To assess the effectiveness of peer-supported HCV treatment for PWUID in Georgia	Findings demonstrate that a peer-support intervention implemented in a harm reduction centre in Tbilsi, Georgia contributed to HCV treatment uptake and retention among PWUID (98% of participants who started treatment completed it)	Mandatory face-to-face sessions with peer-support worker	Therapy
Lancaster, Sutherland, & Ritter, 2014	Quantitative study	Australia	To investigate whether there is heterogeneity of opinion about a range of drug policy interventions (including treatment, harm reduction, and drug legalization) among people with different experiences of drug use, by comparing the views of people who inject drugs with the views of people who regularly use ecstasy.	There were significant differences between PWUID and people who use ecstasy in reported levels of support for all harm reduction and treatment interventions. This heterogeneity speaks to the diversity of experiences and attitudes within what is perceived to be only one interest group. This study highlights the need to better understand the attitudes of PWUD across a full range of identities and experiences, in order to better represent their interests in drug policy deliberation.	Face-to-face surveys conducted with groups of PWUD, recruited via word of mouth and street-based advertisement	Consultation

Marshall et al., 2015	Literature review	Canada	To identify and synthesize information that could better inform those who work with peers in harm reduction initiatives	164 documents included in review; Marshall et al identified obstacles and facilitators to peer involvement at the systemic, organizational, and individual levels	36 different peer roles were identified from the included studies	Marshall et al classified studies according to Pretty's participation typology. The majority (107) of included articles were classified as "functional" forms of engagement, which translates to informing, consultation, and placation on Arnstein's Ladder
Marshall et al., 2017	Program evaluation	Canada	To explore the psychological impacts of being a peer-trainer in a Montreal-based take home naloxone program	Findings suggest there are psychological benefits from participating in the peer-trainer role, including feelings of empowerment and recovery. There are also challenges associated with the peer-trainer role.	Six peer-trainers were recruited by Meta D'Ame, a peer-run organization in Montreal	Citizen control
Marshall, Piat, & Perreault, 2018	Literature review	Canada	To explore the literature on the behavioural and psychological impacts of acting as a peer-helper in THN programs	27 articles were included in the rapid review; in this review, peer-helpers were categorized according to intervention: opioid overdose prevention, mental health, and HIV/AIDS. Peer-helper roles were associated with behavioural and psychological benefits, including increased empowerment, self-esteem, and recovery.	Peer helpers in opioid overdose prevention, mental health programs, and HIV/AIDS interventions	N/A – literature review, thus no first hand engagement efforts with PWUD
Newland & Treloar, 2013	Program evaluation	Australia	To evaluate a DUO-delivered peer education program, whose aim was to	The peer education program was successful in disseminating HCV	DUO-delivered peer education project with 17 peer educators	Citizen control

			contribute to HCV prevention by encouraging the adoption of safe injection practices among PWID	prevention information to the targeted community. Findings highlight the importance of peer educators addressing a broad range of issues, demonstrating the use of equipment, responding to issues important to the targeted community, and acting as advocates to demonstrate credibility and build trust.		
Patterson, Weaver, & Crawford, 2010	Mixed-method study	United Kingdom	To assess the role of service user groups in the local organization and delivery of drug treatment services in the UK	User groups were seen as fundamental to user involvement. Key challenges in service user group involvement: managing power relations, regular group attendance, recovery, concerns related to the exposure of 'vulnerable' users to stressful situations, disjunction between agency and user expectations.	The formation of service user groups is as follows: self-organized (32%), assembled by drug treatment agencies (32%), or collaboratively between users and agencies (36%)	Consultation
Rance and Treloar, 2015	Program evaluation	Australia	To investigate the 'therapeutic alliance' via a consumer participation initiative (the CHANGE project) introduced within three Australian drug treatment settings	The consumer participation initiative promoted engagement and interaction between service users and staff beyond the usual confines of the user/staff relationship. For some service users, the opportunity to be heard was synonymous with having their humanness recognized and	An Australian drug-user organization (the NUAA) was contracted by the New South Wales Ministry of Health to implement consumer participation initiatives in three drug treatment facilities.	Partnership

				acknowledged. The traditional 'us vs. them' notion was challenged, and a more collaborative ethos of working together emerged. Central to changing the user/staff dynamic were references to "level playing fields".		
Small et al., 2012	Program evaluation	Canada	To describe the evolution, structure, and impacts associated with the Injection Support Team (IST), a novel drug-user-led program that performs regular patrols of alleys, streets, and parks in Vancouver BC in order to provide education and support to individuals who experience difficulty injecting or who require assistance with injecting.	The IST is composed of "hit doctors" who perform outreach 5 days a week. These team members provide important information, strategies, and education on injection technique, foster competency in self-injection, manual assistance with injection, and assisted injections.	Peer led – drug user organization (VANDU)	Citizen control
Stengel et al., 2018	Qualitative study	Senegal	To determine the potential and feasibility of peer-based outreach work in Dakar, Senegal through peer-based harm reduction education	Four themes emerged: (1) peer educators as bridge to 'responsibilization' through awareness-raising activities; (2) awareness-raising activities as enactment of recovery; (3) awareness-raising through social network diffusion; and (4) the contexts and constraints of peer outreach engagement through	Peer-based outreach using peer educators developed in partnership with ANCS (a civil society organization focused on responding to HIV in Senegal)	Partnership

