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Hospital Care: Experiences of People Who Use Drugs

**What we heard at the town hall meeting on experiences
of people who use drugs accessing hospital care**



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The Ontario Drug Policy Research Network

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Background

The Ontario Drug Policy Research Network (ODPRN) launched an initiative in 2022 to create a platform for meaningful conversations between citizens of Ontario to discuss drug policy topics of interest. This initiative is being led by the [ODPRN Citizens' Panel](#), a group of volunteer Ontarians who have collectively come together to ensure that the ODPRN appropriately identifies issues of importance to the public, and incorporates these priorities into all aspects of our research.

This ODPRN town hall was focused on the experiences of people who use drugs when accessing hospital care, and took place in November 2023 as part of a series of town halls on various topics related to drug policy in Ontario. The topics of the previous town halls include [attention deficit hyperactivity disorder \(ADHD\) into adulthood](#) and [experiences accessing treatment and services for depression](#). These topics were chosen based on a province-wide survey ODPRN conducted in late 2021 on what medication topics matter most to Ontarians as well as priorities identified by the ODPRN Citizens' Panel, Stakeholder Advisory Panel and the Ontario Opioid Drug Observatory Lived Experience Advisory Group (LEAG).

People who use drugs are more likely to present to emergency departments (ED) or access hospital care, an Ontario study reported that people who use drugs access ED and hospital services seven to eight times more frequently compared to those who do not.¹ Despite this, many people report facing various barriers when accessing and receiving healthcare including: healthcare provider stigma and discrimination, inadequate pain management and organizational factors including requirements for abstinence.² These barriers may negatively impact quality and access to care and patient outcomes with people who use drugs being more reluctant to access hospital care³ and more likely to self-discharge.^{4,5} Furthermore, the intersection between race, ethnicity, gender, socioeconomic status, and substance use can influence experiences of discrimination within the healthcare system, exacerbating barriers for people accessing hospital care.^{5,6}

Understanding the lived experiences of people who use drugs and their families in accessing hospital care are vital in identifying opportunities to change and improve the hospital healthcare system. Specifically, identifying barriers to care, and understanding what can be done to provide trauma-informed and accessible care in a safe environment is important to improve future quality of care.

In total, 88 people attended this town hall. Seven individuals shared their own personal stories, while many other attendees contributed to the discussion and asked questions through the virtual chat room. Tara Gomes and Zoë Dodd facilitated the discussion throughout the meeting and made introductory remarks before inviting speakers to share their personal experiences. To help ensure a safe space for all participants, two trained counsellors (specializing in the areas of trauma, substance use, and harm reduction) were available virtually for anyone requiring additional confidential support during and after the meeting.

The ODPRN would like to thank all of the attendees who courageously and honestly shared their stories in this forum given the recognized challenges and the risks of experiencing further discrimination or marginalization, when publicly discussing their personal experiences.

Hear from the participants



Listen to the individuals who shared their experiences during the Town Hall <https://odprn.ca/town-halls/pwud-hospital-experiences/>

Objective

The objective of this town hall and of this accompanying report is to identify gaps and opportunities for improvement in the healthcare system that can be used by researchers, healthcare providers, and policymakers to help enhance the experiences and health outcomes of people who use drugs when accessing hospital-based care.

Recommendations

The following recommendations were developed by summarizing the collective experiences of participants shared during the town hall with the goal of optimizing care for people who use drugs in a hospital environment.

Reducing stigma and discrimination and the impact of prior hospital experiences

Hospitals are a critical touchpoint for people who use drugs.⁸ Yet, stigmatizing and discriminatory attitudes from healthcare professionals can lead to poor communication and a risk of overlooking the health concerns of people who use drugs resulting in delayed identification and diagnosis of health issues.^{9, 10} During this meeting, attendees shared examples of stigma discrimination they personally experienced in hospitals including the timeliness of care (e.g. increased waiting times), health concerns not being taken seriously, and inaccurate information or assumptions recorded in medical charts. In particular, we heard of many instances of delayed diagnosis and treatment for infective endocarditis (an infection of the innermost lining of the heart),¹¹ which sometimes led to serious subsequent medical events. It was felt by people who use drugs that they were treated differently by hospital staff and clinicians who they encountered including changes in body language and attitudes, and that treatment was influenced by their previous medical history related to their substance use. Some participants recounted that these misconceptions continued after they stopped using drugs, as medical records will contain details on care provided in previous years.

