"Having a voice and saving lives"



A survey by and for people who use drugs and work in harm reduction

Cover photo by Sean LeBlanc

Published July 2019

This document was created by the CRISM People with Lived Expertise of Drug Use (PWLE) National Working Group (in alphabetical order):

Brandi Abele – Canadian Association of People who Use Drugs (CAPUD) Jennifer Bowser – Halifax Area Network of Drug Using People (HANDUP) Loretta Brown – Vancouver Area Network of Drug Users (VANDU) Julien Carette – HANDUP Frank Crichlow - Counterfit Harm Reduction Project, CAPUD Alexandra de Kiewit – CAPUD Hugh Lampkin – VANDU Dawn Lavand – The Manitoba Harm Reduction Network Sean LeBlanc – Drug Users Advocacy League (DUAL), Ottawa Inner City Health Alex Sherstobitoff – BC/Yukon Drug War Survivors, Rural Empowered Drug Users Network (*REDUN*) Rick Sproule – DUAL, Ottawa Inner City Health, CAPUD Natasha Touesnard – HANDUP, CAPUD Karen Turner – Boyle Street Community, CAPUD Dean Wilson – BC Centre on Substance Use (BCCSU)

With additional support from:

Tamar Austin – BCCSU Jade Boyd – University of British Columbia, BCCSU Kelsey Van Pelt – BCCSU

*This report is dedicated to Rick Sproule

Suggested Citation: CRISM PWLE National Working Group. (2019). "Having a voice and saving lives:" a survey by and for people who use drugs and work in harm reduction. Vancouver, Canada: BC Centre on Substance Use.

Acknowledgments: We would like to thank all of the participants who contributed to this report as well as the 2018 Stimulus conference organizers, Canadian Research Initiative in Substance Misuse (CRISM), British Columbia Centre on Substance Use (BCCSU), and our funders: the Canadian Institutes of Health Research (FRN 154824), Vancouver Foundation (UNR17-299), and St Paul's Foundation.



We acknowledge that this work took place on the unceded territories of the x^wmə0kwəýəm (Musqueam), S<u>kwx</u>wú7mesh (Squamish), and SəÌílwətał? (Tsleil-Waututh) Nations as well as Treaty 6 territory and traditional lands of the Plains and Wood Cree, Assiniboine, Saulteaux, Tsuu T'ina, Nakoda, Chipewyan, and Metis.

Contents

Introduction	5
Background	5
CRISM People with Lived Expertise National Working Group: What is it?	7
2018 Stimulus Conference	8
Activism Artwork from 2018 Stimulus Conference	9
The Survey	10
Our Research Findings	11
The Benefits of 'Peer' Work	13
Negative Aspects to 'Peer' Work	16
Recommendations for Change	20
Conclusion	21
Appendix	22
References	23

Introduction

In response to limitations of conventional drug services, peer-based models of care have become a significant and expanding component of harm reduction interventions in Canada,^{1,2,3} which has recently moved more toward overdose prevention and addiction treatment. Within drug-related social and health-based service provision, peers are defined as people with lived expertise of drug use, who work in harm reduction services and organizations. However, in the field of harm reduction, the term 'peer' has also been used to demarcate an invisible boundary that results in material inequities between harm reduction professionals who use(d) drugs and those who openly do not. In this report, we acknowledge the contradictions inherent in the usage of the term 'peer' (by not using it or using it consciously), and draw upon findings from a recent study by and with community harm reduction mobilizers from across Canada who use(d) drugs, highlighting some of the experiences of those impacted by these invisible boundaries. Our project findings are important given the magnitude of preventable drug overdose deaths driven by a poisoned illicit drug supply and the increased up-take of people with lived expertise of drug use working in overdose prevention sites and harm reduction services. This report provides some background to these issues and to the establishment of the CRISM People with Lived Expertise (PWLE) National Working Group (responsible for this report), and outlines our research survey findings and resulting recommendations for change.

Background

Since the early 1900s, people who use illicit drugs have experienced legal and social discrimination, stigma, and marginalization. Drug policies are gendered, racialized, and class-based; thus, the impact of drug prohibition plays out differently for diverse men and women, transgender, non-binary and two-spirit peoples. The consequences of illicit drug use are directly associated with one's social status. Therefore, poor and racialized people (including women and gender diverse people) experience more harm (i.e., police encounters, arrests, imprisonment, child apprehension). They also experience more health harms (i.e., overdose deaths, HIV/AIDS, & Hepatitis C infections).

