Dialogue Summary

Supporting Pregnant, Lactating, and Parenting People Who Consume Cannabis in Ontario

17 & 18 May 2021

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McMaster Health Forum and Forum+

The goal of the McMaster Health Forum, and its Forum+ initiative, is to generate action on the pressing health- and social-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 and social systems – locally, nationally, and internationally – and get the right programs, services and products to the people who need them. In doing so, we are building on McMaster's expertise in advancing human and societal health and well-being.

Authors

François-Pierre Gauvin, PhD, Senior Scientific Lead, Citizen Engagement and Evidence Curation, McMaster Health Forum

Wilson MG, PhD, Assistant Director, McMaster Health Forum, and Associate Professor, McMaster University

Allyson Ion, PhD, Assistant Professor (CLA), School of Social Work, McMaster University

Aunima Bhuiya, M.Sc., Co-Lead Evidence Synthesis, McMaster Health Forum

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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

The deliberations initially focused on the most important challenges in supporting pregnant, lactating and parenting people who consume cannabis in Ontario. In addition to the features of the problem articulated in the evidence brief, participants emphasized four challenges: 1) uncertainty from a lack of evidence makes it challenging to make informed decisions related to cannabis consumption; 2) risk perception varies greatly (between individuals, providers, organizations and systems); 3) coordinated approaches are limited by fragmentation at many levels; and 4) stigma and discrimination can limit the capacity to mobilize communities and to engage in individualized and person-centred approaches.

There was broad agreement about the importance of the three elements of a potentially comprehensive approach to address the problems included in the evidence brief: elevating the voices of pregnant, lactating and parenting people who consume cannabis (element 1); co-designing harm-reduction models and tools focused on supporting pregnant, lactating and parenting people who consume cannabis (element 2); and supporting the uptake of harm-reduction models and tools, and a broader paradigm shift in health and social care (element 3). Several key principles to underpin future actions emerged from the deliberations, including: using a harm-reduction and strengths-based approach; prioritizing a collaborative approach (e.g., meaningfully engaging communities that are the most affected, and stakeholders from across sectors); ensuring approaches are grounded in equity and anti-racist approaches ("policies are not colour-blind"); and focusing on being person-centred (e.g., asking why cannabis is being used, which was viewed as the starting point for building individualized, strengths-based harm-reduction approaches). Participants also deliberated about an overarching element focused on removing structures that perpetuate the problems identified.

Participants identified two overarching implementation considerations to move forward: 1) the need for implementation to be considered through the lens of concerns about surveillance and policing; and 2) the need to address implementation gaps where government authorities have unmet responsibilities (e.g., for the educational mandate for cannabis given that reliable information needs to be shared with all Canadians to help increase awareness and reduce stigma). They also acknowledged some major barriers to move forward, including the challenge of changing the narrative about cannabis consumption during pregnancy, lactation and parenting (e.g., the predominant 'risk' perspective); and the challenge of engaging powerful stakeholder groups who may be risk averse (e.g., the regulatory colleges).

Having discussed barriers, participants identified five features of the current landscape that could collectively create a window of opportunity to move forward: 1) leveraging or making better use of existing (underutilized) resources; 2) harnessing the modernization of the child-welfare system with a "here to help" model which provides a key opportunity for advancing a meaningful shift; 3) drawing lessons from the HIV community (e.g., unpacking research evidence alongside people's lived experiences); 4) leveraging existing research programs and research leadership to amplify the voices of pregnant, lactating and parenting people who consume cannabis, develop co-design projects of harm-reduction models and tools, and identify measures and indicators that are important to service users); and 5) leveraging the Provincial System Support Program at the Centre for Addiction and Mental Health to work with local communities and key partners to create and sustain system improvements.

For next steps, participants underscored the need to: explore the possibility of creating an alliance of agencies that are cannabis-friendly (and advertising it so that service users know) to break down silos and have cross-sectoral conversations; develop new client-facing tools that are more positively worded; review intake processes for programs and services and appraise their inclusivity; support the development of a learning collaborative with care providers; encourage the development of service-user-powered projects that are led by service users; provide training and support to those who are committed to co-design, but may not yet have the capacity; and critically engage and encourage stakeholders in health and social systems to "weed out our biases."

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

The deliberation focused on the most important challenges in supporting pregnant, lactating and parenting people who consume cannabis in Ontario. Participants emphasized four key challenges:

- uncertainty from a lack of evidence makes it challenging to make informed decisions related to cannabis consumption;
- risk perception varies greatly (between individuals, providers, organizations and systems);
- coordinated approaches are limited by fragmentation at many levels; and
- stigma and discrimination can limit the capacity to mobilize communities and to engage in individualized and person-centred approaches.

