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Shaping Future Investments in Community-Based Research on Cannabis and Mental Health

A Community-Based Research Forum

Summary Report

Mental Health Commission of Canada

About the day

On July 16, 2019, the Mental Health Commission of Canada (MHCC) brought together more than 60 experts, including people with lived experience of substance use and/or mental health problems and illnesses, family members, caregivers, policy makers, service providers, and community-based researchers at Ottawa's Bayview Yards to discuss funding priorities for community-based research on cannabis and mental health.

The diverse group drew on a rich mix of lived, practical, and professional experience to consider the principles that should guide community-based research in this area — inclusiveness, safety, and respect at the highest level — along with questions or issues to be explored, such as:

- cannabis and its effects
- uses and applications of cannabis
- what influences people's choices around cannabis use
- cannabis and culture
- problematic use and treatment
- demographics, diverse populations, and cannabis use
- the impact of legalization
- cannabis and driving
- stigma
- trauma and suicide
- informing care providers

This report provides a concise account of the day's discussions and key takeaways, which will inform the MHCC's call for community-based research proposals later in 2019.

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"We're not here today to talk at you.
We're here to hear from you."

Christopher Canning

Introduction

Canada is just the second country to legalize cannabis for non-medical use. This decision has created an unprecedented opportunity for research into the effects of cannabis use on many aspects of health, including mental health. In recognition of that fact, the 2018 federal budget granted the Mental Health Commission of Canada (MHCC) $10 million over five years to support research on the relationships between cannabis use and mental health. In July 2019, the MHCC brought together substance use and mental health experts from across the country to identify priority areas for exploration.

The Shaping Future Investments in Community-Based Research on Cannabis and Mental Health forum relied on the expertise of people with lived experience of substance use and/or mental health problems and illnesses, family members, caregivers, policy makers, and community-based researchers to discuss appropriate approaches to and topics for community-based research.

Kitigan Zibi **Elder Verna McGregor** opened the forum with a welcome and blessing, touching on the role of traditional medicines, including cannabis, in Indigenous culture and practices.

The event had four main goals:

- Develop a common understanding of community-based research and its foundational principles.
- Identify research priorities in cannabis and mental health to inform the MHCC's upcoming request for community-based research proposals.
- Share current evidence and research gaps in cannabis and mental health.
- Develop recommendations for participants' ongoing involvement throughout the project's life cycle.

In his framing of the discussion, **Christopher Canning**, the MHCC's director of mental health and substance use, emphasized the need for research to help us understand the relationship between cannabis use and mental health outcomes. Referencing a recent MHCC-funded literature review and environmental scan by a University of Calgary research team, he noted that the results of past research into cannabis and mental health have often been clouded by the context of criminalization. Fear of legal consequences may have discouraged people from admitting cannabis use. As well, observed outcomes could at least be partly attributable to interactions with the justice system and the stigma of behaviour classified as criminal.

The gaps in cannabis and mental health research that have already been identified include

- the impact of cannabis use on mental health outcomes
- the impact of mental health problems and illnesses on cannabis use
- the potential therapeutic benefits of cannabis use for mental health outcomes

- effective treatment options for cannabis use disorder
- the links between THC[1] and CBD[2] potency, frequency of use, and age of initiation on mental health outcomes
- the need to centre the lived experiences of diverse and marginalized populations and support research led by those populations.

This last point is key, according to Canning. People with lived experience have vast amounts of knowledge to inform studies and benefit communities, individuals, and researchers. To prioritize these specific voices and perspectives, he added, those chosen as forum participants included a significant number of people with lived experience of mental health problems and illnesses and/or substance use.

Canning leads off the discussion at the MHCC community-based research forum.

[1] Tetrahydrocannabinol, the main psychoactive ingredient in cannabis.

[2] Cannabidiol, one of the highest-proportion cannabinoids in cannabis.

"A trusting alliance between researchers and community members is key. Without it, a project just won't work."

Tim Aubry

What is community-based research?

