Panel Summary

Preventing and Managing Infectious Diseases Among People who Inject Drugs in Ontario

8 February 2019

McMaster University | HEALTH FORUM

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McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

On the 8th of February 2019, the McMaster Health Forum convened a citizen panel on preventing and managing infectious diseases among people who inject drugs in Ontario. This summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

Panellists focused the deliberation about the problem on two sets of challenges. The first related to the structural factors that drive the challenges in providing effective prevention, treatment and management of infectious disease. These included: 1) the broad range of complex and inter-related factors that contribute to addiction and the risks associated with injecting drugs; and 2) enduring stigma within health and social systems and in society related to drug use which creates barriers to accessing needed supports for addiction and for infectious diseases. The second set focused on specific challenges related to the prevention, treatment and management of infectious diseases, including: 1) services and supports have not been designed with the needs of those who inject drugs in mind; and 2) services are not standardized across the province and peers are not consistently engaged in the design and delivery of services.

After discussing the challenges, panellists reflected on three elements of a potentially comprehensive approach for preventing and managing infectious diseases among people who inject drugs in Ontario. An important theme from the citizen panel that spanned all of the deliberations about the elements was the need to prioritize the engagement of peers in all approaches in order to leverage the trust that they are uniquely posed to build with people who inject drugs. Other suggestions from panellists for approaches to prevent and manage infectious diseases include: developing targeted educational materials and public campaigns to reduce public stigma; improving access to community-based care by providing outreach and mobile services as well as enhancing navigation supports; and improving the coordination of specialty and community care through the implementation of transition services such as wellness checks or transitional housing.

In relation to potential barriers and facilitators to moving forward, panellists focused on the enduring stigma towards those who inject drugs and a lack of political will as key barriers. For facilitators, panellists emphasized the need to take advantage of opportunities to engage a more diverse array of stakeholders in efforts to address the issue, noting that this could help broaden discussions and challenge pre-conceived notions and entrenched biases.

"If you go in [to hospitals] and have a history of drug use, you are treated like a second-class citizen"

Discussing the problem: What are the most important challenges to preventing, treating and managing infectious diseases among people who inject drugs?

During the deliberation about the problem, panellists agreed with many of the points raised in the citizen brief about what is driving the problem. In deliberating about the problem based on their lived experiences they focused on two sets of challenges.

The first related to the structural factors that drive the challenges in providing effective prevention, treatment and management of infectious diseases. These included:

- the broad range of complex and inter-related factors that contribute to addiction and the risk associated with injecting drugs; and
- enduring stigma within health and social systems and in society related to drug use which creates barriers to accessing needed supports for addiction and for infectious disease.

The second set focused on specific challenges related to the prevention, treatment and management of infectious diseases. These included:

- services and supports have not been designed with the needs of those who inject drugs in mind;
- services are not standardized across the province; and
- peers are not consistently engaged in the design and delivery of services.

We review each of these challenges in turn below.

A broad range of complex and inter-related driving factors contribute to addiction and risks associated with injecting drugs

Panellists identified both structural and programmatic factors that contribute to addiction. For structural factors, many panellists pointed to the underlying factors that drive addiction, such as trauma, mental health issues and physical pain, along with social determinants of health such as housing. In particular, many panellists noted that when these factors are combined they create extremely difficult circumstances.

All panellists also described the lack of programs and supports that are available to address these underlying factors. Key examples provided included lack of private insurance to cover dental care (which can result in people experiencing

Box 1: Key features of the citizen panel

The citizen panel about preventing and managing infectious diseases among people who inject drugs in Ontario had the following 11 features:

1. it addressed a high-priority issue in Ontario;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three options for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

more pain) and needed pharmaceutical treatments or addictions treatments. In speaking to this type of challenge, one panellist stated that "when you are living on the street, accessing dental care is really difficult … and if you have serious problems with your teeth you are just looking for something to take the pain away."