				awareness-raising activities.		
Taylor et al., 2019	Quantitative study	Portugal	To survey prospective clients to determine their willingness in using a mobile drug consumption room in Portugal (a first of its kind)	There is a high level of willingness to access the MDCR, mainly for reasons of hygiene, privacy, and security. Continual participation of PWUD is necessary in order to maximize the effectiveness of the MDCR.	Peer workers administered the survey to users, and interfaced with community members	Partnership
Ti, Tzemis, & Buxton., 2012	Literature review	Canada	To summarize the available evidence on peer engagement among PWUD in policy and program development	19 documents included in the review; many barriers prevent PWUD from engaging in decision-making processes, including stigma, discrimination, and other structural-level barriers	N/A	N/A –– literature review, thus no first hand engagement efforts with PWUD
Tookey et al., 2018	Case Study	Canada	To gain an understanding of the facilitators and barriers in the transition from client to support worker within a multi-disciplinary HCV treatment program, from the perspective of two individuals who underwent this transition	Five themes emerged during the analysis of facilitators and barriers: (1) the role of prior experiences; (2) changes in substance use practices; (3) shifts in relationships with community members and friends; (4) supportive organizational and structural factors; and (5) role transition as a journey.	Peer Community Support Worker (CSW) within an HCV program. CSW responsibilities include: group facilitation, public speaking, training other peer workers, client accompaniment to appointments, one-on-one client support, admin support	Placation
Treloar et al., 2011	Program Evaluation	Australia	To evaluate consumer participation projects conducted within five drug treatment services in Australia. The goal of each of the five projects was to involve consumers at the organizational level of	None of the five projects reached their stated goal within the project timeline. In each of the five cases, there were delays and disruptions to the project primarily due to a lack of resources. A key finding	Consumers involved in various consumer participation efforts at five drug treatment facilities (3 OST, 1 detox centre, and 1 residential rehab centre) in Australia	Delegated power

			service planning and delivery.	was the shift in focus surrounding "stability": at baseline, many staff perceived stability as a requirement for effective consumer participation. At postimplementation, staff focused on whether the service itself had the level of stability required to effectively involve consumers.		
Treloar et al., 2015	Qualitative study	Australia	To examine two community-controlled peer support services (from the client, staff, and peer-worker perspectives), in order to facilitate increased access to HCV treatment	Clients, staff members, and peer-workers all noted the peer support services contributed to engaging clients, building trusting relationships, and providing instrumental support for clients in accessing HCV treatment. However, not all clients were aware of the peer-programing or had the opportunity to meet with their peer support worker.	Peer support workers were employed by the NSW Users and AIDS Association (NUAA) at two OST clinics. At Clinic 1: two peer support workers (clients of the clinic) who engaged with clients in the waiting room only. At Clinic 2: one peer support worker (who was not a client of the clinic) consulted with clients and was given access to 'staff only' areas.	Placation
Van Hout & McElrath, 2012	Qualitative study	Ireland	To explore user and provider perspectives and awareness regarding service user involvement (particularly around the Service User Support Team, or SUST) in West Ireland; to examine the benefits and challenges of implementing service user forums in West Ireland	Service users and providers had poor understandings of SUST, and involvement of service users with SUST was low. Both users and providers reported hearing about SUST through one-way, non-participatory information-sharing methods (ex. the distribution of leaflets). Other challenges hindering service user involvement	12 service users and 30 service providers were interviewed about Service User Support Team (SUST), a support and advocacy structure for current drug users and those in recovery, which operates within the Western Region Drugs Task Force	Informing

				include: user passivity, financial and time constraints, user-provider power differentials, lack of public transport in rural areas.		
Wilson, Vannice, Hacksel, & Leonard, 2018	Qualitative study	Canada	To identify current challenges facing peer programming within harm reduction agencies in Ottawa, Canada	Peer workers struggled to separate their two identities: peer worker, and drug user. Many peer workers found it difficult to: (1) report issues of triggering, (2) disclose when they needed extra supports from the harm reduction agency they work for, and (3) move beyond peer worker positions into jobs that do not depend on their identity as 'drug users'.	Peer workers from three community harm reduction agencies	Partnership

Table 4: Rationale for assigning each study to a 'rung' on Arnstein's Ladder, based on the definition of that 'rung'