Community-based research can have many definitions and encompass a variety of approaches. To get participants working from a common understanding, **Tim Aubry** provided an overview of the concept.

SPEAKER

Tim Aubry, Centre for Research on Educational and Community Services, University of Ottawa

Aubry defined community-based research as an approach involving collaboration between researchers and community members, particularly those who may be affected by the results. It occurs along a spectrum that begins with *consultation* (researchers consulting with community members), progresses to *collaboration* (researchers and community members making decisions together), and concludes with *control* (community members being empowered to lead research themselves with input from academic researchers, as required).

While no two community-based research projects will be exactly alike, they all share some common characteristics:

- All participants contribute to all phases of the research.
- Researchers and community members recognize each other's expertise.
- There is a balance between rigorous research and tangible action.
- The partners commit to a long-term relationship built on trust, collaboration, shared decision-making, and shared ownership of the research.
- In addition to producing research results, the project builds local capacity and sustainability.

Aubry noted that while conducting a successful community-based research project can be challenging, the benefits are well worth the effort. Involving the community helps ensure that research focuses on what is important while keeping researchers accountable to the community. Community members enrich results with their insights, which may be more meaningful and actionable than purely clinical, objective findings.

"It can be helpful to anchor what we're trying to do here today in the wisdom of Einstein: you can't solve problems with the same thinking that created them."

Sylvia Cheuy

Engaging and mobilizing collective wisdom

Tamarack Institute facilitator **Sylvia Cheuy** got the group thinking about how to have a rich and productive dialogue on cannabis and mental health. She began by pointing out that our personal experiences shape how we think about specific issues and by slowing ourselves down and appreciating other people's experiences we can be more innovative together.

Cheuy introduced a few key concepts to help structure the day's discussions and inform the design of community-based research going forward:

FACILITATOR
Sylvia Cheuy, Tamarack Institute

- **Two kinds of wisdom.** Two types of wisdom are equally valid and indispensable to high-quality research: *content* expertise (traditional subject matter expertise) and *context* expertise (gained through lived experience).
- **Human-centred design.** This approach to design is based on the understanding that all problems are solvable when the person or group facing that problem is involved. It emphasizes the importance of keeping the research focused on this group and begins with the admission that no one yet knows the answer.
- **Two ways of speaking.** Organizations and individuals have different ways of speaking: organizations are typically systematic and look for actionable information (patterns and themes); in contrast, individuals often share stories. While both ways of speaking have value, we must intentionally identify the common themes in our stories to translate them into a language organizations can understand and use.

"What I've learned, you can't learn in school. [Researchers and organizations need to] honour expertise with actions, not words. Put your money where your mouth is."

Forum participant

Centring lived experience perspectives

Community-based research is relatively new. Researchers and organizations are still learning how to do it well. Cheuy posed a few questions to help participants reflect on their experiences and begin clarifying the expectations communities may have about cannabis and mental health research.

Questions

1. What is your experience with research, if any? Has your opinion of research changed over the years? If so, how?
2. As a person with lived experience, what has been the biggest challenge or barrier to having your voice and opinion heard?
3. What advice would you give those looking to get involved with community-based research on cannabis and mental health?
4. What final thoughts would you like to share about cannabis, mental health, or community-based research?

In response, participants shared the following key points from their small group discussions.

Lived experience is a form of expertise.

- Stigma continues to be a problem. People want to be treated as peers, not patients. The effects of previous criminalization and its associated stigma also need to be addressed.
- Some people fear being "othered" — not being treated as equal — if they share their lived experience.
- People with lived experience need to be seen as credible. Some initiatives are trying to strengthen the perception of that credibility, e.g., the Centre for Addiction and Mental Health's joint project with Yale University, called Let's Lead, which helps people with lived experience become transformational leaders.
- People who have grown cannabis for years (i.e., prior to legalization) have knowledge about the plant, its effects, and what produces good-quality products. That deserves recognition.

