Patient and Community Advisory Committee Meeting Summary

September 15, 2020 and October 27, 2020

In attendance: Beth, David, Devan, Jonah, Julie, Kathleen, Lilian, Marney, Marilyn, Mary, Michelle, Nadine, Nicole, Paula, Sarah B, Sarah S, Tamara, and Zal. Marlee joined the September meeting and sent her apologies for October. Suzanne joined the October meeting.

Background

Over 6 meetings (July 2019 – August 2020) committee members have shared observations and advice with CADTH, reflecting the scope of the committee's and CADTH's mandates. As recorded in past meeting summaries, the committee advises that CADTH build the cultural and structural competence of staff and committees, more broadly recognize evidence gaps, and proactively engage different communities to involve them in assessments.

We revisited opportunities identified by individual members and by CADTH staff in response to committee members' observations. Seventeen potential goals were highlighted and mapped to CADTH's framework for patient involvement in health technology assessment (HTA). Committee members were asked to prioritize the 17 goals for attention by CADTH and the committee. Some members expressed discomfort prioritizing advice for action and a concern was raised that the task reinforced individual focus and colonial practices. Many members felt certain actions were "*absolute musts,*" such as greater involving Indigenous communities in CADTH's work.

A member expressed an expectation that, given the diversity of Canadians, all populations should be represented in the evidence examined, and all should contribute to decisions. Another member countered that unfortunately this is not the reality in health policy-making in Canada and why it needs to be called out, "*that's why we're here,"* so that there are deliberate and careful efforts to improve diversity and inclusion in health technology assessments that inform policy decisions in Canada.

Another member reflected that the prioritization of advice was limited by the relationship of advice to the existing framework on patient involvement in HTA. They suggested the committee identify and articulate core principles to guide the committee's future work and communication of advice.

Members discussed each of the 17 goals, identifying multiple reasons why these were important for CADTH to explore. In October, Suzanne joined staff attending the meeting with the committee for a reflection on where CADTH is on the journey toward the goals identified by the committee, and how the committee can help CADTH move forward. Goals discussed are listed here, grouped into 4 themes.

Theme: build cultural and structural competency of CADTH

As observed by a committee member, patients do not exist in mutually exclusive categories – someone can be in a 'disease group' but also need other forms of justice to be addressed. Also observed was that Indigenous health authorities use a holistic model in lieu of a biometric model that the wider health care system relies on. One member shared a touching story about a First Nations elder who, upon hearing of the member's work with CADTH, implored the member to "*make sure our voices are heard*."

CADTH drug reviews and assessments are used by Indigenous Services Canada to help determine health benefits for First Nations and Inuit supported by Non-Insured Health Benefits. Health ministries, health authorities, and publicly funded drug programs across Canada support Indigenous people. Building awareness and relationships would help address gaps in feedback specific to Indigenous groups, which is not necessarily coming from participating health charities or patient input.

Advice from the committee:

- Build cultural and structural competency of CADTH staff and expert committees. Ensure all learn about intersectionality, colonialism, racism, and residential schools.
- Build relationships with First Nations Health Authority, Indigenous-led health centres, and Indigenous-led research centres.
- Ensure strong Indigenous presence on CADTH advisory and expert committees.

On CADTH's journey toward cultural competency, we will meet our goal of having 80% of staff participate in Indigenous cultural awareness training by March 2021. During 2020, Learning Exchanges were created by staff and have been regularly used to learn about Black Lives Matter and health care experiences of First Nations, Metis, and Inuit Peoples. It was recognized there is an opportunity to increase diversity on CADTH committees and its board. It was also acknowledged that CADTH has few relationships with Indigenous health care organizations or communities, beyond our work for Indigenous Services Canada.

CADTH needs the committee to support us through the Learning Series for Staff, to explore intersectionality, racism, discrimination, and to learn from patient stories. The committee can help us develop strategies for recruiting and supporting a greater diversity of advisory and expert committee members than exists currently at CADTH.