Uncertainty from a lack of evidence makes it challenging to make informed decisions related to cannabis consumption

A recurring theme that emerged during the deliberation about the problem is the lack of robust research evidence about the harms and benefits of cannabis consumption during pregnancy, lactation and parenting. This generates uncertainty and makes it challenging to make informed decisions related to cannabis consumption.

This issue is further complicated by two factors. First, the evidence that does exist is often too far removed from what would be helpful for pregnant, lactating and parenting people to make decisions, which points to the need for additional resources such as decision aids. Second, the wide range of cannabis products (e.g., low-THC products, edibles, beverages, extracts) complicates decisions even further since these products are often not accounted for in existing research evidence.

In this context of uncertainty, participants indicated that in their experience, many care providers do not feel comfortable engaging in conversations about cannabis consumption. As one participant said: "There are concerns mostly around [the] many confounding factors. Nobody feels comfortable [talking about it]." As a second participant pointed out, this situation leads many care providers to recommend against using cannabis: "We don't really know, so we'll say not to consume." Yet,

Box 1: Background to the stakeholder dialogue

The virtual 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 potentially 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 elements of an approach to addressing it, 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- and social-system leaders typically need to engage elected officials, boards of directors and others about 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.

participants acknowledge the need to have evidence-informed, and nuanced conversations about cannabis consumption. Given this, participants emphasized that more robust primary studies are required, as well as more evidence products to guide people to make decisions (e.g., decision aids, infographics to present research evidence in a way that can support conversations, and real-world evidence summaries).

Risk perception varies greatly (between individuals, providers, organizations and systems)

Another recurring theme was that risk perception about cannabis consumption varies greatly. Several participants emphasized that risk may be defined differently by individuals, providers, organizations and systems. While risk is often framed from the perspectives of risk on pregnancy outcomes or on child development, such perspectives often do not consider the risk of stopping consumption or the ways that risk mitigation or harm reduction is facilitated through the consumption of cannabis for pregnant individuals and parents. As one participant said: "What [pregnant, lactating and parenting people] identify as 'the risk' differs widely." Such variation underscores the need for additional evidence to understand risk perception from different perspectives and to use that information to co-design individualized approaches. A few participants highlighted promising projects, such as a community-informed project led by the Native Women's Association of Canada to help Indigenous women, girls, and gender-diverse people make informed decisions about cannabis use. The project examines risk perceptions to create culturally safe, gender-based, trauma-informed cannabis public-education and awareness resources.

The lack of primary evidence on cannabis consumption appears to be blurring conversations about risk (e.g., what do we know about the effects of different types of cannabis strains, products or frequency of consumption). As one participant said: "There are lots of myths out there." In the absence of evidence-informed decision supports, pregnant, lactating and parenting people make decisions based on anecdotal evidence ("this is all we have").

Lastly, participants indicated that providers, organizations and systems are more inclined to adopt conservative approaches towards cannabis consumption (and thus recommend abstinence) given the uncertainty about the risk. Others also indicated that providers and organizations working in different systems (e.g., health, social, child-welfare and justice systems) may perceive risk quite differently depending on their perceived roles. For example, some may have a "duty to report" or a "duty to respond," which may affect their perceptions of risk and how they would respond to the disclosure of cannabis consumption in a service context.

Coordinated approaches are limited by fragmentation at many levels

Several participants emphasized that coordinated approaches to support pregnant, lactating and parenting people who consume cannabis are limited. They indicated that such limitations were due to the fragmentation at many levels, including within the child-welfare system, between the health system and relevant services provided through social systems, and at the level of policy. This fragmentation was identified as creating siloed approaches to policy development and delivery of services and supports. One participant illustrated this fragmentation with the example of obstetrical care, indicating that it is a "widely shopped service" and people are willing to go hours away to get what they want: "There is not a great platform to standardize and hold ourselves accountable. It varies so much." At the same time, some participants indicated that obstetricians often do not know who to turn to if there are 'social' issues with pregnant people, which reinforce the idea that there are many silos.

There is also a disconnect at many levels including from policy/legislation, how regulations are developed and interpreted from such policies/legislations, and how those regulations are implemented at the organizational and provider levels. As one participant said: "We are all bound by the same legislation, but each agency has their own board and ways of doing."

Stigma and discrimination can limit the capacity to mobilize communities and to engage in individualized and person-centred approaches

Another recurring theme was the stigma and discrimination experienced by many pregnant, lactating and parenting people who consume cannabis. Stigma and discrimination can limit the capacity to mobilize communities (e.g., participants withdrawing from research after initially consenting) and to engage in individualized and person-centred approaches.