Trust and respect are critical.

- Researchers must take care not to exploit people with lived experience, especially when it comes to remuneration. People want to feel that their time and input are valued. They also need to be paid fairly (in cash, not with gift cards or other tokens) for their contributions.
- All participants should have something to show for their contributions — and get credit in final publications.

- Communication throughout the process is essential. Research leads should give participants updates along the way.
- Building trust is key (e.g., with youth populations) to eliciting honest answers. Such trust is based on authentic connection. When it's established, it can generate valuable qualitative information.

Research must be feasible and representative.

- One to two years doesn't provide a lot of time for preliminary research and follow-up in a human-centred research project. This could affect the scope of the research being funded.
- It's also important to acknowledge that resources are limited.
- Research should reach beyond urban centres.
- Multiple people with lived experience should be involved in every project, panel, or committee to avoid tokenism and ensure that participants don't feel singled out or isolated.

Co-design is critical.

- Instead of presuming what questions need to be explored, researchers should consult the community on the answers it needs.

Communities should benefit from research that involves and affects them.

- In keeping with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, when research is finished, it needs to be translated and made usable. Empowerment isn't just about being heard. It's also about being able to act and reap benefits.

Issues related to cannabis and mental health are not one-sided.

- Cannabis can be beneficial for some people but can lead to negative mental health outcomes (e.g., psychosis) in others. People, communities, and researchers must be open to talking about all aspects.
- Safe-use education, harm reduction, and prevention are all worth addressing. Peer support and education can help ensure that people (especially youth) who have harmful experiences with cannabis aren't made vulnerable to medical or police systems.
- Trauma, especially in remote Indigenous communities, needs to be truly understood for research on the ground to be authentic.
- Issues around the impact of legalization and the ongoing illegal market need to be understood (e.g., cannabis is still more accessible to many people through the illegal market due to price).

Cannabis research should take the long view.

- A goal of community-based research should be to build the capacity of the community to do its own research and generate its own knowledge.
- Projects should plan to follow up with participants about implementation to "keep them in the circle."
- The pace of implementation needs to be considered realistically — and accelerated when possible. It takes as much as 15 years for research to have an impact.
- Part of the aim of cannabis and mental health research should be to build cannabis literacy among physicians, creating connections between them and the community.

"When we talk about mental health, it's not only about medical definitions, it's about oppression and how people break down when they don't have access to human rights, housing, education, and health care."

Forum participant

Principles and values to guide community-based research

To prepare for the afternoon's discussion on research priorities and set the tone for the conversations, **Cheuy** asked participants to come up with a set of principles and values that should guide community-based research.

In response, the group agreed that the following principles would be important.

Inclusiveness

- Research projects should involve as many community members as possible. Researchers should consider asking to join community members in *their* spaces rather than inviting them to their own spaces.
- Everyone involved should have a say in setting clear goals and expectations and have the chance to be heard and validated throughout.

Safety

- It can be difficult to share stories, so it's important to create a safe space with no judgment.
- Safety measures (e.g., having clinical support workers) should be available, and all participants should be made aware of them.
- It is important to establish agreements about confidentiality, so people can speak freely.
- Safety should extend to clinicians, physicians, and researchers who may have lived experience but hesitate to admit it. Their sharing of personal experiences could be helpful to others.
- Participants should take the risk exposing their own ignorance by asking questions when they don't understand and encourage others to do the same.
- It is important to acknowledge power differentials and be open to sharing power. Give people with lived experience leadership or facilitation roles.

Respect

- Respect is key to creating a safe space. All participants should be mindful of their language and avoid stigmatizing labels.
- Understand that everyone has their own experiences and that everyone's experiences are valid and valued.
- Make "ally-ship" a verb — don't just call yourself an ally, make sure your actions support it. Prioritize respect and empathy, acknowledge people's strengths, actively prevent and challenge oppression, and acknowledge and take responsibility when you make a mistake.
- Make connections and relate to each other as people.

