

Research & Practice Notes

Ensuring that people who use drugs are safely and equitably included at meetings and conferences

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Collaborating with people who use or used drugs (PWUD) in research and policy fora and incorporating their perspectives in decision-making processes is a crucial step towards mitigating drug policy-related harm. PWUD are experts in drug use and equipped to share their experiences and knowledge and impact drug policy change. However, equitable inclusion of PWUD in conferences and other fora is typically inadequate. PWUD were central participants in the planning and implementation of the Stimulus 2018: Drugs, Policy, and Practice conference. Conference planners made considerable effort to ensure PWUD attendees had their physical and emotional needs met, including access to overdose prevention services. However, guidance is needed to better safeguard the physical and mental health of conference attendees who use drugs. This Research & Practice Note aims to initiate discussion on this underexplored topic and provide ideas for the safer inclusion of PWUD within research and policy fora.

Background

Stigma, criminalization of drugs, and contamination of the illegal drug supply with novel synthetic opioids such as fentanyl and other analogues are significant drivers of opioid-related mortality (Donroe et al. 2018). Opioid-related drug poisonings in 2022 killed an estimated 81,806 people in the United States and 7,557 people in Canada (National Institute on Drug Abuse 2024, Public Health Agency of Canada 2024). In response, public health officials in both Canada and the United States have, to varying degrees, reduced barriers to medication treatment for opioid use disorder, facilitated the distribution of naloxone and overdose-reversal education, and expanded access to supervised consumption services (SCS) (Kerr 2019, Naeem et al. 2022). Unfortunately, these measures have been insufficient in scale to significantly reverse national mortality trends (National Institute on Drug Abuse 2024, Public Health Agency of Canada 2024).

To mitigate harm and prevent death, civil society actors have reasserted calls for drug policy development to be conducted through processes that balance scientific evidence with the knowledge and experiences of people who use or used drugs (PWUD) (Touesnard et al. 2021, AIDS United 2021, International Network of People who Use Drugs (INPUD) 2020). This is consistent with broader public health commitments to equity and the inclusion of those directly impacted by policy decisions (Camhaji et al. 2022, Ti et al. 2012). Sustained and equitable engagement of PWUD within public health and drug policy fora is necessary to engender mutual understanding and respect between policymakers and PWUD, enable PWUD to more actively participate in policy-making activities, and facilitate the development of interventions that reflect the needs, desires, and human rights of PWUD and avoid unintended consequences of bad policy (Camhaji et al. 2022, Ti et al. 2012). However, meaningful engagement of PWUD (i.e., shared decision making) and adequate accommodations for their safety remain inadequate in many public health and drug policy fora (INPUD 2021, Ti et al. 2012, Madden et al. 2021).

Historically, inter- and intranational fora for knowledge sharing about drug policy, such as commissions, conferences, and other meeting venues, have at times been exclusive or only nominally inclusive of PWUD (Byrne & Albert 2010, Efthimiou-Mordaunt 2015, INPUD 2020). Participation in such events typically necessitates significant social and financial capital (e.g., invitation to participate; travel funds; a lack of a criminal history for travel visa acquisition) and adherence to pre-planned agendas and specific cultural norms (e.g., formal clothing and language). These factors, along with fears of disclosure, systemic stigma (i.e., stigma embedded in laws and institutions of power), drug criminalization, and power imbalances can preclude PWUD from participating in vital knowledge dissemination and creation, as well as influencing policy decisions that have potential to impact their health and wellbeing (Pauly et al. 2014, Temenos 2016, Ti et al. 2012).

To ensure equitable representation, PWUD have been forced to self-organize and legitimate their presence within drug policy-related venues, explicate conditions for participation, and negotiate for influence over proceedings and outcomes (Touesnard et al. 2021, AIDS United 2021, INPUD 2020, Jurgens 2008). For example, in the early 1990s, the emergence of HIV/AIDS and increased rates of hepatitis C catalyzed PWUD to mobilize and attend international drug policy conferences and advocate for the establishment, legalization, and funding of harm reduction interventions such as needle and syringe programs (Jurgens 2008). In the 2000s, the International Network of People who Use Drugs (INPUD) formed, which builds the capacity of PWUD to work alongside policymakers and government officials and advocates for high-level and sustained partnerships between PWUD and policy actors (INPUD 2020). By 2016, due in part to the efforts by PWUD, the United Nations General Assembly had declared that PWUD should participate in drug policy formulation, implementation, and evaluation processes (Madden et al. 2021).