Participants indicated that there is a need to drive social changes to address this, which will require a better understanding of the needs and realities of pregnant, lactating and parenting people who consume cannabis (particularly those who are the most vulnerable and marginalized). They also emphasized the need to address systemic stigma and discrimination. As one participant said: "[Systemic stigma and discrimination] should be a stand-alone issue, not an add-on. It's a huge piece that needs a deeper dive if we want to provide services." Another participant referred to racist drug policies having a disproportionate impact on racialized communities and creating a climate of fear for racialized pregnant, lactating and parenting people who consume cannabis: "Fear-based decision-making has caused much pain to families."

A few participants gave the example of the Ontario government's decision to cease the practice of birth alerts in 2020. Birth alerts were notifications sent by children's aid societies to hospitals when they believed a newborn may be in need of protection. Many pregnant, lactating and parenting people (particularly among racialized and vulnerable communities) were concerned about being reported to the child-welfare system because of their cannabis consumption. While participants indicated that the cessation of the birth-alert system was a step in the right direction, others pointed out that many providers and organizations are still working from that mentality.

DELIBERATION ABOUT ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH

There was broad agreement about the importance of the three elements of a potentially comprehensive approach to address the issue that were included in the evidence brief: elevating the voices of pregnant, lactating and parenting people who consume cannabis (element 1); co-designing harm-reduction models and tools focused on supporting pregnant, lactating and parenting people who consume cannabis (element 2); and supporting the uptake of harm-reduction models and tools, and a broader paradigm shift in health and social care (element 3).

However, during the deliberations, several key principles to underpin future actions emerged, which included:

- using a harm-reduction and strengths-based approach;
- prioritizing a collaborative approach (e.g., meaningfully engaging communities that are the most affected, and stakeholders from across sectors);
- ensuring approaches are grounded in equity and anti-racist approaches ("policies are not colour-blind"); and
- focusing on being person-centred (e.g., asking why cannabis is being consumed, which was viewed as the most important starting point for building individualized, strengths-based harm-reduction approaches).

We discuss in more details below the insights shared by participants in relation to the three elements in the brief, as well as a fourth new element focused on removing structures that perpetuate the problems identified.

Element 1 – Elevating the voices of pregnant, lactating and parenting people who consume cannabis

The focus of element 1 is to elevate the voices of those with lived experience to ensure that maternity care, social work, and child-welfare practices are informed by the best available evidence, and also operate from an equity, human rights, and social-justice perspective for all family members. This is particularly important in the context of those who experience intersecting axes of oppression (e.g., race, gender, class and sexual orientation), to ensure that the solutions respond to their needs and realities. In addition, this element could help to better understand their care needs and decisional needs, which is critical to develop effective harm-reduction models and decision supports.

This element could include a range of strategies, including (but not limited to):

- using research strategies to illuminate the realities of those who have historically been oppressed, stigmatized or marginalized (e.g., arts-based approaches such as Body Mapping and Photovoice);
- using other types of care settings or venues where they may feel comfortable talking about their care needs and decisional needs (e.g., outreach activities, group-based care, peer-based supports, community-based supports);
- integrating advocacy support (e.g., support from peers, doulas, social workers, midwives, etc.);
- identifying strategies that help to address stigma; and
- identifying strategies that encourage empowerment and agency around cannabis consumption decision-making throughout the perinatal and parenting journey (e.g., shared decision-making).

When discussing element 1, participants pointed out the difficulty of having nuanced conversations about cannabis consumption during parenting, lactating and parenting. To address this, they emphasized the need to raise public awareness about the issue (and about what is known from research evidence), to hear the voices of those consuming cannabis (to understand their realities), and to create spaces for safe conversations.

Some participants indicated that it remains challenging to engage pregnant, lactating and parenting people who consume cannabis (particularly those most vulnerable and marginalized). One participant pointed out

that using social media has been most effective so far (e.g., the SheCann community where women can share their journey with medical cannabis), but social-media users may not be representative of all demographics.

Element 2 – Co-designing harm-reduction models and tools focused on supporting pregnant, lactating and parenting people who consume cannabis

The focus of element 2 aims to mobilize existing knowledge and experiences from all stakeholders to co-design harm-reduction models and tools. Such models and tools could then be implemented within health and social-work education programs, maternity care, child-welfare practice settings, and other allied health- and social-care settings.

While co-designing harm-reduction models and tools resonated with participants, participants emphasized that there is a need to acknowledge that pregnant, lactating and parenting people may have 'limited bandwidth' to engage in such activities. Therefore, successful co-design will be most likely when the process is grounded in their realities, and when they are asked what they need to be able to engage in a meaningful way. As one participant said: "What is reasonable for you to do, without asking you to do all the work. If the patient voice is important, you need to give them the tools." A second participant went further: "I also think we don't have to come up with all the answers. As professionals, we often make this mistake of believing that we have to have every corner covered and that will ultimately dictate the process. We need to allow service recipients to take on some of the control and they advise how the process should look."