"Knowing that our message helped someone is a big part of what we get out of this, and why we agree to share our stories."

Forum participant

Recommended priorities for research on cannabis and mental health

The final group discussion of the day focused on identifying priorities for community-based cannabis and mental health research: what we should collectively be asking and how research can respond**. Cheuy** provided three questions to guide the discussion and report-back process.

Questions

1. Individually identify what you think the research priorities should be in cannabis use and mental health, and why.
2. Share your responses at your table.
3. From your conversation, identify your group's top three to five priorities.

The group conversations resulted in a long list of potential research topics. While presented individually, common themes emerged in writing this report. The following proposed topics are organized under those headings to assist further analysis and assessment going forward. Although some suggestions are not directly related to cannabis and mental health, they open up avenues to be explored through future research investments. It is our hope that other cannabis-related research initiatives can also make use of them to inform their own priorities.

Cannabis and mental health

- What is the relationship between mental health and cannabis? Do mental health problems or illnesses precede cannabis use? Or, does cannabis use precede mental health problems or illnesses?
- What factors contribute to the relationship between cannabis use and psychosis? Does cannabis induce psychosis? Is there evidence of this?
- What are the mental health impacts of occasional use? Of regular use?
- How are mental health outcomes affected by abstaining from or reducing the use of cannabis?

Cannabis and its effects

- What are people's experiences when they use cannabis?
- What are the perceived benefits of cannabis use?
- What are the physical health impacts of occasional use? Of regular use?
- How can we determine who might benefit from cannabis, who might be harmed, how and why — looking at mode of administration, cannabinoids, dosage, genetics, epigenetics, environment, and more?

- What are the effects of specific components of cannabis/cannabinoids?
- How do cannabinoid receptors function? What don't we understand about them?
- What is the impact of cannabis on youth brain development?
- How does cannabis interact with other drugs, such as antidepressants or anti-anxiety medications?
- What are the effects of maternal exposure to cannabis during pregnancy and breastfeeding on mothers and infants? Can those effects be separated from other maternal drug use?
- What are the impacts of parental cannabis use on children?

Uses and applications of cannabis

- Do people use medicinal cannabis and non-medicinal cannabis for different or similar reasons? Is it a question of what they have access to?
- Can cannabis be used as a treatment for physical illnesses (e.g., cancer)? For mental health problems and/or illnesses?
- Can cannabis be used to treat chronic pain and, if so, how does it affect mental health?
- Can cannabis be used as harm reduction alternative to other substances?
- Can cannabis be used to treat post-traumatic stress disorder and/or concurrent disorders?
- Are edibles a viable treatment for helping people withdraw from using cannabis in other ways?

What influences people's choices around cannabis use

- What factors lead people to use cannabis? What are people's motivations for using cannabis?
- Do cannabis producers influence people's decisions to use?
- Do people misuse cannabis because of lack of education in schools? Would better education lead to more informed choices?

Cannabis and culture

- What are the cultural practices/beliefs about cannabis use?
- Could we design a research methodology guided by the medicine wheel?

Problematic use and treatment

- What factors lead to unsafe use?
- Are there predictors of problematic use?
- What are culturally safe methods for helping people stop cannabis use?
- Could we create a toolkit of treatment resources?

Demographics, diverse populations, and cannabis use

- What do we know about seniors and cannabis use? (Seniors are a growing demographic.)
- How is cannabis used in racialized and black communities? What kinds of intersectionalities occur? (In other words, how do social, political, and economic factors come into play and interact with each other?)
- What is the impact of racialization on criminalization?
- At what age(s) do people start using cannabis?

The impact of legalization

- What is the impact of legalization?
- How should we define standardized levels of intoxication and impairment?
- How do we address the side effects of cannabis?
- What should be the approach to product labelling?
- Now that cannabis is legal, how do we support people who were (or still are) criminalized for their involvement with it?

Cannabis and driving

- What is it like to drive while high? How does cannabis affect different bodies/drivers?
- Can we develop evidence-based laws and policies on driving?