Although there is support for the participation of PWUD in policy fora, academic literature has neglected the potential physical or emotional harms PWUD may encounter when attending conferences or similar events and methods to mitigate these harms (Ti et al. 2012). PWUD who travel to a new location may be at increased risk of drug-related harm, including drug poisonings and death, due to social, financial, and mental health factors, a lack of familiarity with local drug markets, and a lack of access to harm reduction supports or medication treatment (Touesnard et al. 2021, Brooks et al. 2020). Past research with PWUD who work or volunteer in harm reduction or advocacy organizations has documented tokenism, stigma, and power imbalances; worsening of, or insufficient support for, physical and emotional health challenges; and inequities in financial compensation, job-related benefits, and skill development opportunities (Greer et al. 2020, INPUD 2020). The extent to which these harms are experienced by PWUD who plan, implement, or attend conferences is poorly understood. Nevertheless, specific efforts are required to protect against these potential harms when convening PWUD to participate in conferences or other policy fora.

The Stimulus 2018: Drugs, Policy and Practice in Canada drug policy and harm reduction conference collaborated with PWUD in conference planning to facilitate the participation of PWUD.

The authors of this Research & Practice Note include the primary planners of the conference and allied academics. The co-authors collaborated to describe the successes and challenges of the 2018 conference after conference planners received feedback from attendees indicating a need to spark further discussion on the safety and equity of PWUD at conferences.

Co-planning the Stimulus 2018 Conference With People Who Use drugs

The Stimulus 2018: Drugs, Policy and Practice in Canada conference was hosted from October 3-5, 2018, in Edmonton, Alberta, a city in western Canada, by Streetworks, an Edmonton-based harm reduction organization. Conference planning was led by MT and SJV, who have significant experience working in leadership positions at harm reduction organizations and had planned numerous similar conferences before. MT and SJV planned the conference with a conference planning committee, which comprised representatives from local, provincial, and national organizations of PWUD (e.g., Alberta Addicts Who Educate and Advocate Responsibly, Canadian Association of People Who Use Drugs (CAPUD)) and employees of various harm reduction and drug policy organizations.

To attempt to build trust and share power equitably, the conference planning committee met early and frequently and aimed to establish and maintain regularly scheduled monthly or weekly meetings. The committee democratically agreed on roles and responsibilities and adhered to the principle of ‘Nothing about us without us’, which conveys the belief that PWUD have valuable experience and knowledge and are positioned to identify and effect change (Jurgens 2008). Conference planners who use drugs were recognized as experts, held veto power, and were given scholarships to attend the conference in return for their time and expertise. Despite attempts by conference planning leaders to collaborate with PWUD in planning activities, some conference planners who use drugs were unable to consistently participate, perhaps due to competing priorities or living situations not easily conducive to tasks associated with conference planning (e.g., irregular work schedules).

Conference planners who use drugs helped select and approve plenary and session themes and mediums. Themes ranged from the role of PWUD in knowledge sharing and service implementation, harm reduction’s transition into the digital age, and the future of interventions such as heroin assisted treatment. One plenary session was autonomously hosted by CAPUD and focused on illegal drug decriminalization. Throughout the conference there was a particular focus on systemic racism and the experiences of Indigenous populations in Canada. Various presentation types were chosen (e.g., poster and oral; art installations; film festival) with the goal of stimulating interest and feedback from individuals from all backgrounds, including PWUD. Additionally, local, provincial, and national organizations of PWUD were provided exhibition booths to promote their message, and local Indigenous, street-involved crafters were able to display and sell their art.

Ensuring Equitable Participation of People Who Use Drugs

Registration, Travel, and Accommodation

Many PWUD are structurally vulnerable, meaning their ability to participate in policy fora can be inhibited by various overlapping socioecological constraints (e.g., lack of funding, criminalization) (Gehring et al. 2022). Thus, efforts were made to financially support and provide accommodations for these attendees. To increase attendance of PWUD, conference planners advertised through CAPUD's contact network, which primarily comprises PWUD. An estimated 25% of the approximately 800 Stimulus attendees identified as PWUD, of which, over 100 received scholarships to pay for travel (e.g., plane tickets, fuel for carpooling), conference registration, hotel, and a per diem (conference planners

who use drugs helped choose the amount of \$50 per day). Scholarship funding came from registration fees and donations from various governmental, business, and non-profit organizations. All scholarship recipients had per diems dispensed daily during which conference planners would check-in with recipients to ensure their wellbeing. Conference planners recognized this as potentially paternalistic but conference planners who use drugs endorsed this as a key strategy to help ensure attendees remained safe during the conference (Touesnard et al. 2021).