Discriminatory and stigmatizing healthcare experiences like these may lead to avoidance of healthcare by people currently or with a history of using substances.¹² This was raised several times during the town hall, with participants describing the negative impact of previous encounters on their decisions to access subsequent care for themselves or family members, with many people reluctant to attend hospitals, even when experiencing serious medical events. Going forward, it was suggested that all hospital staff (including non-medical staff) be required to complete training and education in trauma-informed care, substance use and harm reduction, and on how to create stigma-free environments for people who use drugs to help improve their experiences and enable them to feel that they are in a supportive and non-judgmental space.^{13, 14} Furthermore, the need for a culture-shift in hospitals was identified including the implementation of hospital policies to increase staff accountability, in an effort to prevent stigmatizing behaviors that negatively impact patients. It was also suggested that medical information that is documented in patients' charts should be more readily accessible and that there should be streamlined avenues for adapting, removing, or changing information in medical charts that is incorrect, outdated and/or stigmatizing.

Ensuring adequate pain control and prescriber education

The literature describes that people who use drugs may be at a higher risk of being undertreated for acute pain leading to suboptimal medical care.^{14, 15} Furthermore, due to opioid tolerance, they may also require a higher dose of opioid analgesics compared to opioid-naive patients to manage their pain.¹⁶ We heard of many experiences related to pain management during the town hall, with several examples of people feeling that they did not receive adequate pain relief following medical procedures and that their concerns were not appropriately listened

to by healthcare professionals. Furthermore, participants described that their risk of returning to substance use due to untreated or under-treated pain also increased when their pain management needs weren't adequately addressed, as they would turn to non-pharmaceutical opioids as an alternative to help treat their pain.

Acute pain can be managed effectively in people who use drugs and treatment should provide adequate analgesia and avoid triggering a recurrence of substance use.^{16, 17} There is some hesitancy described in the literature among clinicians when prescribing opioids to manage pain in people with a history of opioid use disorder. Some literature suggests that this can be influenced by beliefs of physicians that patients may be 'drug-seeking'¹⁶ and possible fears of appropriate dosing, potential opioid-induced side effects, and lack of training to appropriately manage pain (e.g. knowledge of possible interactions with medications). We heard of experiences from participants in which significant pain they experienced following surgical procedures was not believed by healthcare professionals and their pain remained undertreated. Additionally, people who were receiving safer supply prior to admission received stigmatizing comments related to their dosage in the hospital. Prescriber education and clear guidance focusing on the safe prescribing of opioids to manage pain among people who use drugs, and in particular for those receiving opioid agonist therapy (OAT) and safer supply could help provide more individualized care plans to safely manage a patient's pain. A more collaborative approach and open discussions between healthcare providers and patients would also benefit the quality of care received.

Improving maternal care and family supports

While stigma experienced by people who use drugs presents various barriers in accessing healthcare, these can be even greater among parents and may further delay their access to health and social care.^{18, 19} Attendees described multiple instances in hospital care as pregnant or nursing parents where they faced many obstacles. Breastfeeding while receiving maintenance methadone as opioid agonist treatment is considered safe^{20, 21} however, we heard about the lack of supports many parents experienced. Examples include parents discouraged from initiating nursing, expressed breastmilk discarded in the hospital and breastfeeding problems attributed to parent's methadone use. Given the health benefits of breastfeeding, providing clinicians and nurses with up-to-date training on breastfeeding and OAT use, could help eliminate these barriers experienced by parents in the future. Participants also described instances in which they received incorrect methadone doses in the hospital, with some healthcare professionals unsure of dosing during pregnancy or breastfeeding. Providing additional education to healthcare staff on the use of opioid agonist treatments such as methadone in pregnancy and breastfeeding, could also help reduce stigma related to its use in a hospital setting.

