Dialogue Summary

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

28 February 2019

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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.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary but the authors had final decision-making authority about what appeared in the dialogue summary.

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Dialogue

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SUMMARY OF THE DIALOGUE

While dialogue participants generally agreed with the four challenges presented in the evidence brief, they focused their deliberations on four broad areas: 1) big picture (e.g., political factors that shape policy) and structural factors (e.g., housing and poverty) continue to drive all other challenges related to injection drug use; 2) gaps in health-system arrangements make preventing and managing infectious diseases difficult; 3) tensions between establishing institutionalized medical models of care versus community-provided and driven initiatives create challenges in getting the right care to those who need it; and 4) choosing how to frame the issue (e.g., as part of the overdose crisis or as part of broader addictions challenges) and which populations to focus on (e.g., those who inject drugs or those who use drugs) determine, in part, which solutions will be pursued.

In deliberating about the elements, dialogue participants focused on three areas requiring action that transcend the elements of a potentially comprehensive approach to addressing the problem that were presented in the evidence brief. The first, which echoes a key theme from a citizen panel convened on the same topic prior to the dialogue, is the need for meaningful and regular involvement of peers in the design and delivery of services to people who inject drugs. Second, participants emphasized the need to create standardized approaches for the collection of data and to ensure data is made available in a timely way. Lastly, several participants emphasized the need to decriminalize drugs to be able to address the big structural barriers faced by people who inject drugs, with the rest of the participants expressing varied amounts of support and reservation for this recommendation. Apart from these three overarching themes, participants focused much of their deliberations on the first element - strengthen efforts to prevent infectious diseases among people who inject drugs - suggesting the broadening of preventive and educational approaches beyond needle sharing, including considerations for regional trends in drug use (including the types of drugs used). For element 2 - enhance the infection-management capacity of community points of contact for people who inject drugs - participants emphasized the expansion of person-centred coordinated care in the community and the need for any new programs to better address the social determinants of health that drive addiction. In element 3 - strengthen patient-centred care in specialty/acute-care settings - participants emphasized that care in acute settings could be further improved by supporting a shift in the culture of acute-care organizations and the professionals who work within them, and strengthening links to models of care that can bridge the gap between specialty/acute and community care.

Finally, dialogue participants identified next steps that ranged from short term to long term. In the short term, participants identified next steps as: 1) develop and implement infection control standards for consumption sites; 2) enhance supports from the medical community for community-based organizations and front-line workers, including establishing partnerships, sharing information, and where possible supporting safe supply; 3) strengthen bridges between acute care and community-based initiatives (e.g., through telemedicine, community liaison workers, rapid addictions management clinic); 4) improve the experience of people who inject drugs in acute care by exploring reasons individuals against medical advice and establishing organizational mental health and substance use strategies; and 5) explore opportunities within the recently announced reforms to the Ontario health system to partner with the consumption and treatment services network, and to consistently include mental health and addictions services as part of Ontario health teams and the 'in-scope' services they provide. In the longer term, dialogue participants identified the potential to partner with the federal government on surveillance and knowledge translation to ensure a full picture of the problem is achieved, and to disseminate best practices, when they emerge, across provinces and territories.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Dialogue participants generally agreed with the four challenges outlined in the evidence brief:
1) injection drug use being associated with increased risk of a range of infectious diseases;
2) stigma and discrimination experienced by people who inject drugs may reduce timely access to care and supports;
3) limited education/training and lack of clear guidelines make the delivery of appropriate care and supports challenging; and
4) fragmentation in system arrangements within and between health and social systems constrain person-centred care.

However, deliberations about the problem focused on four additional aspects that dialogue participants felt deserved more attention:
1) political and structural factors continue to drive all other challenges related to injection drug use;
2) gaps in health-system arrangements make preventing and managing infectious diseases difficult;
3) tensions between establishing institutionalized medical models of care versus community-provided and driven initiatives create challenges for getting the right care to those who need it; and
4) choosing how to frame the issue and which populations to focus on determine, in part, which solutions will be pursued.

We discuss each of these in detail below.

Political and structural factors continue to drive all other challenges related to injection drug use

Dialogue participants spent a significant amount of the deliberation about the problem describing the 'big picture' and structural factors that they identified as driving all other challenges related to injection drug use. In particular, dialogue participants emphasized three 'big picture' items that contributed to the current context, which related to political context, structural challenges and data and research.