Stigma

- How should we destigmatize cannabis use?
- What are the differences (or similarities) between the pre- and post-legalization experiences of stigma?

Trauma and suicide

- Can we better understand the relationship between cannabis use and youth suicide?

> Note: The impact of trauma in the lives of Indigenous people and Indigenous communities runs deep. Even the understanding of the word "trauma" is often shaped by Western knowledge and thinking. To truly understand it in the Indigenous context, some participants suggested that trauma needs to be reconceptualized from an Indigenous point of view and that traditional intervention tools need to be reclaimed.

Informing care providers

- Can we ensure that care providers have all the information they need to make good decisions, e.g., why people use cannabis, why they enjoy it, etc.?

As a further reflection on the day — recalling Cheuy's initial comments about two ways of speaking (structured, thematic, organizational way vs. individual, personal, anecdotal) — participants noted the importance of treating anecdotes as evidence and of continuing to create opportunities for people with lived experience to share their stories.

"The stories shared here today will define future research. Those stories are evidence, and they matter."

Christopher Canning

Closing the research gap on cannabis and mental health

Following the group discussions, **Canning** returned to the podium to highlight some of the key messages heard throughout the day. He also provided additional information on the planned request for research proposals, including next steps.

SPEAKER
Christopher Canning, Mental Health Commission of Canada

Several common threads emerged from the day's discussions. One was the universal acknowledgment that it's important to **compensate all research partners** for their time and expertise.

Canning said that all funding recipients would be encouraged to include space in their budgets for this compensation. Someone suggested including guidelines for doing so in requests for proposals and funding agreements, since funding organizations often have more say than researchers in how budgets are used.

Many participants were interested in the **capacity-building** element of community-based research, as it offers additional benefits and ownership for the community. They wondered if the two-year timeline for MHCC community-based funding was sufficient. Canning recognized these concerns about time and said the MHCC would support training and capacity-building efforts as much as possible.

The importance of **keeping community members involved** while the MHCC develops its community-based research request for proposals (RFPs) — and as projects are carried out — was also mentioned. Participants stressed that finding ways to be involved throughout the entire process was critical — particularly during the final dissemination of research results. Hiring community members for data collection was mentioned as a valuable practice to adopt.

The importance of taking an **intersectional, anti-oppressive approach** was also brought up repeatedly throughout the day. Canning re-emphasized the concept of treating "ally-ship" as a verb, acknowledging and sharing power, and hearing and respecting everyone's perspectives. He agreed that RFPs should include a **glossary of terms** to make them accessible and ensure that all applicants and reviewers understand the key concepts.

Finally, Canning addressed some of the specific needs relating to **research with Indigenous populations**. He agreed that data sovereignty and ownership rests with communities and it is important to ensure that this research be led by Indigenous communities and researchers and be conducted in a way that respects cultural practices and beliefs while meeting Indigenous people's needs.

Funding community-based research through 2022

The MHCC is looking to fund between four and fifteen research projects to address knowledge gaps about the relationship between mental health and cannabis use, with the intent of supporting projects that

- build on strengths, not deficits
- are co-produced, not extractive
- centre lived experience

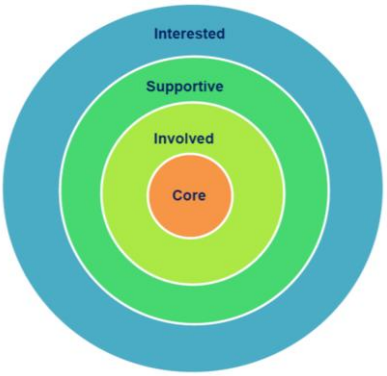
- are culturally safe
- disseminate results for community benefit
- are sustainable.

The timeline for the funding process began with the environmental scan and scoping review conducted earlier this year. That report was followed by conversations with community members (including at this present forum). A second, Inuit-led event in Nunatsiavut to inform the development of the RFPs is being planned for October. The projects will launch in April 2020 and conclude by 2022.