Authors: Bardwell et al., 2018 (a) **Form of Participation (Arnstein's Ladder):** Citizen control **Rationale based on definitions of Arnstein's Ladder:** This study describes programming that is entirely peer-led (a drug-user organization, VANDU, providing volunteer stipends to PWUD). This aligns with the definition of citizen control on Arnstein's ladder because it demonstrates citizens being in full control of the project/program/planning and decision-making.
Authors: Bardwell et al., 2018 (b) **Form of Participation:** Citizen control **Rationale based on definition of Arnstein's Ladder:** This study describes an overdose prevention program that was implemented in two emergency shelters. This program was designed and led entirely by peers. This most aligns with the definition of citizen control on Arnstein's ladder because it demonstrates citizens being in full control of the design and delivery of the overdose response program implemented in the two shelters.
Authors: Brown et al., 2019 **Form of Participation:** Participation **Rationale based on definition of Arnstein's Ladder:** This study describes the mechanisms through which Australian peer-based drug user organizations influence HCV policy sectors. Eighteen workshops were conducted in partnership with 10 drug user organizations. This aligns with the definition of partnership on Arnstein's ladder because peer-based drug user organizations were given an opportunity to be invited to decision-making tables and share their perspectives.
Authors: Callon et al., 2013 **Form of Participation:** Citizen control **Rationale based on definition of Arnstein's Ladder:** This study describes a safer injecting education campaign, a user-led program developed by VANDU. This aligns with the definition of citizen control on Arnstein's ladder because it demonstrates citizens being in full control of a project/program
Authors: Colon et al., 2010 **Form of Participation:** Placation **Rationale based on Arnstein's Ladder:** This study describes patients being recruited from a methadone maintenance treatment program and then trained as peer outreach workers. This aligns with the definition of placation on Arnstein's ladder because at this stage, a few citizens are hand-picked as "worthies" by the powerholders to participate in the intervention (which, in this case, is MMT patients being picked and then trained as peer outreach worker).
Authors: Darke & Torok., 2013 **Form of Participation:** Consultation **Rationale based on Arnstein's Ladder:** This study describes 300 PWUD being recruited from needle exchanges and then asked to share their perspectives and attitudes on prohibition, legalization, and decriminalization of major illicit drugs by responding to structured interviews. This aligns with the definition of consultation on Arnstein's ladder because at this stage there is a two-way flow of information through meetings, hearings, and surveys.
Authors: Dechman, 2015 **Form of Participation:** Delegated power **Rationale based on Arnstein's Ladder:** This study describes PWUD (referred to as 'peer/natural helpers') and the challenges they face when acting as secondary distributors of harm reduction supplies for a needle exchange in Atlantic Canada. The natural helpers find themselves extending far beyond their traditional roles as secondary distribution agents (they act as first responders, provide counselling, assist with injecting, among other things). This aligns with the definition of delegated power on Arnstein's Ladder because it demonstrates citizens taking control of parts of a program/project: the

natural helpers are providing ingenious harm reduction services, but the natural helper role was designed and implemented by the Sharp Advice Needle Exchange (SHARP) and the AIDS Coalition of Cape Breton
Authors: Frank, Anker, & Tammi, 2012 **Form of Participation:** Citizen Control **Rationale based on Arnstein's Ladder:** This study describes the different drug user organizations in the Nordic states. Since this study centres on drug user organizations, it most closely aligns with the definition of citizen control on Arnstein's Ladder.
Authors: Greer et al., 2016 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study evaluates the peer engagement efforts undertaken by the BC Harm Reduction Services and Strategies (BCHRSS) committee. The BCHRSS is made up of representatives from the Ministry of Health, the 5 health authorities, and the FNHA. Drug user organizations were asked to nominate participants as representatives to sit on the committee. In areas where DUOs didn't exist, harm reduction coordinators invited individual peers to sit on the committee. This aligns with the definition of partnership on Arnstein's Ladder because this rung on the latter is characterized by shared decision-making: not only were PWUD invited to sit on the BCHRSS committee, but DUOs were able to nominate their own committee representatives (rather than being hand-picked as 'worthies' by the powerholders, which would constitute a classification of placation rather than partnership).
Authors: Greer & Ritter, 2019 **Form of Participation:** Consultation **Rationale based on Arnstein's Ladder:** This study describes the participation of PWUD and their close affiliates in focus groups, who were consulted on their opinions of Australian drug laws. Focus group participants were recruited by staff at social welfare services in Sydney, Australia. This aligns with the definition of consultation on Arnstein's ladder as this study used a two-way flow of information through the use of focus groups to learn about PWUDs' opinions of Australian drug laws.
Authors: Greer et al., 2019 (a) **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study conducted 13 peer-facilitated focus groups with PWUD. Focus group participants were recruited by peer RAs through word of mouth and by posters at harm reduction agencies. This aligns with the definition of partnership on Arnstein's Ladder because not only is there a two-way flow of information happening but focus group participants were invited to participate by peer RAs (rather than being hand-picked as 'worthies' by the powerholders, which would constitute a classification of placation rather than partnership).
Authors: Greer et al., 2019 (b) **Form of Participation:** N/A. This study was a literature review and did not incorporate first-hand participation efforts of PWUD. The literature review identified issues in compensating peers for their work.
Authors: Hayashi et al., 2010 **Form of Participation:** Citizen control **Rationale based on Arnstein's Ladder:** This study describes programming that is entirely peer-led (a peer-led syringe exchange service developed and implemented by VANDU). This aligns with the definition of citizen control on Arnstein's ladder because it demonstrates citizens being in full control and having full autonomy of the project/program/planning and decision-making.
Authors: Kennedy et al., 2019 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study describes peer worker involvement at four different OPS in the DTES. Only one of the four OPS was entirely peer-run and operated (this OPS was located within a drug user organization in the DTES). The other three OPS were operated by non-