With respect to the political context, dialogue participants highlighted the legacy of the lack of support for harm-reduction policies and programs from the previous federal

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:
1) it addressed an issue currently being faced in Ontario;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three elements of a comprehensive approach for addressing the policy issue;
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three approach elements, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible elements of an approach to addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

government, which participants noted as being partly responsible for lags in the response to the overdose crisis. However, dialogue participants also considered challenges with the political process more generally, suggesting that injection drug use is not a "winning issue" for any government given societal stigma towards those who inject drugs and the range of challenging structural issues they often face (e.g., homelessness and poverty). Building on this narrative, participants described how political and policy processes tend to favour those with political power or the ability to problematize an issue. However, given that people who inject drugs are often "the most marginalized within marginalized populations," one participant stated "that when the issue is marginalized, so too is anyone working on them."

Dialogue participants spent a significant amount of time deliberating about structural challenges. Closely related to the political context, dialogue participants described the stigma and marginalization that results from the use of drugs remaining a crime. Similarly, other participants noted that the criminalization of drugs and concerns about being caught using drives many of the behaviours that place individuals at risk of infection (e.g., keeping their injection practices from friends and family, not seeking medical and social services, and injecting quickly and often in hidden and/or potentially unsanitary locations).

Finally, participants deliberated about the lack of timely data available on injection drug use or on infectious diseases that may result from injection drug use. In particular, participants highlighted a number of challenges in getting access to high-quality data, including concerns about the privacy of individuals, notably those with infections such as HIV which carry with them additional stigma beyond that of injection drug use alone, as well as enduring legacies of violence and criminalization in the process of collecting data on individuals who inject drugs. Other participants described structural challenges that exist in collecting data such as the lack of common indicators across agencies and organizations, limited linking of data, and a persistent focus on data related to the overdose crisis rather than on all aspects of injection drug use.

Gaps in health-system arrangements make preventing and managing infectious diseases difficult

The second aspect of the problem that dialogue participants gave particular attention related to the ways in which financial and delivery arrangements complicate the prevention and management of infectious diseases. In particular, dialogue participants stressed how the lack of coverage for specific health services contributes, in some instances, to the ongoing use of injection drugs among individuals. Participants provided the example of lack of access to and coverage of physiotherapy and psychological services which could help to support some individuals with underlying issues of physical pain or trauma that may be driving their use of injection drugs.

With regards to delivery arrangements, dialogue participants described a wide range of gaps that make the prevention and management of infectious diseases difficult. First, one participant described how the lack of services to address basic hygiene is a key issue for infection. The participant mentioned that while this was not an issue across all injection drug users, for some, the lack of having regular access to a shower or to equipment to keep injection sites clean puts them at substantial risk for infection. Second, participants highlighted the fragmentation of mental health and addiction services among outreach services, primary care and acute care, which makes comprehensive, person-centred and integrated approaches to care difficult to achieve. Third, participants discussed the need for greater involvement of citizens and peers in the design and delivery of care. This was a challenge that was stressed by citizens during a citizen panel on the same topic that informed part of the evidence brief and was mentioned numerous times by dialogue participants as being critical to ensuring services are effective and meet the needs of those people who inject drugs. Finally, dialogue participants brought up stigma and negative attitudes from health professionals towards those who inject drugs as another challenge to managing infections or to supporting individuals in preventing future infectious diseases.

Tensions between establishing institutionalized medical models of care versus community-provided and driven initiatives create challenges for getting the right care to those who need it

The third aspect of the problem that dialogue participants focused on was the tension between institutional and medical models of care versus those that are community-provided and driven. Many participants expressed concern about care provided in hospitals, noting the tensions between the fast-paced, one-off care often provided in acute settings and the individualized care based on trusting relationships that is needed to effectively manage and treat infectious diseases among people who inject drugs. Participants also focused on hospital rules and regulations that challenge the delivery of care for those who inject drugs. Specific challenges that were identified included: hospitals' zero-tolerance policies for drugs brought in from outside sources; policies against prescribing opioids to avoid withdrawal; and rules and regulations against smoking on hospital property (which may help patients to reduce the discomfort of withdrawal symptoms). Participants described how these rules and regulations make hospitals very difficult places for people who inject drugs to receive care, given that adhering to them results in many individuals having to experience withdrawal to receive inpatient care, and that this often results in people leaving against medical advice. To address these issues, some participants suggested that services for those who inject drugs be moved out of hospitals and redistributed to community-developed and driven initiatives, which they perceived to be more amenable to the unique considerations for the population (we return to this idea in the elements section). However, other participants noted that while hospitals had significant reforms to make to ensure they are safe places to receive care for those who inject drugs, they remain an integral part of the health system and for the delivery of care, particularly for select acute infectious diseases such as endocarditis.