Since 2010, overdose deaths have been rising in Canada.⁴ Almost ten years later, Canada's overdose epidemic remains a major public health challenge. In response to the crisis, novel harm reduction and addiction treatment interventions have been scaled up in specific regions across Canada, including some with significant involvement of people with lived expertise of drug use: at overdose prevention sites; through witnessed injection programs; and within health navigation. This follows a large body of evidence indicating that the involvement of people who use(d) drugs extends the reach and *effectiveness* of interventions, including by reaching those who do not access traditional public health programs.^{5, 6, 7, 8, 9, 10}

Significantly, the involvement of people with lived expertise of drug use has also resulted in increased diversity within many of these service settings, with socially and economically marginalized women and

Indigenous people who use(d) drugs taking a particularly prominent role in emerging programming. This has potential benefits that have not been adequately examined, as most work on these approaches – amidst the overdose epidemic and otherwise – has homogenized the roles of people who use(d) drugs rather than more broadly considering their diversity.

Working in harm reduction programs (e.g., providing new/sterile equipment, administering naloxone, overdose protocols and/or first aid, and supervising drug consumption) can also have positive health impacts for experienced community harm reduction mobilizers themselves.^{11, 12} However, while such initiatives have proven effective in decreasing drug-related illness and death among people who use drugs, recent research has pointed to unintended negative impacts of health models reliant on care provision by those with lived expertise of drug use.^{4, 13} For instance, people with lived expertise of drug use working in harm reduction risk overextending themselves beyond employment parameters with few systems in place (e.g., employment advocacy) for support.^{1, 9, 14, 4} Further, continued exposure to stigma, workplace discrimination, and/or power imbalances between staff with lived expertise of drug use and staff without, as well as the impact of high stakes employment (e.g., dealing with overdose deaths), can have significant consequences for community harm reduction mobilizers in terms of burn out, relapse or increased problematic drug consumption, disparity, trauma, and grief. With growing awareness that the participation of people with lived expertise of drug use in harm reduction care can have both health benefits and unintended consequences, their participation in Canada's overdose response commands further investigation and recognition.

In this report, we begin to address this gap by highlighting the findings of a survey we conducted in 2018 that draws upon the perspectives of a diversity of people with lived expertise of drug use now working in harm reduction, drug user unions/groups, and overdose-related intervention across Canada. While people with lived expertise of drug use are being increasingly engaged in harm reduction and addiction treatment interventions, in many cases without accompanying employee supports, there is a need for continued investigation into the effectiveness of these programs and the impacts on employees. The factors that promote meaningful involvement have not been investigated fully and opportunities to involve those with expertise of drug use in the delivery of substance treatment programming remains under-explored.

CRISM People with Lived Expertise National Working Group: What is it?

This survey study stems from a five-year research initiative that operates as a component of the Canadian research consortium, CRISM (Canadian Research Initiative in Substance Misuse), with researchers (people with and without lived expertise of drug use) associated with four regional nodes across Canada: British Columbia; Ontario; Quebec/Atlantic regions; and the Prairies. At the outset, lead researchers (without lived expertise of drug use) from each CRISM node invited an average of two people with lived expertise of drug use working in harm reduction/drug user unions in their region to join the CRISM People with Lived Expertise (PWLE) National Working Group. For example, the lead researcher in Vancouver, BC approached the board of directors for the Vancouver Area Network of Drug Users (VANDU) about the project and asked if they could recommend two people who might join the project. A third member was recommended through their activism networks as someone who could provide rural representation. In total, fifteen community harm reduction mobilizers/researchers with lived expertise of drug use from across Canada now make up the CRISM PWLE Working Group.

Our CRISM PWLE National Working Group meetings were initiated in April of 2018. Because the group is drawn from people across Canada, we most often meet every three to four weeks via a scheduled conference call. Members of the CRISM PWLE National Working Group are compensated for their participation in the group. At our meetings, we talk about pertinent issues related to drug use and health and human rights, including ongoing discrimination of people who use drugs, regional (lack of) distribution of harm reduction services, the overdose crisis, structural violence (e.g., gendered violence, poverty, colonialism and systemic racism, drug laws) and the need for more diverse and culturally responsive services. We also discuss the need to fully recognize the work of people who use drugs as an essential component to services, as well as the hardships, inequity, lack of compensation, and emotional toll of the work. Knowledge sharing among members provides opportunities for identifying and addressing regional differences as well as providing support across regions.

During our meetings, we brainstorm about timely research projects that we can collaborate on despite our geographical distance, projects that can highlight member experiences, work, and priorities. Our work is informed by community-based research (CBR) practices with structurally marginalized communities, including CBR protocols developed by people with lived expertise of drug use and drug user unions. We apply CBR to our project objectives and qualitative method design, which was developed in consultation and collaboration with people with lived expertise of drug consumption who work in harm reduction across Canada. Through robust discussion over several months, the group identified an initial project to commence highlighting inequities experienced by people who use(d) drugs working in harm reduction. We decided on a short, one-page survey, with survey questions emerging directly from our meetings. This report includes our research findings from the national survey project (additional projects are in progress).

