Patient and Community Advisory Committee Meeting Summary

February 4, 2020; Teleconference 4-6 pm EST

In attendance: Beth, David, Devan, Jonah, Julie, Kathleen, Lillian, Marilyn, Marlee, Marney, Mary, Michelle, Nicole, Paula, Sarah B, Sarah S, Tamara, Zal.

Perspectives Map

In the Terms of Reference, the Committee is asked to help raise awareness of the needs of all of those who use the Canadian health care system, especially the vulnerable and disadvantaged, (workstream 1). As identified in September 2019, the committee saw value in CADTH greater interacting with:

- Individual patients and families
- Most vulnerable end users, such as those living in poverty, possibly explored via social workers and community focused organizations,
- First Nations, Metis and Inuit communities, including non-band affiliated Indigenous communities,
- Those living in northern, rural, and remote areas of Canada, and
- Youth.

Engagement with the above patient communities can contribute to discussions with federal / provincial / territorial bodies on assessments CADTH will undertake and involves those for whom the assessment will impact. These diverse perspectives are also needed to better understand broad barriers to care and the supports Canadian families and communities require to carry out treatment plans and to use health technologies (drugs, medical devices, procedures) optimally.

To support the committee's work, CADTH prepared a perspectives map, identifying how CADTH currently interacts, sources evidence about, and considers, each of the different communities identified in CADTH Single Drug Reviews, large Health Technology Management projects, and Rapid Responses. It is our starting point. Together, we'll plan where we want to go moving forward.

Members expressed surprise at the lack of interaction with First Nations, lower income communities, and rural communities, especially in the Single Drug Reviews. CADTH was reminded that *"patients, in general, are a marginalized and vulnerable population. Breaking into silos entrenches hierarchical power environments used to separate people and keep people marginalized. But, in fact, the entire constituency is marginalized."*

On patient input to CADTH Single Drug Reviews, "*there's a possibility that an exploitation of patients and patient groups can occur through this process.*" Recognizing the purpose is to understand the disease and living with the disease, anther member emphasized that direct interactions with patients would be useful.

"What really stood out to me is the lack of a patient involvement in participation in the process from end to end. I didn't see patients involved as partners in research, didn't see them being involved as partners in setting the research question. I saw them as being inserted at various places throughout the process rather than being real partners throughout the entire process from end to end."

Advice: Shift from '*extracting perspectives'* to '*building relationships*,' recognizing that perspectives come from within the context of the situation and within the relationship.

Explore greater interactions with members of LGBTQT+ communities and new Canadians, in addition to the communities previously identified (individuals, most vulnerable end users, First Nations, Metis and Inuit, rural and remote, and youth).

Acknowledge that the problem does not lie with the community and their engagement. The responsibility lies with CADTH to ensure communities are comfortable interacting. More emphasis on communicating with the end user (those whose lives are being impacted) would be beneficial to CADTH.

Consider additional opportunities to interact with nurses, nurse practitioners, social workers, support workers, outreach workers, and peer facilitators who work in a lot of marginalized communities and have unique perspectives on peoples' wellbeing, especially those experiencing poverty or living in rural and remote environments.

Specific to drug reviews, an important discussion with patients and healthcare providers is around any conditions tied to the funding recommendation. Currently, patients / public only become aware of conditions when the CADTH Common Drug Review process is complete.

CADTH Reflection: Beyond CADTH, some scientists believe large, double-blind, randomized controlled trials alone will discover whether something works or does not. Other scientists see the world as more complicated, that there are value judgements involved in framing a scientific question and in understanding the evidence that addresses it. To reflect a complex world, many perspectives are needed to create and interpret experiments. This tension plays out when involving patients, clinicians, policy makers, funders, industry, and other stakeholders in HTA.

Accessibility at CADTH

We asked committee members to reflect on their experiences with CADTH over the past year, including recruitment. What could CADTH have done better to accommodate your needs? How can we build more inclusive participation?

Several members were happy that CADTH is engaging in this conversation. Examples of what is working well included openness to questions, sharing documents/slides in advance and providing access to webinars for extended learning. One member found our website useful to explore different topics and processes in more depth. Members receive hourly honorarium for meeting preparation, meetings, and travel, which was appreciated. Quick processing of the honorarium form and immediate communication if a cheque is returned, or such an error arises, demonstrates respect of members' contribution and helps support participation.

Turning to meetings, a member explained the unique challenges of travelling from a rural and remote location and the physical hardships that accompany it – recovery time is essential. Another member echoed these sentiments for the disability community, *"Unless you're a person who has to cope with getting in and out of places and things like that, you really can't have an understanding of what makes something truly accessible."* Members were happy with September's meeting venue.

Advice: For events, proactively consult with a disability group, recognizing there are many different types of disabilities. Any community in Ontario larger than 5,000 population is required to have an accessibility advisory committee made up of community members. This could be a resource for CADTH to start with. Patient groups have checklists for accessible events; also Government of Canada's Guide to Planning Inclusive Meetings and Ontario's Planning Accessible Events.

Consider American Sign Language interpretation and /or live closed captioning. Adding closed captioning for events on-line could also be a possibility. Set up meeting spaces to allow people with vision challenges to sit closer to the front.

For CADTH's website, ask different groups to provide feedback on accessibility. The committee's online forum could also be used more often and effectively, with an alert when new posts are added.

Recognizing that CADTH is a publicly funded organization, members encouraged CADTH to see the public as an important audience. Plain language summaries for reports and recommendations are critical to have valid and authentic communication, where people are at.

CADTH Reflection: Three meetings have been hosted as teleconferences. Most members used a webcam to participate, including CADTH staff with individual webcams. Each participate is equally visible. This is helpful to see expressions of understanding (or confusion), to see who wants to ask a question, and helps avoid power dynamics of 'outsiders' joining a 'boardroom' remotely.

While speakers provide presentations in enough time to be uploaded, explaining why it is helpful to share presentations with the audience (for enlargement, for notetaking, for translation) will likely motivate more speakers to comply with the request.

Next Meeting

There was interest in having an informal meeting with the Board of Directors and/or the patient and public members on CADTH's expert committees at the CADTH Symposium (April 18 – 21), as well as meeting the new CEO when Brian's successor is announced. (On March 9, CADTH cancelled our symposium, in line with Public Health Agency of Canada's advice against large gatherings during the COVID-19 outbreak). Members would also like to review goals and Terms of Reference to ensure we are on track. CADTH staff noted that we are in the planning stages for the next multi-year Strategic Plan to direct CADTH's work and how committees will help to guide us. More details to come as they become available.

Committee members were interested in an update on the Canada Drug Agency, but CADTH does not have any further information on this.

Actions

1. When sending in Honoraria, CC PatientEngagement@cadth.ca to allow Patient Engagement team to monitor the process. Please contact Kathleen at Kathleen.Burns@cadth.ca if compensation is not received within 2 weeks.
2. Committee members will work on either Accessibility or Perspectives Map feedback presentations for April meeting (3-4 hours of preparation time). Members are welcome to work solo or pair up to work on this.