Parents felt that they were treated differently from other new parents at the hospital and described the fear of being reported to Child Protective Services due to hospital policies or being separated from their newborn; with some babies separated from their parents directly after birth with no communication. As a result, a suggestion for improvement was preventing the separation of new parents from their newborns to help empower parents in their hospital experience and ability to parent safely and bond with their baby. Rooming-in programs would enable parents to stay with their children after birth in hospital, with many benefits highlighted in prior studies including shortened hospital stays and a decreased need for pharmacotherapy.²² Attendees described how the experience of being a first time parent was overshadowed by feelings of anxiety, feeling judged by staff and being asked inappropriate questions during their stay, with some falsely accused of consuming substances while pregnant. Consequently, after negative in-patient hospital experiences, many new parents feared or delayed asking for help in the postnatal period, particularly related to treatment for substance use with concern of being separated from their family.

Going forward, given the widespread and common challenges experienced by pregnant and parenting people who participated in this town hall, there is an urgent need to prioritize the creation and expansion of hospital programs that offer supportive, stigma-free care for parents who use substances and their newborns. More

transparent communication between multidisciplinary teams and parents in the hospital, such as flagging to new parents any potential visits from social workers or child protection services, was also suggested as this could help relieve the fear of unplanned visits and enable parents to prepare for them by explaining the processes involved. Given the many challenges described by families in reuniting with their children (e.g. refused access or denied information), supporting parents and families in this process is vital for the future. Finally, improving the availability of childcare services for parents who may want to attend hospital appointments or additional substance-related supports could also help alleviate stress for parents.

Updating hospital policies and providing peer support

Structural stigma in healthcare occurs when policies and practices produce inequitable access to health care for people who use drugs.¹⁰ We heard experiences in which people were initially refused access to essential health care in emergency departments due to previous trespass orders from the hospital. Instances like these could lead to people having to drive to an alternative hospital or care facility, particularly in the absence of family members or other community supports who are able to advocate them. Furthermore, we heard that when people enquired about hospital policies relating to the treatment and the care people who use drugs receive, they were informed there were none. Without clear and consistent hospital policies, health care workers are more likely to employ their own personal beliefs when treating people who use drugs, which may be rooted in stigma.¹⁷ Therefore, hospital policies need to be reviewed and updated to ensure that they appropriately describe the expectations for hospital staff and healthcare providers by implementing non-stigmatizing and equitable approaches to care. This may include details on the response and role of security, with some attendees describing negative experiences when interacting with security staff resulting in them feeling disempowered and anxious during their hospital stay.

Participants also mentioned that they were unsure of their own rights in a hospital environment, such as how to access information from their medical charts or what additional supports were available to them. It was suggested that many people who use drugs will bring friends or family with them to the hospital to help advocate on their behalf, and that the availability of peer support workers or mentors in a hospital environment could act as a 'positive point of contact' to help increase people's feelings of safety, encourage patient autonomy, and reduce staff stigma.²³ Integration of accessible peer support workers throughout the hospital system could also help people advocate for and communicate their needs to hospital healthcare providers and other staff throughout their stay. However, peer support workers during the town hall shared their own experiences of being dismissed in hospitals and feeling judged when advocating for patients. Accordingly, peer support workers need to be considered as part of the healthcare system. It was also suggested that people with lived experience could play a vital role in the training and education of hospital staff, healthcare providers, and new trainees by sharing their perspectives and recommendations with a collective goal of providing trauma-informed, destigmatizing care. Broadly, to support future improvements in the care received by people who use drugs in hospitals, additional resources are urgently needed to integrate and address the recommendations made throughout the town hall.

About the ODPRN

The Ontario Drug Policy Research Network (ODPRN) was established in 2008 in an effort to ensure that drug policy decision-makers had high-quality evidence in a timely manner to advance evidence-informed drug policy and decision-making in Ontario. The ODPRN also leads the Ontario Opioid Drug Observatory, which brings together knowledge users, researchers and data to inform and evaluate opioid policy across Ontario. This innovative drug policy research program bridges a network of scientific thought leaders with drug policy decision-makers to meet a goal of improving the health status of Ontarians by also integrating the perspectives and experiences of people with lived and living experience.

For more information, visit odprn.ca.

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