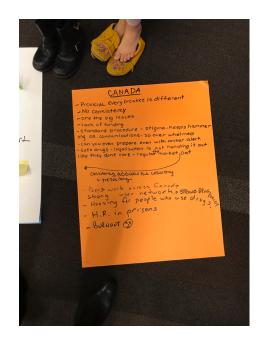


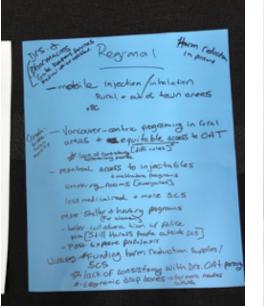
2018 Stimulus Conference

In October 2018, the CRISM PWLE National Working Group had the opportunity to meet face-to-face at the *National Stimulus: Drugs, Policy and Practice in Canada* conference, a three-day gathering held in Edmonton, Alberta. *Stimulus* proved a useful site to administer the survey as numerous people with lived expertise of drug use working in harm reduction or at drug user unions attended the conference from across the country. The conference brought together over 1,250 participants, including community members, service providers, healthcare providers, and researchers to share best practices and knowledge. Harm reduction services were provided on site or within close distance of the convention centre; services included a *Stimulus*-based overdose prevention site, a drug checking centre, a supply centre, and a treatment centre. One of the conference's results was a call to action from the 93 attending organizations demanding that the Canadian government: 1) provide a safer supply of drugs and the full spectrum of substitution options; 2) decriminalize possession of drugs for personal use; and 3) expedite and expand implementation of evidence-based harm reduction interventions.

Satellite Session: Brainstorming and Identifying Key Issues

We attended a satellite session one day prior to the conference so that we could finally meet in-person and get to know one another better before the three-day conference. At our face-to-face meeting, following introductions, members discussed pertinent issues in their regions (e.g., a lack of drug substitution services and options outside specific urban centres). Then we brainstormed about our work, solutions, and projects to educate people about our efforts and the shifting needs of people who use drugs.





Depends in audience Journals for PWIE - Direct face to face at places People megnent. - identify village well - Open house - entertainment - Reports for non-pule - Canada-Wide Peer navigation

Above: Brainstorming examples from Stimulus Conference

Activism Artwork from 2018 Stimulus Conference



Above: Queer Coping Mechanisms by Cara Alex Seccafien & Benni MacDonald



Right: Positive Resistance Quilt by Kat Wahamaa

The Survey

At the conference the CRISM PWLE National Working Group set up a table in a common area to distribute our one-page survey and to educate conference attendees about our group and research project. The lead researcher and project coordinators worked at the table throughout the conference while CRISM PWLE National Working Group members attended various conference panels. The survey included short questions about hours, place of work, and geographical location, and included a section for respondents to write in their own words about the benefits and the negative aspects of 'peer' employment and their recommendations for employment equity for people with lived expertise of drug use. Surveys took 5 - 10minutes to complete and participants received a \$10 honorarium for their time. In total, fifty surveys were completed between October 2-5, 2018.

Following the conference, the lead researcher and research coordinator read and analyzed the surveys. Demographic data was compiled from the surveys into a spread sheet and analyzed using Microsoft Excel. All identifiers were removed for the purpose of confidentiality. Written survey responses were thematically analyzed using inductive coding. Thematic codes were then discussed by the CRISM working group to ensure that they represented the range of responses by survey participants. The CRISM working group then reviewed and commented upon draft documents of this report and debated significant issues, including the lack of representation of people of colour and the usage of the term 'peer.' Preferred terms were expert, community harm reduction mobilizers, people who use(d) drugs, and people with lived expertise of drug use. The study received ethical approval from the Providence Healthcare/University of British Columbia Research Ethics Board.

Our Research Findings

The survey participants held diverse positions and were engaged in outreach, navigation, needle exchange, and overdose prevention work. They held positions as workers with lived expertise of drug use, as coordinators, supervisors, and managers.

Characteristic	Count (n=50)	%
Mean Age	43.8	
Gender		
Men	23	46
Women	24	48
Non-Binary or Gender Diverse	2	4
Two-Spirit	1	2
Ethnicity/Race		
White	21	42
Indigenous	14	28
African, Caribbean, Black	3	6
East or South Asian	2	4
Other	2	4
No Entry	8	16
Node (Geographic Area)		
British Columbia (Abbotsford, Nanaimo, Nelson, Surrey, Vancouver, Victoria)	27	54
Prairies (Calgary, Edmonton, Winnipeg)	13	26
Ontario (Ottawa, Toronto)	4	8
Quebec/Atlantic (Montreal, Halifax, St. John's)	6	12
Hours of Work		
Part-time or less	20	40
Full-time or more	21	42
Varied Greatly	8	16
No Entry	1	2