In addition, some panellists noted that even when programs or supports were available, they were not always attuned to an individual's unique circumstances. For example, participants identified the need for programming to be flexible based on an individual's evolving needs. This included the need to provide harm-reduction services for those people who are not yet willing or able to stop using drugs, and ensuring there are sufficient addiction treatment options for those who are willing and ready to stop using.

Enduring stigma within health and social systems and in society related to drug use creates barriers to accessing needed supports for addiction and for infectious diseases

All panellists felt strongly that stigma was a significant barrier to accessing needed health and social services. For example, many stated that they receive worse care from health professionals as someone who injects drugs than other members of the public. In addition, many panellists described how stigma associated with injection drug use has resulted in them being labelled as an addict, which leads to health professionals assuming that they were displaying "drug-seeking behaviour" when seeking care for important health needs. One panellist noted that this challenge was compounded by living in a rural area where they were more likely to be seen and recognized by the same health professionals who would make it difficult to access care when they need it. Many panellists described how stigma was not limited to interactions with health professionals, but transcended their experience interacting with service providers across social services as well.

Finally, panellists described how enduring stigma from the public limited the development and implementation of programs and policies needed to strengthen health and social care for people who inject drugs. Panellists stressed that negative stereotypes held by the public limit the extent to which individuals who make funding decisions will be likely to prioritize the development of needed programs and policies. One panellist expressed that these negative perceptions feel arbitrary given the many other substances that are broadly accepted in society (e.g., alcohol and caffeine) and for which individuals are not punished for their use.

Services and supports have not been designed with the needs of those who inject drugs in mind

Throughout the deliberations on the problem, panellists consistently returned to the point of how services and supports have generally not been designed with the needs of people who inject drugs in mind. This includes when services are available, where they are provided, and unique considerations of those who use drugs that should be included in the design of supports and services. With regards to when services are available, one panellist noted that many harm-reduction and community-based services operated from nine-to-five, but that those who inject drugs require services or support beyond "business hours." As a result, people who inject drugs end up either delaying or not seeking care, or visiting the emergency room.

Many panellists also emphasized challenges about where services and supports were located. Panellists generally supported existing mobile efforts, such as needle-exchange programs and mobile overdose-prevention vans, which are available in some communities to take individuals overdosing to the hospital. In addition, several noted that the existence of single sites in large communities (either large in population or in geographic area) was problematic. In particular, they emphasized that those who inject drugs will often move around to different "hot spots" and may have difficulty travelling to a particular site, potentially reducing the effectiveness of the services.

Services are not standardized across the province

In deliberating about the problem and describing the services available in each of their communities, several panellists expressed frustration about the lack of standardization across the province in terms of what services are available or how they have been implemented. For example, some panellists spoke about the establishment of safe injection/consumption sites and their coordination with other types of care such as community health centres. While this was seen as a good model, some noted that these types of resources and linkages had not been established across the province. Two panellists suggested that a key reason for this is the different amount of resources invested in communities across the province. Building on this, some panellists remarked that services were significantly underfunded compared to the magnitude of the problem.

Similarly, another panellist described how the lack of standardization may also stem from the significant differences in types of drugs consumed across the province and in the risks that occur from these substances. For example, some participants described how methamphetamine had only recently become a significant issue in Hamilton.

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- **How many participants?**
  11
- **Where were they from?**
  Champlain; Erie St. Clair; Hamilton Niagara Haldimand Brant; North West; and Toronto Central LHINs
- **How old were they?**
  18-24 (0), 25-44 (4), 45-64 (3), 65 and older (2), not reported (2)
- **Were they men, or women?**
  men (5) and women (6)
- **What was the educational level of participants?**
  22% completed elementary school, 11% completed high school, 11% completed community college, 11% completed technical school and 22% completed a bachelor's degree/post-graduate training or professional degree
- **What was the work status of participants?**
  33% self-employed, 44% working part-time, 11% disabled, and 11% retired
- **What was the income level of participants?** 11% earned less than $20,000, 0% between $20,000 and $40,000, 44% between $40,000 and $60,000, 0% between $60,000 and $80,000, 11% more than $80,000, and 33% preferred not to answer,
- **How were they recruited?** Recruited either randomly through Asking Canadians or were referred to us from members of our steering committee or key informants.