Overall, participants agreed that greater collaboration was needed between institutionalized models and those that are created and driven by the community. However, select participants warned that bridging these two models may result in greater bureaucracy and medicalization of community initiatives, which in turn may reduce their efficiency and effectiveness. Other participants noted that greater integration of these services may present concerns about individuals' privacy of information shared between organizations given the sensitive nature of infections and existing stigma towards those who inject drugs.

Choosing how to frame the issue and which populations to focus on determine, in part, which solutions will be pursued

The fourth aspect of the problem that participants deliberated on was the overarching question of how to frame the issue of infectious diseases among individuals who inject drugs. Dialogue participants noted that the framing of the issue and the target population affect the types of solutions that could be pursued and how much traction the issue gets from stakeholders.

With regards to the overarching framing, participants questioned whether the issue of infectious diseases should be nested within the current overdose crisis given the significant political and policy attention that it is currently receiving. Alternatively, others suggested that it be framed as a key focus for efforts to strengthen health and social systems to support mental health and addictions. Those suggesting this framing indicated that it could help support the consideration of broader solutions with greater overlap for infectious diseases, but identified the concern that there currently seems to be less traction and dedicated resources for it.

Similarly, participants deliberated on whether to frame the target population as those who inject drugs or whether to expand it to consider those who use drugs more broadly, given the overlap in the populations and movement between the two (e.g., progression to and away from use of injection drugs).

DELIBERATION ABOUT ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH TO ADDRESS THE PROBLEM

In deliberating about the elements, dialogue participants focused on three areas requiring action that transcend the elements presented in the evidence brief: 1) the need for meaningful and regular involvement of peers in the design and delivery of services to people who inject drugs; 2) the need to create standardized approaches for the collection of data and to ensure it is made available in a timely way; and 3) the decriminalization of drug use to address structural barriers experienced by those who inject drugs. We return to these three overarching themes after summarizing dialogue participants' deliberation about each of the three elements of a potentially comprehensive approach to address the problem that were presented in the evidence brief.

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

Dialogue participants spent the majority of the deliberations about the elements focused on this element. Participants identified four types of activities that could be used to complement those suggested in the evidence brief, which include: 1) providing better and broader education that goes beyond needle sharing; 2) involving peers in developing and delivering prevention services; 3) drawing on existing resources in the health system to avoid re-creating the wheel; and 4) prioritizing low-barrier care.

Providing better and broader education that goes beyond needle sharing

Dialogue participants emphasized that, historically, prevention and education efforts have focused on reducing needle sharing among injection drug users and while this has been successful, dialogue participants described a need to go beyond this approach. One participant stated that "everyone knows not to share needles, but we haven't been providing education about other equipment." Participants suggested that this messaging needs to also include information about sharing cottons, cookers and water, which could also contribute to infections. In addition, participants considered integrating local knowledge into education efforts, including considerations about local drug use patterns and drug supplies that may result in greater risks for infectious diseases. Importantly, participants suggested that education be provided to all front-line workers who may be interacting with individuals who inject drugs to ensure repetition and multiple points of access to information.

Involving peers in developing and delivering prevention services

Dialogue participants considered how peers could play a central role in prevention services. In particular, participants suggested they may be critical for crafting prevention messages that would resonate with individuals who inject drugs, and to advise on the development of other preventive interventions to avoid using ineffective and expensive approaches that do not work. In addition, dialogue participants considered how peers may also help to deliver prevention and harm-reduction services, such as being employed as staff at sites that offer safe consumption and treatment services. However, one participant mentioned that while the inclusion of peers could help to better tailor services, it is important not to "overshoot" what is expected from peers, especially in ways that may trigger past trauma.

Drawing on existing resources in the health system to avoid re-creating the wheel

Building on the previous point, dialogue participants all recognized that a number of different organizations and agencies in Ontario have a significant history of providing prevention and harm-reduction programs for individuals who inject drugs, as well as in engaging peers in the design and delivery of these services. With that in mind, participants all agreed that before pursuing any of the suggested sub-elements, it is critical to determine what resources already exist, both to guide the development of any new prevention efforts and to

support organizations in successfully engaging those with lived experience. For example, participants suggested looking first to organizations such as the Community AIDS Treatment Information Exchange (CATIE), that have developed both Ontario- and Canada-focused resources on these topics.