Table 1. Survey participants' demographics

The survey participants self-identified race/ethnicity and gender. Table 1 simply summarizes diverse responses to the open questions about race/ethnicity, gender, age, and place of residence. Response rates for all survey questions were high, with an average 95.5% response. Even Question 3, which asked participants to identify race/ethnicity and was optional, received a high rate of response at 84% (see Table 4 in Appendix). Survey participants identifying as white (42%) comprised the largest group, and the second largest group was made up of those whose self-identified race/ethnicity was Indigenous

(28%), followed by African, Caribbean, Black (6%); East or South Asian (4%); and Other (4%). The mean age of survey participants was approximately 44 years of age, and there was a near even distribution of men (48%) and women participants (46%). Additionally, 4% of participants identified as non-binary or androgynous, and 2% of participants identified as Two-Spirit. The majority (54%) of participants were from the British Columbia node, specifically Vancouver, while the Prairies (Alberta, Saskatchewan and Manitoba) produced the second largest proportion of survey participants at 26%. In terms of occupations, the majority of participants worked in harm-reduction services. While hours of work varied greatly, 40% of participants reported working part-time hours or less, and 42% reported hours that qualified as full-time or greater. The majority of participants were salaried.

Forms of "Peer" Payment	Participant Responses (n=50)	%
Salaried	18	26
Volunteer	9	18
Stipend/honourarium	20	40
By the hour	19	38

Table 2. Peer payment methods

Survey participants identified *stigma* as the largest issue impacting their work as a person with lived expertise of drug use, followed by lack of salary and benefits, and pay inequities between employees with lived expertise of drug use and employees without.

Issues the Most Impact Peer Work	Participant Responses (n=50)	%
Stigma as peer	28	56
Health issues	19	28
Unequal work environment	21	42
Pay differences for "peers"	26	52
Lack of benefits	26	52
Lack of salaty	27	54
Safety	14	28
Trauma (from front line work during the overdose crisis)	25	50
Social assistance (welfare/disability) impacting pay amounts	18	36

Table 3. Issues that most impact peer work *Participants could report multiple issues

Three open-ended questions were also included in the survey:

- 1. What benefits do you experience as a 'peer' working in harm reduction?
- 2. What negatives do you experience as a 'peer' working in harm reduction?
- 3. What recommendations or changes should be made in your organization to make 'peer' work more equitable and/or safe?

Survey participant responses are highlighted below.

The Benefits of 'Peer' Work

Participants identified a range of positive elements attributed to their employment, including personal benefits (building of skills and confidence), community benefits (saving lives, sharing knowledge, and destigmatizing drug use), and relationship building (forming trust).

Lived Expertise Valued in the Work Place

In particular, participants described the significance of working as someone with a personal history of drug use, as it allowed for shared knowledge, the building of trust, and the forming of meaningful relationships – as the following quotes indicate:

I am working with people I love and nobody knows how we feel and what we need more than those who feel it.

(Participant 7, 40-year-old white woman from Vancouver)

Because I lived it, I can relate to people.

(Participant 50, 56-year-old Metís man from Edmonton)

Numerous participants stated that their lived expertise and insights were valued by their clients and coworkers, and that being an employer with lived expertise of drug use or actively using drugs helped them create compassionate and non-judgmental work environments and brought them insights that would otherwise be absent.

Relationship building is huge. Those who are aware of my status build more trust and state they relate better.

(Participant 8, 38-year-old woman from St. Johns—ethnicity not identified)

Participants noted that an additional aspect of being valued for one's expertise was the increased opportunities to be heard, to have a voice in contexts where drug users' expertise has historically been denied and/or dismissed.

It wasn't too long ago that what I had to say was dismissed based by appearance and how I lived my life. Today I have a voice and am able to use it to speak for those who have not found their own voice yet.

(Participant 30, 39-year-old South Asian woman from Surrey)

Empowerment & Confidence-Building

Participants explained ways in which learning what people needed, and knowing that they were able to help a community filled with people they genuinely cared about, brought a certain level of fulfillment.

Every ounce of my work provides me with infinite benefits. These benefits are creating and being blessed by the most genuine, raw, meaningful relationships. Witnessing hope and joy in the midst of death and sorrow. Determination, resiliency, and empowerment that I get to be a part of and have my own strengthened alongside. Watching the victories, celebrating even the smallest ones. Coming together in grief; pushing through for change – united.

(Participant 1, 28-year-old white woman from Abbotsford)

They described feeling a sense of satisfaction from their work and their ability to link community members to necessary services including harm reduction supplies, daycare services, and social services. Participants commented that having useful knowledge to share served to build confidence:

It boosts my ego knowing that I am doing good by helping another human being. Knowing that my knowledge through lived experience is useful.

(Participant 11, 53-year-old white man from Ottawa)

There is nothing better than making a difference in someone's life. It fills my heart, not my pockets.

(Participant 33, 41-year-old woman from Vancouver, ethnicity not identified)

Helping people helps me.