Peers are not consistently engaged in the design and delivery of services

All panellists strongly agreed that peers were not sufficiently engaged in the design and delivery of services. Many panellists questioned why peers were not more actively engaged at all levels of care. In particular, some noted that engagement of peers in acute care such as in hospitals could help to reduce some of the barriers that people who inject drugs experience when seeking specialized care. A few panellists emphasized that the inclusion of peers in their care helped to reduce their fear of health professionals. They also noted that peers could signal to other individuals who use drugs the services and professionals that could be trusted to provide non-judgmental care. Further, two panellists, who were working as peers, described how their inclusion as workers at harm-reduction services allowed them to provide advice to individuals about their injection practices that would reduce the risk of infection. This included the need to ensure that syringes as well as other injection equipment are sterile, and providing information about safe practices for preparing and cooking drugs prior to injection.

In hearing the experience of those who were either actively engaged as peers or had received care from teams of professionals that included peer workers, other panellists questioned why they were not more routinely engaged in care processes or the design of services. In particular, two participants who were peer-support workers expressed frustration about not being engaged in steering committees that design and implement services in the community, and are instead limited to a narrow service-delivery role. Both individuals described that allowing individuals with lived experience to participate in decision-making processes could help to bring forward the unique considerations of the population and further tailor services to improve their effectiveness.

"Providers need to be as diverse and open-minded as the people they treat"

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three approach elements (among many) for preventing and managing infectious disease among people who inject drugs:

1) strengthen efforts to prevent infectious diseases among those who inject drugs;
2) enhance the infection-management capacity of community points of contact for people who inject drugs; and
3) strengthen patient-centred care in specialty/acute-care settings.

The three approach elements can be pursued together or in sequence. A description of these options, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event.

An important theme from the citizen panel that spanned all of the deliberations about the elements was the need to prioritize the engagement of peers in all approaches to address the challenges. Panellists specifically emphasized peers as being critical to any policy and programmatic action because of the trust that they are uniquely poised to build with people who inject drugs. Given the pervasive stigma associated with injection drug use, panellists viewed this ability to build trust and rapport as being essential to help engage and retain

people in the care they need, especially in settings (e.g., hospitals) where there are often many challenges in doing so. Moreover, several participants also emphasized the importance of peers not only being engaged in care and service delivery, but also in processes to develop and implement policies and programs. We provide additional specific examples related to peer engagement in the summary of each of the elements below.

Element 1 – Strengthen efforts to prevent infectious diseases among those who inject drugs

The discussion about the first element focused on strategies to strengthen efforts to prevent infectious diseases among those who inject drugs. As outlined in the citizen brief, this could include:

- enhancing efforts that:
  - prevent or reduce injection drug use (for example, efforts to better connect people to social supports such as housing that are important to address underlying drivers of substance use), and
  - reduce the risk of infectious diseases among people who inject drugs (for example, using harm-reduction initiatives such as needle-exchange programs, supervised consumption/injection sites, opioid substitution); and
- investing in education efforts among people who inject drugs to focus on:
  - understanding their risk for infectious diseases,
  - how to minimize the risk of infection and any resources that may be available to support risk reduction,
  - what early symptoms of infectious diseases to look for and the consequences of delayed treatment, and
  - what services for reducing risk and treatment are available and where they can be accessed.

Box 3: Key messages about strengthening efforts to prevent infectious diseases among those who inject drugs (element 1)

Three values-related themes emerged during the discussion about element 1:

- Empowerment
- Expertise

Three values-related themes emerged during the deliberations about element 1. The first value was empowerment of the public with information and of individuals who inject drugs

with education about how to prevent infectious diseases. In particular, panellists emphasized the need for targeted educational materials for individuals in different age groups including throughout middle school, high school and post-secondary education, as well as for older adults who may be using prescription opiates. Panellists also proposed the use of public campaigns to reduce stigma about injection drug use. One group of panellists suggested the development of a Family Drug Awareness Challenge or a similar campaign that had a call to action and an element of competition to encourage broad participation.