peers (for example one was operated by staff of a non-profit housing building). Thus, this most aligns with the definition of partnership on Arnstein's ladder because it demonstrates citizens working in partnership with powerholders (the non-peer OPS operators) to share power and decision-making over how the OPS sites are implemented.
Authors: King, 2011 **Form of Participation:** Informing **Rationale based on Arnstein's Ladder:** This study describes service users from MMT programs. Both service providers and service users agree that service users should have a say in determining their care needs within the MMT program, service users had little influence over the treatment they received, and they had no representative role at decision-making tables. This study most aligns with the definition of informing on Arnstein's ladder because the powerholders acknowledged that the service users (or 'citizens') should have a say in their treatment, however this was never incorporated into MMT programming. Furthermore, the MMT service users experience a one-way flow of information, where they are not given the option to provide feedback, criticism, or to participate in negotiations.
Authors: Kikvidze et al., 2018 **Form of Participation:** Therapy **Rationale based on Arnstein's Ladder:** This study describes a peer-support intervention consisting of three mandatory face-to-face sessions for PWUD who have been diagnosed with HCV. The study does not specify whether these mandatory sessions were designed by the peer workers. This aligns with the definition of therapy on Arnstein's ladder because incorporating 'mandatory' sessions into this study's treatment intervention implies "curing" citizens by requiring them to participate in face-to-face session.
Authors: Lancaster, Sutherland, & Ritter, 2014 **Form of Participation:** Consultation **Rationale based on Arnstein's Ladder:** This study describes whether there is a heterogeneity of opinion among PWUD regarding drug policy interventions. PWUD completed structured face-to-face surveys, and they were recruited by word of mouth, street-based advertisement, peer-referral, or through syringe exchange programs. This aligns with the definition of consultation on Arnstein's ladder because PWUD were consulted on their beliefs and opinions surrounding drug policy issues through surveys. This demonstrates a two-way flow of information, a key characteristic of Arnstein's definition of consultation.
Authors: Marshall et al., 2015 **Form of Participation:** N/A – This study was a literature review and did not incorporate first-hand participation efforts of PWUD. This study used Pretty's participation typology to classify participation types. The majority of included studies were classified as "functional" forms of participation according to Pretty's typology. This translates to informing, consultation, and placation on Arnstein's ladder.
Authors: Marshall et al., 2017 **Form of Participation:** Citizen control **Rationale based on Arnstein's Ladder:** This study describes PWUD being recruited by a DUO in Montreal (Meta D'ame) to participate as peer-trainers in a take home naloxone program. This aligns with the definition of citizen control on Arnstein's ladder because the implementation of peer-trainers to the THN program was entirely user-led.
Authors: Marshall, Piat, & Perreault, 2018 **Form of Participation:** N/A – This study was a literature review and did not incorporate first-hand participation efforts of PWUD. Specifically, this study conducted a literature review examining the psychological impacts of working as a peer-helper in THN programs.
Authors: Newland & Treloar, 2013 **Form of Participation:** Citizen control **Rationale based on Arnstein's Ladder:** This study describes peer educators participating in an HCV prevention education program, a program that was delivered by a DUO in Australia. The peer educators were asked to participate by the DUO as well as trained by the DUO. This aligns with the