(Participant 43, 57-year-old Indigenous man from Edmonton)

Knowledge & Skill Building

Participants reported that their work not only helped them realize their own value, but also allowed them to have a voice amidst those who were considered "experts" in the field. Furthermore, the work allowed participants to build upon their own skillset. Communication, negotiation, and life skills were reportedly acquired by participants through their organizational role, along with the opportunity to learn about diverse people. Additionally, participants reportedly enjoyed an increased knowledge of harm reduction strategies as well as increased access to resources (e.g., housing).

I get to interact with all the people on the street. I get to make sure that people have access to clean harm reduction supplies. I get to be in the loop with helping our clients get housing, into detox, or even just to talk.

(Participant 2, 38-year-old white woman from Surrey)

The #1 benefit to me is the ability to give back and save lives.

(Participant 27, 44-year-old man from Vancouver, ethnicity not identified)

Lived expertise was perceived as especially beneficial for community members when employees with lived expertise occupied a position of power, as expressed in the following quote:

As a peer supervisor, I get to allow the peers working alongside me to use their drug of choice while on shift. The peers working under my supervision are able to have the issues that affect users negatively in other jobs overlooked and not held against them while working in our peer program.

(Participant 6, 45-year-old white woman from Vancouver)

Workers who no longer actively used drugs also felt that they could serve as examples to those who were currently using drugs, with one participant stating:

This kind of work I feel is helping me realize my value as a human being in being an example of someone that doesn't use drugs anymore. Showing that it can be done in the same token I find helps me face my demons head on. Being present with peers and around usage reminds me what I don't want to be doing in my life anymore and shows me that we have to work hard to remain clean.

(Participant 37, 31-year-old man from Nanaimo—ethnicity not identified)

Furthermore, participants reported that as people with lived expertise who possessed a range of valuable skills, they had the opportunity to challenge stereotypes and preconceived notions about people who use(d) drugs.

The benefits I experience are disseminated, information about my HIV, HCV, Drug Use, Harm Reduction. Knowing that through [my work] that I saved a life. Just in general [it's beneficial] for people who have stigma to teach, to not feel like scum, a lowlife. (Participant 11, 53-year-old white man from Ottawa)

I feel like I help people, I help change the status quo, normalize drug use, defend me and my comrades' rights.

(Participant 17, 26-year-old white Androgyne from Montreal)

Overall, survey participants described a range of personal benefits generated from working as a person with lived expertise of drug use in harm reduction. They also saw the ways in which these benefits extended into the communities in which they belong and work.

Negative Aspects to 'Peer' Work

While the benefits of having people with lived expertise working in harm reduction were significant, several key concerns arose when survey participants were asked about their negative experiences working as someone with lived expertise of drug use.

Tokenism

Tokenism and the devaluing of survey participants' lived expertise, along with discriminatory attitudes and institutional inequities, were commonly discussed themes. Minimal efforts of inclusiveness and tokenistic engagement were repeatedly identified by people with lived expertise of drug use as issues. One participant noted:

Pay me much more. Let me use openly at work. Listen to me. Stop fetishizing/tokenizing me (I don't speak for all drug users so they should stop asking me). Acknowledge I'm a victim of the drug war and my colleagues are then more privileged.

(Participant 17, 26-year-old white androgyne from Montreal)

Another participant noted that, while their presence as a PWLE was valued, their expertise was undervalued:

Sometimes I'm not as valued as a "professional" with a Master's [degree] but lived experience is important too.

(Participant 31, 18-year-old Indigenous/Mexican woman from Abbotsford)

Participants noted that identifying as a 'peer' can risk overshadowing their expertise:

I don't often disclose my 'peerness' due to a concern of not being taken for what I am. (Participant 8, 38-year-old woman from St. Johns, ethnicity not identified)

One participant succinctly summarized the feelings of many of the survey respondents who work in harm reduction services:

When do I stop being a "peer"? (Participant 42, 24-year-old two-spirit Indigiqueer Cree and Ojibwe Femme from Winnipeg)

Unrecognized work/expertise and wage inequities

Participants reported that within their organizations they were not taken seriously or as seriously as the academics, "experts," or other professionals they worked with. Survey participants described feeling as though, despite having valuable insights, expertise, and lived expertise to draw from, they often received

patronizing responses from non-drug users within their organization. Especially concerning for participants was the wage inequity between employees who use(d) illicit drugs and employees that openly did not (including academics, social workers, and service providers). Repeatedly, respondents reported that despite participating in and completing the same type or amount of work, they were paid less (with fewer benefits) than those with more education:

At times, I feel underpaid due to lack of formal education. Some authorities view my work as less than that of my co-workers with degrees.