In response, 1 member emphasized the importance of diversity:
"We can learn all we want, but if you don't live it, you can never truly understand the complexities and difficulties faced by the diverse communities that make up our country. The best that any group or committee can do, is make sure that there is true diverse representation."

Theme: more broadly identify evidence gaps

As discussed in July 2020, clinical trials generally do not include those who are Black; First Nations; Metis; Inuit; living in northern, rural, or remote communities; seniors; youth; medically complex; or who are experiencing barriers to receiving health care. When CADTH makes recommendations without explicit consideration of these communities, CADTH may contribute to health inequalities.

As articulated by 1 member, to address accountability to Canadians, CADTH should implement reporting practices that clearly outline the limitations in evidence, with emphasis on northern, rural, and remote evidence gaps. Greater focus on diversity of clinician type and regions of practice when gathering expert committees, advisory committees, and clinical panels can contribute to identification of evidence gaps during deliberations. Members agreed that specifying where evidence gaps exist is a necessary step for those gaps to be filled and for decision-makers and stakeholders to understand what is unknown.

CADTH's framework for patient engagement in HTA articulates the goal of the regular review of engagement processes to support continuous improvement. Members warned CADTH to avoid the pitfalls of checking off a box if patient input or stakeholder feedback was included in an HTA, as this is not the same as meaningful engagement.

Advice from the committee:

- Via CADTH's Scientific Advice program, encourage companies to consider implications of narrow patient population recruitment as clinical trials are being planned.
- Explicitly recognize where there are evidence gaps arising from a lack understanding of how the technology is experienced by different communities.
- Conduct an evaluation of stakeholder engagement (including patients, clinicians, academics, industry) to identify missing voices, relevance of insight provided during input / feedback, and opportunities for focused engagement.

CADTH regularly includes Limitations or Research Gaps in our reports, but these tend to focus on the limitations within published literature, rather than considering which patients or communities were not included in the research, or the evidence that exists outside of published trials. Drug companies are strongly encouraged to consider the implications of patient recruitment via CADTH's Scientific Advice program. Evaluations on the use of patient input in CADTH Reimbursement Reviews have been published previously (Berglas 2016; Rozmovitz 2018; Mercer 2020) but have not explored who is and who is not contributing, or on the use and impact of stakeholder feedback.

CADTH needs the committee to help us by continuing to notice who is missing and to call it out to us. We also need members to use their own experiences to challenge assumptions made by CADTH.

Theme: proactively engage with stakeholders

In July 2020, the committee encouraged CADTH to "*evolve the feedback model*" currently in place, to one where the onus is on CADTH to seek responses from stakeholders (patients, clinicians, communities). CADTH completes between 60 and 80 drug reviews per year and 20 and 30 larger projects involving stakeholder feedback. The majority of CADTH Rapid Responses do not solicit feedback, as they involve a rapid search and synthesis of published evidence. There are opportunities for greater involvement and exploration of new approaches for engagement with new CADTH projects.

Members observed that hospitals and other health care settings, including long-term care, have family advisory councils with individuals committed to making change that could be tapped for support. Members cautioned that not every hospital has such a committee and to be mindful to include rural, remote, and northern perspectives.

Advice from the committee:

- Increase opportunities to dialogue with patients by drawing from pools of advisors from existing Patient and Family Advisory Councils in hospitals, long-term care, mental health, and other health authorities. Collaborate with institutions to work with their advisors.
- Develop social media engagement guidelines and work with influencers to interact with on social media groups where many disease specific conversations happen.
- Seek out engagement opportunities with nurses, nurse practitioners, social workers, support workers, outreach workers, and peer facilitators who work in communities identified as marginalized.
- Meet with patients and patient groups during assessments to discuss important outcomes and ask questions. CADTH would share evidence uncertainties to encourage dialogue.