Travelling to the conference was challenging for some PWUD. Not every PWUD had government-issued identification, and some felt uncomfortable boarding an airplane. When feasible, local PWUD or harm reduction organizations organized carpools. Identification was not required for these attendees to participate in the conference or stay at the hotel. MT and SJV had hosted attendees of prior harm reduction conferences at this hotel and thus had a successful working relationship with hotel management. While registration and accommodations were encouraged to be booked in advance, some flexibility was required. A few PWUD did not register for the conference or a hotel room but arrived expressing a desire to participate. These individuals were registered for the conference for free. Conference planners had pre-reserved a block of rooms and those who arrived without reserving a hotel room were given a free hotel room or shared a room with others.

Establishing a Respectful and Safe Environment

Prior to the conference, hotel staff were provided harm reduction training (e.g., naloxone was kept at the hotel front desk); guidance on how to respectfully communicate with attendees; and tips on how to better ensure staff safety (e.g., how to avoid needlestick injuries with improperly discarded needles and syringes). People local to the area and with experience in providing harm reduction services volunteered to liaise between hotel staff and PWUD, when necessary, to ensure positive experiences for all attendees staying at the hotel. Additionally, conference planners briefed conference venue security guards on how to respectfully engage with anyone they encountered actively using drugs to reduce the risk of negative interactions.

Accommodating Drug Consumption

Important steps were taken to safeguard the physical safety of PWUD at the conference. An overdose prevention site (OPS) for the consumption of non-inhalation drugs was available within the conference centre to all conference attendees (Brooks et al. 2020). OPS are temporary spaces where PWUD can access drug consumption supplies, consume drugs, and be monitored by people trained to respond to drug poisonings (BC Centre for Disease Control 2019). In Canada, OPS require a formal exemption from the federal *Controlled Drugs and Substances Act* to legally operate. In 2018, the province of Alberta held delegated authority from the federal government to issue exemptions for the operation of temporary OPS. This provincial authority streamlined the application process, and expedited securing a temporary exemption (see Brooks et al. 2020 for more detail on the process). The OPS was located on the primary floor of the conference space, in a separate room with a large curtain obscuring the view, and was staffed by volunteer conference attendees, some of whom identified as PWUD. According to anecdotal data gathered by OPS staff through voluntary comment sheets, a few attendees felt slightly uncomfortable with the large size and proximity of the OPS to the main conference hall and mentioned how some OPS staff appeared to lack experience working in drug poisoning prevention.

To accommodate drug consumption outside of the conference hours, certain hotel rooms were identified as spaces where attendees could consume non-inhalation drugs and access drug consumption supplies and naloxone kits. Volunteers offered to observe attendees and intervene if a medical crisis occurred. Additionally, recognizing that drug type, strength, and price can vary significantly (Kerr 2019), local PWUD created a pamphlet with information about the local illegal drug market, clear warnings about the strength of fentanyl within the local drug supply, and information on reducing the risk of drug

poisoning and other negative health outcomes. The pamphlet was distributed at the conference space and hotel. Checks of the washrooms and outside spaces were also conducted to ensure the safety of attendees who may have decided to use drugs outside the venue or hotel. Participants who inhaled drugs were encouraged to smoke outdoors and bring someone with them. Attendees took advantage of various other services at the conference, including drug testing, drug consumption supplies, naloxone kits, and drug poisoning response training. Conference planners informed attendees of other SCS in the area and partnered with a local medical clinic to coordinate the dispensing of opioid agonist medications and other prescriptions, as required. If an attendee needed further support, they were provided referrals to local health and social services. No drug poisonings occurred at the conference OPS, and none were reported to conference planners to have occurred elsewhere.

Mitigating Emotional Distress

Conference organizers were also cognizant of the emotional distress attendees may experience during the conference. Many of the sessions focused on drug poisoning deaths, which is a painful topic for many. As such, psychosocial supports were available, including supportive listening volunteers, an Indigenous Welcoming Room which offered traditional smudging and food, and interactive art installations through which attendees could honour those lost to the War on Drugs. Ancillary events provided opportunities for PWUD to meet and support one another. Free hug volunteers provided an opportunity for consenting attendees to receive and provide human touch, which was a unique opportunity for physical connection and emotional reassurance.

Lastly, experience from previous conferences indicated that attendees sometimes report ‘conference drop’ (i.e., development or an exacerbation of emotional distress once the event has ended and conference friends and supports are no longer available). Conferences are brief but intense events, and participants can experience a range of emotions from joy to despair. Members of the conference planning committee encouraged attendees to emotionally support each other via phone calls or online and offered to connect attendees to mental health supports post-conference. Despite concerted efforts by conference planners, a few attendees expressed to conference planners that they had experienced some emotional distress during and after the conference, thus these support services may not have been sufficient.