definition of citizen control on Arnstein's ladder because all aspects of the peer education program were overseen by the DUO.
Authors: Patterson, Weaver, & Crawford, 2010 **Form of Participation:** Consultation **Rationale based on Arnstein's Ladder:** This study describes drug user service groups, and the extent of drug user service groups being involved in the delivery of local services. User groups reported having representation at decision-making tables, as well as participating in agency training, recruiting agency staff, and quality assurance programs. However, user groups described being 'consulted' as the most common method of participation.
Authors: Rance & Treloar, 2015 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study describes an Australian drug user organization (the NUAA) being contracted by the New South Wales Ministry of Health to implement consumer participation projects in three drug treatment facilities. This aligns with the definition of partnership because the consumer participation initiative was developed and implemented in partnership between the NUAA and the NSW Ministry of Health.
Authors: Small et al., 2012 **Form of Participation:** Citizen control **Rationale based on Arnstein's Ladder:** This study describes the Injection Support Team (IST), a drug-user led program created and implemented by VANDU. This aligns with the definition of citizen control on Arnstein's ladder because all aspects of the IST program were overseen by VANDU.
Authors: Stengel et al., 2018 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study describes the use of peer-based outreach work in Dakar, Senegal. The peer-based outreach initiative was designed "in partnership between an HIV civil society organization (the ANCS) and a self-organized advocacy group of people who use drugs" (Stengel et al., 2018, pp. 2). This aligns with the definition of partnership on Arnstein's ladder because at this rung, citizens and powerholders agree to share decision-making.
Authors: Taylor et al., 2019 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study describes the use of surveys to determine whether PWUD would access a mobile drug consumption room in Portugal. The surveys were designed and administered in partnership with peer workers. This most aligns with the definition of partnership because at this rung, citizens and powerholders agree to share planning and decision-making.
Authors: Ti, Tzemis, & Buxton, 2012 **Form of Participation:** N/A – This study was a literature review and did not incorporate first-hand participation efforts of PWUD.
Authors: Tookey et al., 2018 **Form of Participation:** Placation **Rationale based on Arnstein's Ladder:** This study describes the use of Peer Community Support Workers (CSWs) within an HCV program. The CSWs were recruited by the Program Manager. The CSW roles include client support, group facilitation, public speaking, training other CSWs. The CSWs were not involved in the development and implementation of the program. This most aligns with the definition of placation on Arnstein's ladder because this stage citizens are 'hand-picked' for participation, and there is no shared decision-making at this stage.
Authors: Treloar et al., 2011 **Form of Participation:** Delegated Power **Rationale based on Arnstein's Ladder:** This study describes the evaluation of consumer participation in the organizational levels of drug treatment service planning and delivery. This aligns with the definition of delegated power on Arnstein's ladder because consumers were involved in decision-

making roles in the planning and delivery of services (and at this stage on Arnstein's ladder, there are negotiations between citizens and powerholders resulting in citizens holding power at decision-making tables).
Authors: Treloar et al., 2015 **Form of Participation:** Placation **Rationale based on Arnstein's Ladder:** This study describes peer support workers being implemented at two OST clinics. In one of the clinic sites, the peer workers were only able to engage with clients in the waiting area, and were not granted access to other 'staff only' areas of the clinic. This most aligns with Arnstien's definition of placation because at this stage citizens are beginning to have some degree of influence (peer support workers are providing services at OST clinics), however there is still tokenism at play (peer workers were not treated as equal to non-peer staff, as they were not given access to the 'staff only' areas of the clinic).
Authors: Van Hout & McElrath **Form of Participation:** Informing **Rationale based on Arnstein's Ladder:** This study describes the Service User Support Team (SUST) and their work in increasing service user involvement in Ireland. SUST is a community employment scheme for those in recovery, and acts as a support and advocacy structure for PWUD. SUST was designed and operated by the Western Region Drugs Task force (WRDTF, a task force set up by the Irish government). This aligns with Arnstein's definition of Informing because the task force was set up by the government, and not by PWUD. Additionally, while the aims of SUST is to promote user involvement, many service users reported hearing about SUST through one-way, non-participatory, information-sharing methods (ex. The distribution of leaflets).
Authors: Wilson, Vannice, Hacksel, & Leonard, 2018 **Form of Participation:** Partnership **Rationale based on Arnstein's Ladder:** This study describes the planning and implementation of peer workers at three community harm reduction agencies in Ottawa. This aligns with the definition of partnership on Arnstein's ladder because at this rung, citizens and powerholders agree to share decision-making in the planning and implementation of programs/projects.

Discussion

In the form of a scoping review, this thesis mapped out the peer-reviewed literature on including people who use drugs in the development and delivery of harm reduction services and drug policy. This scoping review identified several countries that encourage the involvement of PWUD in the development and delivery of harm reduction initiatives, including Canada and Australia. Evidence from this scoping review provided insight on the various peer roles PWUD undertake when participating in the planning and delivery of harm reduction services and drug policy. It also provided information about the forms of participation used when engaging people with lived experience of drug use. To my knowledge, this is the first scoping review to explore peer roles and forms of participation among PWUD included in the development and delivery of harm reduction services and drug policy.

