Patient and Community Advisory Committee Meeting Summary

February 16, 2021

Attendees: Beth, David, Devan, Heather, Jonah, Julie, Kathleen, Lilian, Marilyn, Marlee, Marney, Mary, Michelle G, Michelle M, Nadine, Nicole, Paula, Sarah B, Sarah S, Suzanne, Tamara, and Zal.

Executive Update

The meeting opened with an update from CADTH's President and CEO (Suzanne McGurn), discussing CADTH's commitment to addressing anti-Indigenous racism in health care. In response to recent events in Canada, there has been a call to action with all levels of government, health authorities, and pan-Canadian Health Organizations to leverage their capacities to address racism in an ongoing way. CADTH has committed to this by enhancing and expanding staff cultural learnings, exploring embedding an equity lens in CADTH's work, building on the Learning Series (which began as a recommendation from this committee), and exploring working with Indigenous academic and research communities to develop culturally informed and safe approached to care. This will be reflected in the CADTH's 2021-2022 Business Plan.

Strategic Planning

CADTH has started its strategic planning process to ready the organization for its new 3-year strategic plan that will be in place April 1, 2022. The strategic planning process involves working together with internal and external stakeholders to shape our thinking about the future direction of the organization. As part of CADTH's process to develop a new strategic plan, committee members were asked to reflect on the following 4 questions:

Question 1: What are some key changes you anticipate, expect, or hope to see in health care in the next 5 to 10 years?

This was a rich and nuanced discussion. Many members spoke of the shift to virtual care, which is seen as reducing wait times and increasing access to specialists and help for managing chronic conditions. Similarly, several hoped for less red tape and thus faster access to care, with nurses and pharmacists playing a larger role in providing direct care to patients. Other ideas include more collaboration of health authorities and increased appetite for intersectional and culturally appropriate approaches to health care. There is hope for less discrimination and stigma against those who use drugs and a better understanding of trauma-informed practice across health teams.

Future technology including artificial intelligence and new assistive devices to allow people to stay in their homes, as well as advances in gene-based treatments and cannabinoids for treatment of pain and epilepsy, were also mentioned.

Finally, the aftermath of COVID-19 was a major discussion point, including its effects on the opioid epidemic, vaccine hesitancy, short- and longer-term disability as a result of COVID symptoms, recognition of the value of interdisciplinary care teams, and public health funding – including the discussions around National Pharmacare and Canada's Drug Agency.

Question 2: Who are some of the missing voices at the CADTH?

Members highlighted a variety of missing voices, including youth; people living with co-infections; people living with intellectual disabilities; caregivers; nurses; so-called "ordinary people" or the general

public, seniors; people with dementia; and people experiencing poverty (both episodic and generational). There was also concern about CADTH's definitions of rural and remote not matching up with the experiences of people who live in these areas in Canada.

Question 3: In terms of key priorities for CADTH when it comes to patient and community engagement, what are the most important 3-5? Or, in other words, what are actions that, if not taken, would pose the greatest risk to CADTH?

Patients and patient voices need to be better integrated into CADTH and other decision-making entities. Members suggest more active outreach to hear from individuals and lesser heard groups such as seniors, youth, LGBTQ2, newcomers, individuals experiencing poverty, and people with addictions. One suggestion was hosting cross-country consultations, or town hall style meetings.

Question 4: Given the focus on anti-Indigenous racism across the Canadian health care system and CADTH's commitment to working in ways that are anti-racist, we are exploring discussions with First Nations, Métis, and Inuit researchers, initially as a means to encouraging dialogue, as we develop the strategic plan. If we were to proceed, what is the work that you would hope to come out of something like this? What are the ways you might suggest we hold ourselves accountable in these conversations?

Committee members encouraged CADTH to consider how messages are being perceived by Indigenous people and cautioned that intention and perception are not the same. For example, if some jurisdictions use CADTH's recommendation to choose to fund certain drugs or devices while Non-Insured Health Benefits does not, it can create a perception of *"White man's medicine versus Indian man's medicine"* as described by a committee member.

One way to address this is to integrate Indigenous people into senior management and executive level decision-making positions; only Indigenous people can advise CADTH on how to be meaningfully inclusive to their people. Other suggestions include creating a committee of Indigenous advisors to CADTH and/or partnering with Research Canada's new anti-racism committee to work on inclusion.

Members also strongly recommended mandatory cultural training for all staff on an ongoing basis, including a focus on healing and wellness practices that are often overlooked by health care systems.

Learning Series

Committee members were briefly updated on the ongoing Learning Series which has been well attended and popular among CADTH staff. Many attendees noted how much they appreciate hearing personal stories directly from the committee members. Four sessions had been presented by committee members before this meeting, with several more planned for the upcoming months.

Support for Committee Members

A recent incident involved a committee member being verbally harassed after speaking at a conference. Exploration of this topic will continue in future meetings, but appears to revolve around the concept of representativeness.

CADTH is recommitting support for all members. As highlighted in the committee Terms of Reference: "Membership is for individuals, not groups. Members do not represent a specific constituency and are expected to bring views based on their range of experience." Also present on CADTH's website is the

statement that Patient and Community Advisory Committee complements — rather than replaces — existing involvement opportunities. At the next meeting, we will explore how to further explain the role of the advisory committee to interested CADTH stakeholders.

Updates on Past Advice to CADTH

Committee members have highlighted the need for plain language summaries of CADTH reports and recommendations. It was a task specified in CADTH's 2020-2021 Operational Plan, and given resourcing to explore.

Committee members have encouraged CADTH to "*evolve the feedback model*" currently in place, to one where the onus is on CADTH to seek responses from stakeholders. CADTH held a webinar on February 4, 2021 to help all stakeholders understand what deliberative processes are and how they are used by CADTH's expert committees — CDEC, pERC, and HTERP. This was followed by CADTH's first online-only consultation on February 11, 2021 with patient groups that was held to explore how to support patient voices to be meaningfully heard during committee meetings, identifying aspects of deliberations that are important to see in recommendation reports, and how to best to communicate evidence uncertainties. The 2-part consultation was co-created with 3 patient groups.