Recommendations for Future Conference Planning and Research

Increasingly, drug policy conferences and other related fora are expected to collaborate with PWUD in planning activities and proceedings. However, dominant drug policy actors have insufficiently incorporated PWUD in policy making procedures (Madden et al. 2021, INPUD 2021). It is hoped that the practices described herein aid in demonstrating that the safe and respectful inclusion of PWUD in policy fora is feasible.

Conference planners who aim to collaborate with PWUD in the conference planning process should consider starting conference planning early, convening often, and hiring PWUD as paid staff (rather than only providing scholarships). Consideration regarding the method and timing of payments to PWUD may be necessary to accommodate PWUD who, for example, are at risk of losing social benefits that have income limits (e.g., income assistance) (Greer et al. 2020). Taking these steps will hopefully allow some conference planners who use drugs to better dedicate their time and effort to the conference planning and implementation process. Additionally, conference planners ought to build strong ties with drug user groups to facilitate per diem applications, and housing and travel scholarships and reservations prior to the conference.

Conference planners who are committed to providing harm reduction services (e.g., drug consumption supplies, SCS, dispensing of opioid agonist medications) must first consider regulatory and legal barriers. Conference planners may struggle to navigate the provision of services of which their legality is unclear or contested. Additionally, organizers may encounter challenges in balancing the safety, wellbeing, and desires of all attendees, including those who do not use drugs and those who used in the past and want to remain abstinent. This could be accomplished by clearly communicating a few times to all attendees how to access harm reduction services, yet ensure these services are less conspicuous.

Conference planners should aim to organize activities and events during and after the conference for all attendees to participate in, but explicitly encourage PWUD to participate. Additionally, conference planners could ensure awareness of, and access to counselling services (both formal and informal, during and after the conference, on-and off-site). These steps may facilitate friendships and support networks and foster PWUD to continue to attend conferences and participate in policy-making fora.

Empirical research and comprehensive evaluations are needed to identify how to effectively collaborate with PWUD in planning activities and how to ensure their safe and meaningful inclusion during conferences. Importantly, researchers should also elicit the perspectives of attendees who do not use drugs, as well as hotel and conference venue security and other staff members, to attempt to ensure the needs of all conference planners and attendees are met.

Stimulus benefited from a national policy environment conducive to offering OPS and other harm reduction services in novel settings. Considerable thought is needed on how to ensure the safety of PWUD who attend international conferences, which may be more challenging due to barriers accessing travel documents and risks associated with transporting drugs across borders or purchasing and/or using them while abroad. In some cases, it may be appropriate to rule out locations where the local drug supply is highly volatile and robust harm reduction supports are unavailable. Additionally, PWUD who live in countries unsupportive of harm reduction, or those who attend conferences that are less amenable or even antagonistic towards harm reduction and the inclusion of PWUD, may face unique challenges ensuring their inclusion and physical safety.

Conclusion

Stimulus conference organizers made considerable effort to collaborate with PWUD in conference planning and to ensure PWUD attending the conference had their physical and emotional needs met. While organizers received positive feedback from PWUD, conference planners experienced challenges. Empirical research and formal guidance are needed to facilitate the meaningful inclusion of PWUD while ensuring their physical and mental well-being.

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Conflicts of interest

SJV was compensated for organizing the Stimulus conference. The other authors declare that they have no competing interests.