With upcoming large projects in mental health, virtual care and peer support, CADTH will try new approaches for engagement and report publicly on the experiences.

CADTH needs the committee to help us design our approach to building a pool of patient collaborators and to connect with organizations to work with their advisors.

Theme: Inclusive decision-making

Members expressed that patients should be included in all committees and panels at CADTH, as they have the lived experience to know what changes need to be made in the health care system. CADTH can use intersectional approaches to recruit for diversity and avoid tokenism. Strong facilitation and deliberative process can support inclusion of voice if there are perceived power imbalances. Members agreed that involving patients in committees should not replace the Patient and Community Advisory Committee, recognizing the distinct roles of each committee.

Members questioned the wisdom of creating reports if only a small proportion of the Canadian population can currently understand them. A member emphasized that CADTH Recommendations need to be written at a Grade 8 reading comprehension level so larger portions of the population CADTH is serving can understand them. Accessibility of materials is an important step toward greater participation.

Advice from the committee:

- Involve patients on all CADTH expert committees, advisory committees, the board, and panels to clarify assumptions and contribute to the shared expertise of the group.
- Create plain language summaries for reports and recommendations for authentic communication.

As of 2020, CADTH has members providing patient and/or caregiver perspectives on 2 drug expert committees (pERC and CDEC), and public members on the CADTH Board and the medical device expert committee (HTERP). Other than the Patient and Community Advisory Committee, and its representative at the Device Advisory Committee, no other advisory committees or implementation panels at CADTH includes patients.

CADTH needs the committee to help us explore and articulate the anticipated impact of patients' involvement as part of the integrated expertise during deliberations, as compared to (or in addition to) involving patients in other parts of the HTA process (topic selection, assessment, and supporting uptake of recommendation). A clear description of the goal will avoid tokenism and will support constructive progress to greater inclusion. CADTH will also need strategies for recruiting and supporting patient and community advisory and expert committee members.

Overall, the CADTH leadership team encouraged the committee to continue to press CADTH for progress, arguing *"if we know better, we can do better."*

Executive update

Suzanne McGurn (CADTH's President and CEO) shared a high-level update on CADTH's 2021 strategic focus and feedback from the recent CADTH Board retreat. Health care priorities from the Throne Speech (September 23, 2020), were highlighted for the committee and include topics of long-term care, people with disabilities, mental health, virtual care, and Pharmacare.

Self-evaluation for CADTH committees

The meeting continued with a presentation from the CADTH governance team highlighting the results of a recent committee survey. Based on the results, the committee members are content with the direction of

the committee and pleased with the support given by the chair, Marney. Committee members would like more communication from CADTH around when their advice has been useful to or directly influential to CADTH's work.

Several members mentioned that the increase in meeting regularity over the last few months has increased engagement. The committee was divided on whether holding meetings on the weekend would be better than weekdays, with several noting it would reduce time off work and others citing that their family responsibilities made weekday meetings easier. Most members would like to switch virtual platforms from Go to Meeting to Zoom and take advantage of the increased functionality (such as the raise hand feature).

Learning Series for Staff

The final agenda item in October was to discuss the Learning Series first proposed in the summer, based on the personal reflections and suggestions provided by committee members. Listening to and understanding patient perspectives is an integral part of CADTH's work. As such, CADTH needs patients, their families, and patient groups to share their experiences and knowledge with us.

This series of intimate conversations will be led by individual committee members on a topic of their choosing with a small cohort of CADTH staff participating. In this activity, the role of the committee is not to provide solutions. Their role is to raise the issue and give perspectives for CADTH staff to consider in forming solutions. This series is designed to be casual and accessible, hopefully inviting questions and deeper understanding of the committee members' stories and the experiences of health care system users in general. CADTH staff will be encouraged to sign up and participate actively.

Many committee members immediately expressed interest in participating in the series, with several asking specific logistical questions. The series will begin in late 2020 and continue into 2021.