(Participant 46, 27-year-old white woman from Fort Saskatchewan)

Furthermore, some participants felt that their role as workers required them to engage in greater amounts of emotional labour that consistently went unrecognized and unpaid, as the following responses illustrate:

low wages, no benefits

(Participant 15, 55-year-old Black man from Toronto)

Wage disparity and lack of job security [are negatives to my experiences]. I am the supervisor of the site, the one with all the responsibility. The people I train that work for [the site], and I am their supervisor, make \$5/hr more than I do. As well I opened [these sites] without a vacation or stress leave and would have no job security if I took a leave but the 3 fulltime [site] staff that began working in our sites [after me] are all on stress leave of 3-5 months securely. (Participant 6, 45-year-old white woman from Vancouver)

Another worker noted that, given the disproportionate hardship many PWLE experience (e.g., discrimination, the targeting of poor and racialized groups by law enforcement), additional support, with attention to the impact of these inequities, was needed from employers:

Meal support. I need understanding and support with transport to work but most employment won't or can't support bus fare. It costs me money to start work, clothes, bus fare, food for lunch. (Participant 42, 24-year-old two-spirit Indigiqueer Cree and Ojibwe Femme from Winnipeg)

The required support was envisioned as salaried support with benefits, rather than gift cards and stipends:

My peer work is valuable so I should be paid in money, not gift cards or stipends. It should be just as equal as a paid worker [who has not used criminalized drugs].

(Participant 11, 53-year-old white man from Ottawa)

It should be noted, however, that for some workers on disability benefits, payment for work by stipends worked well. For many participants, wage discrepancies and a lack of benefits were further evidence of tokenism, as were perceptions that their lived expertise, knowledge, and contributions were not valued as highly as those of co-workers who had attained higher levels of education.

Participants described feeling that despite contributing immense amounts of labour to their organizations and communities, they were not promised the same sorts of security and protections that employees who were not "peers" were able to enjoy (e.g. unemployment benefits or extended health plans).

I need to educate my colleagues all the time (I'm the only peer at [site of employment]). I do more emotional work than my colleagues but [am] paid the same/this invisible workload isn't recognized/. My job doesn't end when I leave my job but I'm not paid more. At the beginning, I felt "lower" in the hierarchy at my job. Now it's better but I'm not "in the group" like everyone else. (Participant 17, 26-year-old white androgyne from Montreal)

Participants noted that the unofficial harm reduction work they engaged in also went unrecognized if they were still active in their substance use. According to participants, providing harm reduction services to their community and ensuring that those who did not access official services were still receiving harm reduction supplies were not considered employment skills and did not qualify a person for any sort of funding or support. This provided further evidence of the ways participants' work and contributions were devalued.

Stigma and Discrimination

In addition to tokenistic engagement and wage inequities, participants wrote about the stigmatizing and discriminatory experiences they had while interacting with non-drug using co-workers, as well as institutions like the police and social services. Stigma and discrimination could be further compounded for racialized participants, especially Indigenous community members who stated that in addition to discrimination resulting from substance use, they also had to contend with racialized stigma and discrimination. One Indigenous participant described being held to unattainable measures not expected of those who are non-Indigenous:

...As a First Nations Male we experience a lot of co-opting of our narrative (no offense) by academics and [are] held to impossible standards.

(Participant 12, 53-year-old Kway-luth man from East Vancouver)

In certain cases, participants described the extent to which stigma and discrimination due to their history of substance use impacted their ability to work:

STIGMA! Even 3 years into my recovery, worked up from the bottom to a paid "professional" position and yet when I walk into meetings w/ the mayor, @ the city, or even @ community meetings w/ executive directors of organizations that serve our community & other service providers, I am often ridiculed or ignored & not even acknowledged. Worst still, is being targeted & having others (esp. "professionals") call or do other things to try & get me removed from my position, etc.

(Participant 1, 28-year-old white woman from Abbotsford)

Regardless of whether participants were active in their drug use or working in a "professional" role, they still had to contend with stigma and discrimination on multiple levels, both at work and outside of work.

The criminalization of people who use drugs further serves to stigmatize and impact the ability of people who use(d) drugs to fulfill their roles as harm reduction workers. For example, one 43-year-old white gender fluid participant from the north coast of BC included not only "patronizing responses from nondrug user 'experts'" but also "risks of being 'outed' to RCMP [Royal Canadian Mounted Police] and MCFD [Ministry of Children and Family Development] in my community" as significant barriers to working in harm reduction. Participants further cited active dismissal by law enforcement and medical professionals as a problematic aspect of their work:

Where I live, the Vancouver police don't give a care in the world. A lot of hospitals just push people away. It's like they want us not to bother them, because I've seen a lot of things happen. Also, sometimes we get attitude from the people out there suffering.