References

- AIDS United. (2021) *Meaningful Involvement of People Who Use Drugs*. AIDS United. <https://aidsunited.org/meaningful-involvement-of-people-who-use-drugs/>
- BC Centre for Disease Control. (2019) *Harm Reduction Services—Recommendations for overdose prevention at meetings and events—2019*. BC Centre for Disease Control. <https://towardtheheart.com/assets/uploads/1551725576tKX5ZUMIWc6Dw6HiFHYbnmw5wDxYxSNVzkgZArT.pdf>
- Brooks, H. L., Husband, C., Taylor, M., Sherren, A., & Hyshka, E. (2020) Supporting the full participation of people who use drugs in policy fora: Provision of a temporary, conference-based overdose prevention site. *International Journal of Drug Policy*, 84(102878), 1–5. <https://doi.org/10.1016/j.drugpo.2020.102878>
- Byrne, J., & Albert, E. R. (2010) Coexisting or conjoined: The growth of the international drug users' movement through participation with International Harm Reduction Association Conferences. *International Journal of Drug Policy*, 21(2), 110–111. <https://doi.org/10.1016/j.drugpo.2009.10.009>
- Camhaji, A., Racotta, M., Martín-del-Campo, R., & Franco, J. (2022) Toward a New Drug Policy Agreement. In S.L. Cruz (Ed.), *Opioids: Pharmacology, Abuse, and Addiction* (pp. 59-86). Springer International Publishing. https://doi.org/10.1007/978-3-031-09936-6_4
- Donroe, J. H., Socias, M. E., & Marshall, B. D. L. (2018) The deepening opioid crisis in North America: Historical context and current solutions. *Current Addiction Reports*, 5(4), 454–463. <https://doi.org/10.1007/s40429-018-0228-5>
- Efthimiou-Mordaunt, A. (2015) Junkies in the House of the Lord. *Substance Use & Misuse*, 50(8–9). <https://doi.org/10.3109/10826084.2015.1017336>
- Gehring, N.D., Speed, K.A., Wild, T.C., Pauly, B., Salvaggio, G., & Hyshka, E. (2022) Policy actor views on structural vulnerability in harm reduction and policymaking for illegal drugs: A qualitative study. *International Journal of Drug Policy*, 108, 103805. <https://doi.org/10.1016/j.drugpo.2022.103805>
- Greer, A., Bungay, V., Pauly, B., & Buxton, J. (2020) 'Peer' work as precarious: A qualitative study of work conditions and experiences of people who use drugs engaged in harm reduction work. *International Journal of Drug Policy*, 85, 102922. <https://doi.org/10.1016/j.drugpo.2020.102922>
- International Network of People who Use Drugs (INPUD). (2020) *Taking back what's ours! A documented history of the movement of people who use drugs*. INPUD Secretariat. <https://inpud.net/taking-back-whats-ours-an-oral-history-of-the-movement-of-people-who-use-drugs/>
- International Network of People Who Use Drugs (INPUD). (2021) *The fight for accountability: The right to rights*. INPUD. <https://inpud.net/the-fight-for-accountability-opportunities-to-engage-in-human-rights-advocacy-for-inpud/>

- Jurgens, R. (2008) "Nothing about us without us" - Greater, meaningful involvement of people who use illegal drugs: A public health, ethical, and human rights imperative. International edition. Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute. <https://www.opensocietyfoundations.org/uploads/b99c406f-5e45-4474-9343-365e548daade/nothing-about-us-without-us-report-20080501.pdf>
- Kerr, T. (2019) Public health responses to the opioid crisis in North America. *Journal of Epidemiology and Community Health*, 73(5), 377–378. <https://doi.org/10.1136/jech-2018-210599>
- Madden, A., Lancaster, K., Ritter, A., & Treloar, C. (2021) Making legitimacy: Drug user representation in United Nations drug policy settings. *International Journal of Drug Policy*, 87, 103014. <https://doi.org/10.1016/j.drugpo.2020.103014>
- Naeem, A. H., Davis, C. S., & Samuels, E. A. (2022) The importance of federal action supporting overdose-prevention centers. *New England Journal of Medicine*, 386(21), 1965–1967. <https://doi.org/10.1056/NEJMp2119764>
- National Institute on Drug Abuse. (2024) *Drug overdose death rates*. May 2024. <https://nida.nih.gov/research-topics/trends-statistics/overdose-death-rates>
- Pauly, B., Belle-Isle, L., Cater, J., Willson, M., & Mollison, A. (2014) *Collective voices effecting change: National meeting of peer-run organizations of people who use drugs—Victoria BC, Oct 16/17, 2013*. Canadian Association of People Who Use Drugs (CAPUD). https://solidvictoria.org/wp-content/uploads/2021/02/CAPUD_Collective_Voices_Effecting_Change_National_Report-english.pdf
- Public Health Agency of Canada - Federal, provincial, and territorial Special Advisory Committee on the Epidemic of Opioid Overdoses. (2024) *Opioid- and stimulant-related harms in Canada*. Ottawa: Public Health Agency of Canada. <https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants/>
- Temenos, C. (2016) Mobilizing drug policy activism: Conferences, convergence spaces and ephemeral fixtures in social movement mobilization. *Space Polity*, 20(1), 124–141. <https://doi.org/10.1080/13562576.2015.1072913>
- Ti, L., Tzemis, D., & Buxton, J. A. (2012) Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse Treatment, Prevention, and Policy*, 7(47). <https://doi.org/10.1186/1747-597X-7-47>
- Touesnard, N., Patten, S., McCrindle, J., Nurse, M., Vanderschaeghe, S., Noel, W., ... & Blanchet-Gagnon, M-A. (2021) *Hear us, see us, respect us: Respecting the expertise of people who use drugs*. Canadian Drug Policy Coalition and Canadian Association of People Who Use Drugs. <https://zenodo.org/records/5514066>