The second values-related theme which, as noted above, transcends each of the elements is to value the expertise and lived experience of individuals who inject drugs. Panellists considered how these peers could be used to provide education to those who inject drugs about ways to recognize signs of infection and strategies to reduce the risk of infection when injecting. Further, panellists also suggested that there is a role for peers to educate health professionals who regularly interact with people who inject drugs about specific considerations and sensitivity training relating to injection drug use that may not be top-of-mind to providers.

Finally, the third values-related theme focused on the need for trusting relationships between individuals who inject drugs, peers and professionals. Panellists described how trust between individuals and their care professionals was critical to begin to address underlying reasons for drug use and injection such as enduring trauma, mental health challenges, or physical pain.

Element 2 – Enhance the infection-management capacity of community points of contact for people who inject drugs

The discussion about the second element focused on enhancing the infection-management capacity of community points of contact for people who inject drugs. As outlined in the citizen brief, this could include:

- increasing access to medical care at common places of contact for people who inject drugs, such as community health centres, primary-care practices, organizations providing harm-reduction services and public-health units;
- training staff in the community to recognize, treat and manage infectious diseases among people who inject drugs;
- changing or expanding the roles of certain health professionals; and
- making care more coordinated through 'hubs' located in common community contact points, which could include providing:
  - safe care environments after hospital discharge (such as transitional housing or residential care) where treatment for substance use, safe management of infectious diseases and other complications can be provided, and
  - outreach for people who inject drugs who require follow-up after being discharged from hospital.

Box 4: Key messages about enhancing the infection-management capacity of community points of contact for people who inject drugs (element 2)

Four values-related themes emerged during the discussion about element 2:

- Access
- Trust
- Expertise
- Collaboration of peers and professionals

Four values-related themes emerged during deliberations about element 2. The first values-related theme was the need for improved access to care and support in navigating the health system. Many panellists noted that the existing models of care were not being optimally used by those who inject drugs and suggested improving access to care by providing outreach and mobile services. They also advised on establishing navigation supports (preferably provided by a peer) to improve access to different types of services such as primary care or social supports, as well as employing peers as "street liaisons" to advise outreach services on developing hot spots in a given community.

The second values-related theme, which was also mentioned in the first element, is the development of trusting and respectful relationships between individuals who inject drugs and health professionals. Panellists emphasized the need for respectful relationships to be established with health providers in order for effective care to be delivered. They described the need to provide training and education to health professionals who do not have experience in providing care to individuals who inject drugs. In addition to training that focuses on professionals' soft skills (such as active listening and communication), panellists also suggested that this type of training could bring health professionals' attention to some of the underlying reasons individuals who inject drugs may not seek care (e.g., lack of resources or transportation to get to and from appointments). Building on this, the third values-related theme focused on the need for expertise in providing care to individuals who inject drugs. Panellists expressed that they received better and more appropriate care when professionals were familiar with injection drug practices and had experience providing care to marginalized populations. Panellists also proposed that this expertise could be established through the involvement of peers as members of a care team.

Finally, the fourth values-related theme focused on collaboration of peers and professionals in decision-making and design of services. This theme builds on a challenge that panellists highlighted in the deliberations about the problem, suggesting the involvement of peers in the decision-making and design of services would help to tailor services to meet community needs.