(Participant 34, 50-year-old Indigenous woman from Vancouver)

Participants described the impact of compounding discriminatory practices by "experts," hospital staff, healthcare and service providers, as well as law enforcement:

Tokenism. Exploitation. Paternalism. "Seen as threat." Criminalized. Devalued by some. (Participant 28, 43-year-old white woman from Abbotsford)

Recommendations for Change

Participants' recommendations for improved work spaces focused on increasing equity and capacity building and a call for organizational restructuring that promoted equitable, feminist, and transparent practices and policies. Changes that addressed tokenization and devaluing of people who use(d) drugs and their experiences were of the utmost concern for participants. Equal pay for equal work was one the most recurrent recommendations, along with health benefits and resources that would support people with lived expertise who were working for substance use and harm reduction organizations.

Not only do organizations need to recognize the cost that people who use(d) drugs incur simply attempting to fulfill their work obligations, but factors that facilitate uncomfortable and exclusionary work environments must also be addressed. Addressing power imbalances was recommended as a solution to inequitable work environments, with some participants asking for "more leadership roles" for people who use(d) drugs and also for those systemically marginalized, such as Indigenous employees:

[We need] to make the system set up more available for peer support and aboriginal individuals to be able to be managers and our team leads and to be treated with respect and valued for their lived experience and to be viewed as just as important.

(Participant 44, 32-year-old Indigenous woman from Edmonton)

One 31-year-old man from Nanaimo usefully suggested that organizations,

... run on a model that lets everyone get a chance to facilitate, schedule, 'run the show,' so it can empower the peers who use [drugs] and show they are of value to the team as they are more than a connection to the streets.

Additionally, a 38-year-old Misipawitsik First Nations woman recommended that organizations pair coordinators with and without lived expertise of drug use together so that they could,

...work together with peers as equals learning and growing together. Why set up people for failure?

A few participants expressed the view that people with lived expertise of drug use should not be able to come to work under the influence. However, the majority of participants maintained that they should be allowed to use drugs openly without being stigmatized or discriminated against, and should also be allowed to use the services at their own organizations provided for people who use drugs (such as a safe injection room). Furthermore, an increase in community services was heavily advocated for by participants who recommended supports such as retractable needles, increased access to beds and detoxes, and increased hours for services. In particular, participants emphasized the need for increased support for those living on the streets:

More for the people out on the streets to strongly push for more help from others and ask people what they really want to do. Some people should be out there at all times where ever they are using. (Participant 34, 50-year-old Indigenous woman from Vancouver) Some participants, however, expressed frustration that services were often only accessible to those most destitute, those who were currently living on the streets, while there was an absence of preventative care. Further, a difficult concern expressed by participants was community level hostility towards employees with lived expertise of drug use, which could take the form of harassment and sometimes violence. They noted that some community members seemed to believe that people who use(d) drugs and worked in organizations or held positions on advisory boards felt that they were better than those who use(d) drugs and utilized the agencies' services. Participants themselves expressed confusion over their status, and whether they were still 'peers' if they were no longer actively using drugs. As previously stated, the term 'peer' itself was identified in the survey as an issue, and some participants suggested replacing the word with "experts."

Conclusion

Poverty and economic marginalization shape the lives of many people who use criminalized drugs, including those working in harm reduction services. Due to ongoing colonialism and the legacy of slavery for Indigenous and Black people who use criminalized drugs, racial profiling, discrimination, arrest, and imprisonment are heightened. Thus, Indigenous and Black people are overrepresented in Canadian provincial jails and federal prisons. Indigenous women and girls continue to be subject to gendered violence, as the inquiries on missing women and girls have made clear. Indigenous and Black families are also profiled by child protection services, and families are often torn apart. Due to the ongoing legacy of colonialism, Indigenous peoples and low income/rural communities in Canada have been disproportionately affected by the overdose crisis. For those people and communities most marginalized in Canada, the impact of structural violence, including punitive drug laws and policies, shapes daily life. As one participant stated:

I really feel beat down with the opioid crisis and also I get a little beat up and frustrated with the policies and laws.

(Participant 29, 43-year-old Métis man from Victoria)

In the face of social and legal discrimination, people with lived expertise of drug use who are working in harm reduction services remain dedicated to their work and the people they encounter, even within the context of stigmatizing workplaces, low pay, lack of benefits, little formal recognition, and despair in the face of the ongoing overdose death crisis. It is our hope that our national report will inform workplace policies for people with lived expertise of drug use working in harm reduction services.