Prioritizing low-barrier care

Building on the need for better and broader education, dialogue participants discussed the need to also consider what impact structural factors have on prevention efforts. For example, while many individuals may know not to share injecting equipment, participants mentioned how scarce drug supplies, an urgency to use for fear of being caught in possession of the drug and/or a lack of prioritizing injection safety may all contribute to engaging in risky behaviours. Participants that raised this issue stressed the need to consider ways that low-barrier interventions could be included as part of a broader prevention strategy. For example, one participant highlighted the potential of allowing for injecting shared drugs in sites that offer safe consumption and treatment services.

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

In deliberating about element 2 dialogue participants suggested three additional sub-elements that build on those included in the evidence brief: 1) expanding the availability of person-centred coordinated care in the community; 2) enhancing the capacity to address the social determinants of health that drive injection drug use; and 3) enabling task-shifting across providers to improve the accessibility of care.

Expanding the availability of person-centred coordinated care in the community

Dialogue participants overwhelmingly supported enhancing the availability of person-centred care in the community and strengthening the primary-care services that currently exist. In particular, dialogue participants described the need to tailor the existing services to the needs of those who inject drugs, with one participant stating that "any services that you need to make an appointment for are not going to work," suggesting the development of drop-in care as a more realistic model. However, other participants recognized that the current financial arrangements for primary-care providers would be a key barrier to supporting this type of model, questioning how providers could be paid for this type of work.

Other suggestions to tailor care include improved coordination across health and social systems and, where possible, integration of the two in a similar manner to those currently provided through community health centres. For example, participants mentioned the need for the integration of methadone and hepatitis C treatments with primary- and community-care services. Participants recognized that this approach is not needed for all primary and community care, but needs to be more available in the health system than what currently exists.

Enhancing the capacity to address the social determinants of health driving injection drug use

Some dialogue participants expressed frustration that they were regularly asked to help collect data on the social determinants of health, but saw relatively few efforts in the community to meaningfully address them. While participants generally recognized that some determinants would be difficult, if not impossible, to meaningfully address through programs and services (e.g., widespread poverty reduction, enduring trauma), others such as housing could be improved. Therefore, a few participants suggested the need for improved awareness and integration of services to address social determinants of health in community- and primary-care services.

Enabling task-shifting across providers to improve the accessibility of care

The concept of task-shifting among professionals was highlighted in the evidence brief as a way to further reduce barriers to primary and community care. Dialogue participants generally supported this approach when used to enable better access to care or improve relationships with health providers. For example, participants mentioned that nurse practitioners may have more time available to spend with a client than a physician and, as a result, may be better able to cultivate a trusting relationship. However, participants did not support task-shifting when the primary goal is to save resources. In particular, they highlighted the need to avoid giving people jobs that they are not sufficiently qualified to perform or that may result in unintended consequences. For example, one participant mentioned their experience in working with peers to provide naloxone to individuals overdosing which failed to consider how expanding the peer's role may trigger previous traumatic experiences.

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

Much of the deliberation about element 3 centred around what the role of hospitals and acute-care settings should be for individuals who inject drugs. While participants had mixed views on their support for the continued role of hospitals in the continuum of care for infectious diseases for people who inject drugs, they generally agreed that they remain effective for treating acute and serious infectious diseases such as endocarditis. All participants agreed that there was substantial room for improvement in the care provided in hospital for people who inject drugs and identified the need to: 1) support a shift in the culture of acute-care organizations and the professionals who work within them; and 2) strengthen links to models of care that can bridge the gap between specialty/acute and community care.

Support a shift in the culture of acute-care organizations and the professionals who work within them

All participants agreed that there were cultural norms (reinforced through the rules and regulations described in the problem section) within hospitals and other acute-care settings that challenge the delivery of effective care for those who inject drugs. To inform the development of interventions to shift the culture, dialogue participants suggested implementing the routine investigation of patients who leave against medical advice in efforts to identify ways to better retain patients in care. Participants also remarked that enabling a shift in culture would require training professionals to have a greater understanding and appreciation for the underlying drivers of injection drug use. One way to enable this is to support widespread staff training to provide trauma-informed care and education on the Truth and Reconciliation Commission of Canada and the calls to action. In particular, one participant suggested including this training and education as part of the hospital accreditation process.

Strengthen links to models of care that can bridge the gap between specialty/acute and community care

Finally, dialogue participants noted that a critical component of strengthening acute or specialty care was to ensure that clients are situated within a continuum of support and have the necessary follow-up care. Participants suggested enhancing the models of care such as supportive housing that can help to bridge individuals' care from hospital to the community. Those participants attending from Toronto gave the specific example of Casey House as a possible model to consider. However, other participants pointed out that many clients may not want to be placed in supportive housing and suggested investments in care coordinators or navigators who span both health and social systems and who could enable smooth transitions to community resources.