Involving PWUD: furthering our understanding

I used Arnstein's Ladder of Citizen Participation to help extract information about the 'level' of participation used by harm reduction programs, services, and policy initiatives to engage people with lived experience. Citizen power and partnership were the two most commonly identified forms of participation noted in my scoping review, while manipulation and therapy were the least common (see Figure 5). I used Arnstein's Ladder of Citizen Participation to help me begin to categorize the different types of engagement styles harm reduction initiatives were using to involve PWUD in their work. Using Arstein's Ladder to categorize participation was challenging in that it was often unclear how best to categorize each study's unique use of peer involvement. In their literature review, Marshall, et al (2015) elaborate on their challenges with using Pretty's Participation Typology (Pretty, 1995) by noting "there are several challenges with these categorization systems such as who decides on the level of participation, and whether

"inactive" or "functional" participation is more related to the activity, the individual peer worker, and/or the way the program may be organized" (Pretty, 1995; Marshall et al., 2015, pp.8). Additionally, it is worth noting that while I 'showed my work' and provided rationales (located in Table 4) for how I assigned each study to a particular 'rung' on Arnstein's Ladder, these rationales are based on my subjective understanding and interpretation of each rung's definition.

I also identified a variety of peer roles in the literature, grouped into six categories: delivering harm reduction and health services, peer-delivered education, drug-user organizing, peer support work, PWUD sitting on advisory committees and participating in focus groups and surveys, and finally peers providing their perspectives on drug policy. In my research objectives at the beginning of this thesis, I did not initially aim to identify and describe peer roles. However, when reading the literature and throughout the scoping review process, I found that keeping track of the roles PWUD were undertaking helped better understand and conceptualize how PWUD were involved in decision-making within these harm reduction initiatives. Furthermore, I felt it was essential to include such information within my scoping review findings, as capturing and describing the various peer roles within the literature can provide valuable information for potential stakeholders wishing to include PWUD in the development and delivery of harm reduction initiatives in more meaningful and equitable ways.

Drug-user organizing

Across Canada and around the world, many drug users have mobilized to form user groups and drug-user organizations (DUOs). DUOs allow for the participation and involvement of people with drug-use experience to come together and speak up in unity about their rights, needs, and struggles. It creates a platform for PWUD to have a stronger and unified voice, empowering them to mobilize in order to combat the stigma and discrimination society has

inflicted upon them (Boyd, MacPherson, & Osborn, 2009). Presently, DUOs exist across Canada and around the world, and are most often organized to uphold the health and human rights of PWUD (Boyd & Boyd, 2014).

This scoping review highlighted several examples of PWUD collectively organizing and advocating for the health and rights of PWUD in the form of drug user organizations. Interestingly, the highest forms of participation (according to Arnstein's Ladder) occurred when drug user organizations were involved. In total, this scoping review identified five studies that examined the work of drug user organizations. Of these five studies, four of them (Bardwell et al., 2018, Callon et al., 2013., Hayashi et al., 2010; Small et al., 2012) were about VANDU, the Vancouver-based drug user union, and one study was a commentary exploring the various drug user organizations of the Nordic States (Frank, Anker, & Tammi, 2012). In British Columbia and across Canada, VANDU is well known for their powerful voice in matters relating to drug policy and shifting social attitudes towards PWUD (Kerr et al., 2006; Ti et al., 2012). Three of the four studies included in this scoping review describe VANDU's drug user organizing efforts in relation to harm reduction service provision. For example, Hayashi et al (2010) examines the success of a syringe exchange program created by VANDU called The Alley Patrol. The fourth study, by Bardwell et al (2018), explored the benefits of low threshold employment opportunities at VANDU. These four studies demonstrate the role of drug user organizations (in this case, VANDU's efforts) in engaging people with lived experience in various interventions that help to promote the health and wellbeing of PWUD.

It is worth noting that this scoping review did not identify any peer-reviewed studies describing drug user organizations involved in drug policy planning, development, or other policy-related processes. People with lived and living experience of drug use are key

stakeholders in health, social, and drug policy, as these policies directly affect them (Jurgens, 2008). Furthermore that drug user organizations are some of the most involved, active, and advocative peer groups supporting and representing PWUD, yet this scoping review did not capture any studies that looked at the collaborative efforts between policy makers and drug user organizations. This therefore brings to light an essential gap in the literature: a lack of peer-reviewed studies pertaining to drug user organizations being involved in drug policy arenas.

The involvement of DUOs in consultations, decision-making, or advisory structures related to drug policy issues (at local, provincial/territorial, and federal levels) is essential to promoting and upholding the health equity of PWUD (Jurgens, 2008). Such participation enables DUOs to advocate for and represent the perspectives, aspirations, and experiences of PWUD, which better informs decision-making processes, ultimately allowing for policies to be appropriately tailored to the needs of PWUD. This involvement is paramount now more than ever with British Columbia entering into its sixth year of an overdose crisis resulting from a toxic drug supply and subsequent inaction from policy makers.

It is worth noting that this scoping review yielded three studies which sought to examine PWUDs' perspectives on drug policy issues (Darke & Torok, 2013; Lancaster, Sutherland, & Ritter, 2014; Greer & Ritter, 2019). The findings from these three studies speak to the diversity of beliefs and experiences among PWUD, as well as reinforce the need to better represent a diversity of opinion in drug policy decision-making (Lancaster, Sutherland, & Ritter, 2014).