Element 3 – Supporting the uptake of harm-reduction models and tools, and a broader paradigm shift in health and social care

The focus of element 3 is to operationalize harm-reduction philosophies in health- and social-care practices. It may include (but is not limited to):

- using strategies informed by the 'behaviour-change wheel' to foster health- and social-care provider behaviour change towards harm-reduction philosophies;
- strategies to foster an organizational culture favourable to harm-reduction philosophies;
- strategies to improve community engagement and stakeholder engagement to support a broader paradigm shift towards harm-reduction philosophies (e.g., bringing together stakeholders to examine notions of risk in health- and social-care practice, and to strategize a harm-reduction approach that focuses on prevention and positive support; or convening a community of practice focused on supporting pregnant individuals, parents and families that is guided by harm reduction, intersectional, and strengths-based practice principles).

The need to leverage existing community resources, as well as organizations and key leaders that have credibility, was emphasized by participants. Moreover, some participants highlighted the need to explore the role of licensed cannabis producers and governments (including Health Canada) in shifting the paradigm (e.g., through mass-media awareness and education campaigns).

Lastly, some participants highlighted that it was critical to align the macro, meso and micro levels to achieve a paradigm shift. As one participant said: "The policy is one thing, the legislation is another. And the interpretation may be different by service providers. Addressing the policy, operational, organizational and individual levels needs to tie all this together."

Considering the full array of elements

In considering the three elements, the deliberations turned to the need for a fourth, new element. Several participants felt that the three previous elements missed the opportunity to address the 'systemic' challenges. They pointed out that "policies are not neutral" and indicated that drug policies are "inherently racist." Thus, there was a need to deconstruct or dismantle the system that perpetuates the problems identified.

It was identified that doing this would require a focus on: 1) a commitment to co-designing policies, programs and services with those involved in or affected by the issue (especially with racialized communities); and 2) deconstructing/reconstructing systems with those engaged or leading the existing pieces of the system to be able to also address the underlying social issues. As one participant said: "it shouldn't be the responsibility of women" to do this.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Participants identified a series of overarching implementation considerations to move forward, including: 1) the need for implementation to be considered through the lens of concerns about surveillance and policing; and 2) the need to address implementation gaps where government authorities have unmet responsibilities (e.g., related to their educational mandate for cannabis given that reliable information needs to be shared with all Canadians to help increase awareness and reduce stigma).

Participants also acknowledged some major barriers to move forward, including:

- the challenge of changing the narrative about cannabis consumption during pregnancy, lactation and parenting (e.g., the predominant 'risk' perspective); and
- the challenge of engaging powerful stakeholder groups who may be risk averse.

Regarding the last point, a few participants indicated that it was critical to engage the regulatory colleges if we want to be able to "move the needle." This may require a nudge and individualized approach to get them on board.

Having discussed barriers, participants identified five features of the current landscape that could collectively create a window of opportunity to improve support for pregnant, lactating and parenting people who consume cannabis in Ontario:

- leveraging or making better use of existing (underutilized) resources (e.g., the OMama app connecting people to trusted, evidence-informed information, Cannabis Knowledge Exchange Hub providing evidence-based information on the non-medical use of cannabis and connecting care providers);
- harnessing the modernization of the child-welfare system with a "here to help" model which provides a key opportunity for advancing a meaningful shift;
- drawing lessons from the HIV community (e.g., consensus and position statements that unpack research evidence alongside people's lived experiences, the role of patient advocates and navigators, and the importance of participatory research);
- leveraging existing research programs and research leadership to amplify the voices of pregnant, lactating and parenting people who consume cannabis, developing co-design projects of harm-reduction models and tools, and identifying measures and indicators that are important to service users); and
- leveraging the Provincial System Support Program at CAMH to work with local communities and key partners to create and sustain system improvements.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

In the deliberations about next steps, participants outlined what they would bring back to their respective constituencies and how their suggestions could work to advance the proposed solutions. Together, participants prioritized several actions to improve support for pregnant, lactating and parenting people who consume cannabis in Ontario, which included:

- exploring the possibility of creating an alliance of agencies that are cannabis-friendly (and advertising it so that service users know), with regular meetings to break down silos and have cross-sectoral conversations;
- developing new client-facing tools that are more positively worded;
- reviewing intake processes for programs and services and appraising the extent to which they are inclusive, trauma-informed, non-judgmental and anti-racist ("so we don't have people having to share their trauma again and again");
- supporting the development of a learning collaborative with care providers;
- encouraging the development of service-user-powered projects that are led by service users (as opposed to being led by researchers and other individuals in positions of power);
- providing training and support to those who are committed to co-design, but may not have the capacity yet; and
- encouraging stakeholders in health and social systems to "weed out our biases."

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>> Contact us

1280 Main St. West, MML-417
Hamilton, ON, Canada L8S 4L6
+1.905.525.9140 x 22121
forum@mcmaster.ca

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