Considering the full array of approach elements

As mentioned in the introduction to the deliberation about the elements, participants focused on three areas requiring action that transcend the elements presented in the evidence brief: 1) the need for meaningful and regular involvement of peers in the design and delivery of services to people who inject drugs; 2) the need to create standardized approaches for the collection of data and to ensure it is made available in a timely way; and 3) the decriminalization of drug use to address structural barriers experienced by those who inject drugs.

The first, the need for meaningful and regular involvement of peers in the design and delivery of services to people who inject drugs, echoes key themes from the citizen panel convened on the same topic prior to the dialogue. Dialogue participants repeated citizens' calls for the involvement of peers in the delivery of care, but also pushed for greater involvement in policy and service design, noting that this is commonplace for other conditions like cancer. In considering who to involve, dialogue participants described the need to engage a diversity of peers with a range of lived experiences. Participants emphasized that one peer cannot represent all lived experiences, and tailoring programs and services for diverse clients requires a range of perspectives. Further, two participants mentioned that effective and respectful engagement of peers in the design and delivery of services is different than employing other health and social-care providers, and requires putting in place tailored supports such as counselling that go beyond just supervision from other staff members. Similarly, participants also mentioned the need to ensure that peers are appropriately compensated for their work, recognizing that this is one method of legitimizing their participation as members of the care team.

Second, throughout the deliberations about both the problem and the elements participants highlighted the paucity of high-quality rapidly available data on infectious diseases or injection drug use that exists to inform decision-making about programs and services. While participants mentioned that this challenge stems in part from the difficulty of collecting data from such a marginalized population as well as from privacy concerns for sharing information between organizations, other participants highlighted that actionable changes could be pursued within these constraints. In particular, efforts are needed across agencies to collectively consider what information is required to inform decision-making (including the need to consider a broader array of indicators beyond what is currently available such as greater detail about accidental deaths), as well as ensuring these indicators are consistent across agencies and organizations so they can be linked, where possible.

Lastly, near the end of the deliberations about the elements, dialogue participants discussed the criminalization of drug use and how it reinforces structural barriers for those who use and inject drugs. While all participants understood the effects of criminalization on stigma, creating barriers in accessing and receiving care, and the potential for involvement in the justice system, they did not come to a consensus about the pursuit of decriminalizing drug use. While some participants were in strong support of decriminalization, others expressed significant reservations noting that the evidence on whether this approach is effective from countries that have pursued this route (e.g., Portugal) is lacking, as is any conclusion about unintended effects.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Dialogue participants described three key barriers and two windows of opportunity for moving forward with any of the elements of a potentially comprehensive approach. The three barriers are: 1) at the provider level - the high turnover rate of staff and peers, making corporate memory difficult to maintain; 2) at the system level - limited political will to address the structural factors that drive many of the challenges; and 3) also at the system level - difficulty coordinating with other critical players including the justice system (e.g., health and social services provided in prisons) and Indigenous populations (to ensure supports and services are being provided on and off reserves that include trauma-informed care and traditional ways of knowing). With regards to windows of opportunity, most dialogue participants viewed the recently announced reforms to Ontario's health system, including the creation of Ontario Health Teams, as an opportunity to strengthen person-centred approaches to care and prioritize mental health and addictions services, including harm-reduction services. Further, participants indicated that these changes offer the potential to define what consumption and treatment services are and how they should be provided.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Dialogue participants identified several next steps including five in the short term and one to be explored over the long term. In the short term, participants identified the need to:

1) develop and implement infection-control standards for consumption sites;
2) enhance supports from the medical community for community-based organizations and front-line workers, including establishing partnerships, sharing information, and where possible supporting safe supply;
3) strengthen bridges between acute care and community-based initiatives (e.g., through telemedicine, community liaison workers; rapid addictions management clinics);
4) improve the experience of people who inject drugs in acute care by exploring reasons individuals leave against medical advice and establishing organizational mental health and substance-use strategies; and
5) explore opportunities within the recently announced reforms to the Ontario health system to partner with the consumption and treatment services network and to consistently include mental health and addictions services as part of Ontario Health Teams and the 'in-scope' services they provide.

In the longer term, dialogue participants identified the potential to partner with the federal government on surveillance and knowledge translation to ensure a full picture of the problem is achieved, and to disseminate best practices, when they emerge, across provinces and territories.