Limitations

This topic was deemed important by the BCCDC Peer Engagement and Evaluation Project (PEEP) which included people who use drugs. However, due to the narrow scope of my Masters thesis (as well as the time constraints I encountered while trying to finish this work), it

was not possible to engage PWUD throughout this project. This omission must be acknowledged as a critical limitation, since this thesis emphasizes the importance of including people with lived experience of drug use in any work that is about them. Engaging with PWUD throughout this project would have contributed meaningful sources of information, perspectives, and applicability of the scoping review process and the findings (Levac, Colquhoun, & O'Brien, 2010). Furthermore, engaging with PWUD at the outset of my project (for example consulting with a group of PWUD, or a drug-user organization) to determine if my research objectives, research question, or search terms needed to be expanded upon or changed would have made them more applicable. It would have also been of benefit to consult with PWUD after obtaining preliminary results from this scoping review. Through their perspectives and lived experience, PWUD could help to validate the findings, identify knowledge gaps, discuss limitations, as well as help to inform future policy and research ideas. Ultimately, including PWUD throughout my Masters project would have enhanced the relevance and acceptability of the entire scoping review process, the results, and how I interpreted my findings.

Arnstein's Ladder

Sherry Arnstein's Ladder of Citizen Participation (1969) is over fifty years old, and, although frameworks like Arnstein's are helpful to analyze the distribution of power at a given decision-making table, this conceptual framework has several limitations. One such critique is that Arnstein's ladder assumes participation is entirely hierarchical in nature (Tritter & McCallum, 2006). With respect to this hierarchical nature, *citizen control* is located at the top of the ladder and is assumed to be the pinnacle of citizen participation. As Collins & Ison (2006) note, "citizen control [is] held up as the 'goal' of participation – an assumption that does not always align with participants' own reasons for engaging in decision-making processes (Collins

& Ison, 2006, pp. 2). Arnstein's framework fails to consider that citizens may in fact take part in user involvement processes for a multitude of reasons. Specifically, Arnstein fails to recognize that citizens may wish to participate in some capacity other than to achieve *citizen control*. As Tritter & McCallum (2006) point out, by only recognizing and emphasizing power, Arnstein's ladder fails to acknowledge that for some citizens, participation in and of itself is often the main goal (Tritter & McCallum, 2006).

Limitations of Drug User Organizations

In this scoping review, I identified that the highest forms of citizen participation often occur among drug user organizations composed of people who use drugs. It is worth noting that drug user organizations represent certain groups of PWUD and do not represent all PWUD. While this scoping review has highlighted the many benefits of drug user organizations, an additional limitation of this study is that there may be power dynamics at play even within drug user organizations, which may hinder the participation of other PWUD. These power dynamics may result in individuals or groups of PWUD not seeing themselves as belonging, they may prevent someone from feeling meaningfully included within a drug user organization, or they may prevent someone from joining one altogether. However, it is worth considering there may be other forms of participation among PWUD (independent of drug user organizations) that may be more valuable, appropriate, and meaningful avenues for engaging a broader range of PWUD that are not otherwise represented by a drug user organization.

My scoping review process

While my search terms were developed in consultation with a research librarian, there may be additional peer-reviewed articles not captured by these terms. Additionally, this scoping review only examined the peer-reviewed literature and did not capture the grey literature. The

decision to exclude these was made in consultation with a research librarian. Together we determined that including the grey literature would be beyond the scope of a Masters thesis (due to the sheer volume of it on this topic). Nevertheless, there may be relevant documents existing in the grey literature that were not captured as a result of the limited scope of this thesis. When forming my inclusion and exclusion criteria, it was also decided to exclude the inclusion of PWUD in doing research work. This decision was made to ensure my Masters thesis remained of an appropriate scope, it is possible the synthesis of this scoping review may be lacking in detail.

Like any systematic review, it is important that the scoping review process be conducted in a consistent and rigorous manner. In completing this work, I acted as the sole reviewer, where I was the only one gathering, laying eyes on, and interpreting the data. Being the sole reviewer could lead to personal bias and errors when selecting, reviewing, interpreting, and charting the data. In the second stage of the scoping review process ('identifying relevant studies'), Levac, Colquhoun, & O'Brien (2010) recommend assembling a "suitable team with content and methodological expertise" to identify studies (Levac et al., 2010, pp.4). For example, as the sole reviewer applying the inclusion and exclusion criteria when searching for studies, I may have decided to exclude studies in error (or vice versa). Furthermore, in the fourth stage of the scoping review process ('charting the data'), Levac et al (2010) suggest the research team members, independent of each other, chart the "first five to ten studies using the data-charting form and meet to determine whether their approach to data extraction is consistent with the research question and purpose" (Levac, Colquhoun, & O'Brien, 2010, pp.6). Since I was the sole researcher, I did not have the opportunity to verify with anybody else that my data extraction methods were consistent. If two (or more) reviewers come together to search, identify, extract,

and interpret data, it reduces the potential for personal bias and error, and maintains consistency and rigor throughout the entire scoping review process.