Element 3 – Strengthen patient-centred care in specialty/acute-care settings

The discussion about the third element focused on improving care in hospitals for people who inject drugs, including determining how best to connect them to appropriate follow-up care once they leave hospital. As outlined in the evidence brief, this could include:

Box 5: Key messages about strengthening patient-centred care in specialty/acute-care settings (element 3)

Three values-related themes emerged during the discussion about element 3:

- Excellent outcomes
- Collaboration
- Choice

- creating and using clinical practice guidelines for:
  - treating infectious diseases among people who inject drugs, and
  - addressing the unique health and social needs that need to be considered to provide the best possible care;
- providing comprehensive care for infectious diseases, substance use and mental health problems by establishing:
  - safe interim discharge environments such as transitional housing,
  - rapid addiction access management clinics, and
  - enhanced community access to methadone and buprenorphine/naloxone;
- using new approaches to retain people who inject drugs in the care they need to treat infectious diseases by, for example:
  - placing trained health professionals such as nurses in community points of contact to provide follow-up care for infections and to check peripherally inserted central catheter (PICC) lines'
  - involving peers in the delivery and coordination of follow-up care, or
  - providing supervised consumption sites within hospital settings to help keep people in hospital when needed; and
- providing health professionals and staff at hospitals with training in how to best provide care to a highly marginalized and stigmatized group, such as by:
  - using trauma informed approaches to care, and
  - providing anti-oppression training.

Three values-related themes emerged in relation to element 3. The first values-related theme was an emphasis on excellent patient outcomes through coordinated care. Panellists described the need for better coordination between specialty and community care by establishing transition services such as wellness checks or transitional housing. Importantly, panellists emphasized the need for referrals to be available as soon as individuals are released from acute care, noting that the long delays in accessing rehabilitative services or community mental health services (for those who would like them) result in individuals returning to previous injecting practices, despite a desire for change.

The second values-related theme relates closely to those themes described in both previous elements and focused on collaboration between health professionals, peers and individuals to cultivate an understanding among health professionals of an individual's unique circumstances. Panellists suggested that enhanced collaboration could take shape through the greater involvement of peers in care teams to share their knowledge and educate health professionals. In particular, panellists highlighted the need for greater understanding of the additional challenges that stem from drug use and an awareness of the underlying factors that may drive it.

Finally, the third values-related theme related to enhancing choice in care. Panellists described how, particularly as care becomes more acute, individuals are not consulted or involved in decisions related to their own care. One panellist attributed this in part to embedded stereotypes of those who inject drugs. However, many panellists emphasized that involving individuals in their own care and in the development of their care plan had the potential to improve both adherence to care, given it would be tailored to the individual, and improve self-efficacy by providing a sense of ownership over their own health.

"All you need is that one person you can trust, who is willing to help"

Discussing implementation considerations: What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach for preventing and managing infectious diseases among people who inject drugs in Ontario, panellists examined potential barriers and facilitators for moving forward.

Panellists focused on stigma and the criminalization of substances as the two biggest barriers to change. Most panellists agreed that existing stigma towards those who inject drugs acts as the biggest barrier to making reforms, with many expressing that they thought there would be little political will to make any changes described throughout the dialogue. In particular, one panellist attributed this lack of political will to the criminalization of substances, noting how injection drug use was seen as a personal moral failure rather than a symptom of broader societal challenges.

Panellists also identified some potential facilitators for change, including education from diverse peers and individuals with lived experience to reduce stigma. One panellist suggested taking advantage of opportunities to mix the wide range of stakeholders involved in the issue, including those with lived experience, academics, health professionals and policymakers, noting how open discussions among stakeholders could challenge pre-conceived notions and entrenched biases.

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Conflict of interest

Michael Wilson is a member of the Board of Directors for South Riverdale Community Health Centres (SRCHC) which offers many of the types of services discussed in the citizen brief that informed the panel and the types of services discussed during the panel. No clients or employees of SRCHC were directly recruited to participate in the citizen panel that this brief was designed to inform. Kerry Waddell has no professional or commercial interests relevant to the citizen brief, however, the work of the organization of both authors is sometimes cited. The funders played no role in the identification, selection, assessment, synthesis, or presentation of the research evidence profiled in the citizen brief. Staff of these organizations provided feedback on our approach and on draft material, however the authors could act on their input at their sole discretion.

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