Conclusion

Cheuy introduced the **Stakeholder Wheel of Engagement** and asked participants to indicate their preferred level of involvement going forward as well as any specific ideas about how they'd like to be involved.

- **Core —** those who want to be actively involved in the leadership of the project
- **Involved —** those interested in providing frequent in-depth feedback
- **Supportive —** those who want to occasionally provide some input and support
- **Interested —** those who don't want to be actively involved at this time but want to remain informed about progress and other updates



Stakeholder Wheel of Engagement

Canning thanked participants for the vulnerability they shared, saying the MHCC could not complete this project without their input. He expressed the MHCC's desire to continue involving the day's participants in every way possible.

To close the event, **Elder McGregor** led the group in wishing everyone safe travels by singing a traditional Indigenous travelling song, meant as a send-off to those about to embark on a journey.

Words of the day

Participants were asked to share a word that described how they were feeling at the end of the day. This was their response:

Appendix A

Forum at a glance

Tuesday, July 16, 2019, Bayview Yards | Ottawa, Ontario

TIME	ITEM	SPEAKER
8:15-9 a.m.	Breakfast	
9-9:20 a.m.	Opening protocol and welcome to the territory	Elder Verna McGregor, Kitigan Zibi First Nation
9:20-9:40 a.m.	Welcome and introduction	Christopher Canning, Mental Health Commission of Canada
9:40-9:55 a.m.	Making connections icebreaker	Sylvia Cheuy, Tamarack Institute
9:55-10:15 a.m.	Engaging and mobilizing collective wisdom	Sylvia Cheuy
10:15-10:50 a.m.	Centring lived experience perspectives	Sylvia Cheuy
10:50-11:05 a.m.	Break	
11:05-11:35 a.m.	An introduction to community-based research	Tim Aubry, University of Ottawa
11:35 a.m.-12:30 p.m.	Principles and values to guide community-based research process	Sylvia Cheuy
12:30-1:30 p.m.	Lunch	
1:30-3 p.m.	Small group dialogue on cannabis and mental health	Sylvia Cheuy
3-3:15 p.m.	Break	
3:15-3:45 p.m.	Closing the research gap on cannabis and mental health	Christopher Canning
3:45-4 p.m.	Closing remarks	Christopher Canning

Appendix B

Presenter bios

Christopher Canning is a health leader, researcher, and progressive policy expert. Trained as a sociologist of mental health, he holds a doctorate from Queen's University and was twice a post-doctoral fellow in McGill's Social Studies of Medicine department. Since joining the MHCC in 2012, he has contributed to policy development in several areas related to mental health and substance use in Canada, including cannabis, substance use and mental health integration, child and youth mental health, recovery, access to services, dedicated mental health-care funding, and performance measurement. Christopher brings his own lived experience perspectives to his work and advocacy in the mental health field.

Sylvia Cheuy is a consulting director with the Tamarack Institute's Learning Centre, supporting the collective impact and community engagement areas. Before joining Tamarack, she was the founding executive director of Headwaters Communities in Action and continues to serve on the leadership council of this grassroots citizens' initiative. Sylvia is passionate about community engagement and the unique role citizens play in creating dynamic and well-connected neighbourhoods and communities. She delights in designing and delivering learning opportunities that profile and share resources, tools, and experiences in community building through collective impact. Sylvia is internationally recognized as a community builder and trainer.

Tim Aubry is a professor at the University of Ottawa school of psychology, teaching graduate courses in community psychology and program evaluation. He is also a senior researcher at the university's Centre for Research on Educational and Community Services and holds the faculty of social sciences research chair in community mental health and homelessness. Tim's career has focused on collaborative research projects with community and government organizations that have contributed to the development of effective social programs and policies. He was also Moncton site co-lead and a member of the national research team for the Mental Health Commission of Canada's At Home/Chez Soi demonstration project.

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