Recommendations for future research

While it was important to use a participation framework to capture the different types of participation identified within the peer-reviewed literature, the many challenges of using Arnstein's Ladder highlighted a need for the development of a participation framework specific to the involvement of PWUD in harm reduction initiatives. This framework should build on Arnstein's Ladder (which considers the distribution of power in decision-making) by taking into consideration the structural challenges unique to PWUD, such as stigma.

In order to broaden our knowledge of peer engagement in harm reduction initiatives, it would be beneficial to conduct a scoping review looking at the grey literature on this topic and compare how this is similar or different to the peer-reviewed literature. Additionally, future research should focus on conducting systematic reviews of the literature as it pertains to peer engagement among specific populations of people who use drugs. PWUD are a diverse group who have unique needs, thus looking at the peer engagement efforts among specific populations of PWUD may lead to new insights. Ideas for future research of peer engagement efforts among specific populations of PWUD might include learning more about peer engagement among youth who use drugs, including women and LGBTQ who use drugs in peer engagement processes, and including people who drink alcohol in harm reduction/policy initiatives. Future research on this topic should also look at the involvement of PWUD in research settings, as this topic was excluded due to the small scope of this Masters thesis. It would also be of benefit to examine how systemic and organizational factors influence peer engagement processes (both positively

and negatively). Lastly, it is paramount to further investigate and evaluate the inclusion of PWUD in the planning and delivery of drug policies.

Concluding statement

In the form of a scoping review, this Masters thesis sought to map the peer-reviewed literature pertaining to including PWUD in the development and delivery of harm reduction programs, services, and drug policy. As such, this Masters thesis will advance the conversation regarding the inclusion of people with lived and living experience of drug use in decisions that affect them, as a means to promote their health equity.

This Masters thesis used a five-stage methodological framework to search, extract, and synthesize data that pertained to my research objectives: (1) To identify and conceptually map the peer-reviewed literature (within the most recent ten years) according to studies that describe the involvement of peers in the development and/or delivery of harm reduction programs, services, and drug policy; (2) To identify and describe, within each peer-reviewed article, how peers are being involved in the development and/or delivery of harm reduction programs, services, and drug policy; and (3) To identify and synthesize information that could help inform policy makers, service providers who work with peers in harm reduction initiatives, and others hoping to better and more meaningfully include people with lived experience in the development and delivery of harm reduction services, programs, and drug policies. I incorporated Arnstein's Ladder of Citizen Participation to discern how PWUD were engaged in harm reduction initiatives. Furthermore, my research was informed by a health equity lens: I undertook this topic in order to add to the evidence-base that community participation and social inclusion are means of promoting the health equity of traditionally marginalized groups (in this case, PWUD).

In summary, this scoping review identified the highest levels of participation among PWUD to occur when drug user organizations were involved. The highest degree of participation (i.e citizen power on Arnstein's Ladder) occurred when DUOs had full power and control over

the planning and delivery of harm reduction initiatives. This scoping review has also highlighted the importance of continuing to involve PWUD in the development and delivery of harm reduction programs, services, and drug policy. Doing so will strengthen the voices of PWUD and will allow for such initiatives to be more properly tailored to their needs. This Masters thesis identified and synthesized information from the peer-reviewed literature to better inform policy makers, service providers, and organizations currently working with or are hoping to work with peers in harm reduction initiatives, so that the involvement of PWUD is meaningful, sustainable, and equitable.

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APPENDIX 1 - A summary of Arnstein's Ladder of Citizen Participation (1969)

Non-Participation

1. *Manipulation*: citizens are placed on advisory boards or committees for the purpose of 'educating them'
2. *Therapy*: citizens are subjected to clinical group therapy under the guise of participation, where the focus is on curing them of their 'pathology'

Tokenism

3. *Informing*: seen as a starting point for participation, this is when information is provided to citizens in a one-way manner, with no channel for them to provide feedback or negotiation
4. *Consultation*: consulting citizens on their opinions, however there is no guarantee that these opinions will be taken into account
5. *Placation*: where citizens begin to have some influence and degree of power, however powerholders (who hold the majority of seats) retain the right to judge the advice provided by citizens

Citizen Power

6. *Partnership*: when there is agreement to share decision making and planning, and where power is redistributed through negotiations between citizens and the powerholders
7. *Delegated Power*: where those being included have dominant decision-making authority
8. *Citizen Control*: power is held by the citizens, who have the ability to govern and are in full charge of policy and managerial aspects, and are able to negotiate the conditions under which 'outsiders' may change them