Appendix

Question	Responses (n=50)	%
1. Age	50	100
2. Gender	50	100
3. Race or Ethnicity*	42	84
4. City or town you live in	49	98
5. How many hours do you work a week?	49	98
6. Organization you work for	44	88
7. What position do you currently hold (or have held) and what are your duties?	50	100
8. What benefits do you experience as a "peer" working in harm reduction?	50	100
9. What negatives do you experience as a "peer" working in harm reduction?	49	98
10. What recommendations or changes should be made in your organization to make "peer" work more equitable and/or safe?	47	94
11. How are you paid? (Check all that apply)	46	94
12. Check the issues that most impact your work as a peer. (Check as many as apply)	46	92
Average Response Rate		95.5

Table 4. Survey response rates

References

- 1. Dechman, M.K. (2015). Peer helpers' struggles to care for "others" who inject drugs. International Journal of Drug Policy, 26(5), 492–500.
- 2. Jurgens, R. (2008). Nothing about us without us. Toronto: Canadian HIV/AIDS Legal Network.
- 3. Canadian AIDS Society (2015). *Peerology: A guide by and for people who use drugs on how to get involved*. Ottawa, On.: Author. <u>http://www.cdnaids.ca/druguseandharmreduction</u>.
- 4. BC Coroners Service. Illicit drug overdose deaths in BC January 1, 2008 Dec. 31, 2018 [Internet]. Burnaby; 2019. Available from: <u>https://www2.gov.bc.ca/gov/content/life-events/death/coroners-service/statistical-reports</u>
- 5. Bardwell, G., Fleming, T., Collins, A.B., Boyd, J., & McNeil, R. (2018). Addressing intersecting housing and overdose crises in Vancouver, Canada: Opportunities and challenges from a tenant-Led overdose response intervention in single room occupancy hotels. *Journal of Urban Health*, 91(1): 12-20.
- 6. Goodman, A., Morgan, R. Kuehlke, R., Kastor, S., Fleming, K., & Boyd, J. (2018). "We've been researched to death": Exploring the research experiences of urban Indigenous Peoples in Vancouver, Canada. *The International Indigenous Policy Journal*, 9(2).
- 7. Damon, W., Callon, C., Wiebe, L., Small, W., Kerr, T., & McNeil, R. (2017). Community-based participatory research in a heavily researched inner city neighbourhood: Perspectives of people who use drugs on their experiences as peer researchers. *Social Science & Medicine*, 176, 85–92.
- 8. Hayashi, K., Wood, E., Wiebe, L., Qi, J., & Kerr, T. (2010). An external evaluation of a peer-run outreach-based syringe exchange in Vancouver, Canada. International Journal of Drug Policy, 21(5), 418–21.
- 9. Ti, L., Hayashi, K., Hattirat, S., Suwannawong, P., Kaplan, K., & Kerr, T. (2015). 'Drug users stick together': HIV testing in peer-based drop-in centres among people who inject drugs in Thailand. *Sexual Health*, 12(3), 263–8.
- 10. Greer, A.M., Luchenski, S.A., Amlani, A.A., Lacroix, K., Burmeister, C., & Buxton, J,A. (2016). Peer engagement in harm reduction strategies and services: A critical case study and evaluation framework from British Columbia, Canada. *BMC Public Health*, 16(1), 452.
- 11. Marshall, Z., Dechman, M.K., Minichiello, A., Alcock, L., & Harris, G.E. (2015). Peering into the literature: A systematic review of the roles of people who inject drugs in harm reduction initiatives. *Drug and Alcohol Dependence*, 151, 1–4.
- 12. Small, W., Wood, E., Tobin, D., Rikley, J., Lapushinsky, D., & Kerr, T. (2012). The injection support team: A peer-driven program to address unsafe injecting in a Canadian setting. *Subst. Use Misuse*, 47, 491–501, <u>http://dx.doi.org/10.3109/10826084.2012.644107</u>
- 13. Bardwell, G., Kerr, T., Boyd, J., & McNeil, R. (2018). Characterizing peer roles in an overdose crisis: Preferences for peer workers in overdose response programs in emergency shelters. *Drug and Alcohol Dependence*, 190, 6–8.
- 14. Boyd, J., & Boyd, S. (2014). Women's activism in a drug user union in the Downtown Eastside. *Contemporary Justice Review*, 17(3), 313–325.
- 15. Canadian HIV/AIDS Legal Network. (2015). "Nothing about us without us," Greater meaningful involvement of people who use illegal drugs: A public health, ethical, and human rights imperative. Retrieved September 15, 2015, from <u>http://www.aidslaw</u>
- 16. Dell, C., Lyons, T., Grantham, S., Kilty, J., Chase, W. (2014). Researching with respect: The contributions of feminist, Aboriginal and community-based research approaches to the development of our study of First Nations women's healing from problematic drug use. In R. Berman (Ed.). Corridor Talk: Canadian Feminist Scholars Share their Stories of Research Partnerships (Chapter 3). Toronto: Innana Publications and Education Inc.
- 17. Mooney-Somers, J., & Maher, L. (2009). The Indigenous resiliency project: A worked example of community-based participatory research. *New South Wales Public Health Bulletin*, 20(8), 112–8.
- 18. First Nations Health Authority (Aug. 3, 2017). Overdose data and First Nations in BC: Preliminary findings. Author. 1-13. Available from: <u>http://www.fnha.ca/newsContent/Documents/FNHA_Over-doseDataAndFirstNationsInBC_PreliminaryFindings_FinalWeb.pdf</u>