Patient and Community Advisory Committee Meeting Summary

March 16, 2022

Attendees: Beth, David, Devan, Francesca, Jonah, Julie, Kathleen, Kristen, Lilian, Marilyn, Marlee, Marney, Mary, Nicole, Paula, Sarah B, Sarah G, Sarah S, Shannon, Tamara, Zal.

Welcome

This meeting began with reflections from our committee chair about the recent CADTH Board meeting and a wider discussion about CADTH's upcoming strategic plan. There is an agreed upon strong need to see Diversity, Equity, and Inclusion (DEI) efforts implemented across the organization, while also recognising that CADTH is consistently working to do better in this space, as demonstrated in the 2022-2025 strategic plan guiding principle:

"We [CADTH] will apply a lens of equity and inclusiveness, fostering health systems that reflect the diverse people of Canada."

Patient Engagement Resources

The next phase of this meeting was an update on the resources that are being co-developed by CADTH staff and members of this committee, designed to help CADTH staff and patients to work together and feel supported in their work. There are few resources available for patients working in and supporting Health Technology Assessment and many existing resources are more theoretical (i.e., "why should we engage patients") than practical (i.e., "here are steps to take when you engage patients") in nature.

Prior to this meeting, a sub-group of interested committee members met with members of CADTH's staff to discuss big ideas, begin drafting the workplan, and to consider the importance of having a space to ask questions openly on both sides:

"You won't get in trouble with patients if you tell us the truth. We aren't fragile."

A workplan was presented to the committee and members provided feedback on the proposed resources, which included guidance around honorariums and formal recognition, inclusive language, holding truly accessible events, and an overview of the different roles on CADTH project teams. The proposed honorarium guidance was particularly well received:

"I can genuinely say that it was CADTH paying me on the same level as the other, professional experts, that made me feel like I have something worth saying."

One member stressed the importance of grounding the work in <u>patient engagement principles</u> and understanding what engagement is. Another urged the resource development team to develop a resource to build capacity of CADTH staff in finding patients with DEI principles in mind. Much of the discussion revolved around terminology and the importance of being careful with words and the weight they hold. However, some members expressed a different view:

"As a patient, I don't care what you call me. I care that I have a voice, that you listen, and that I feel valued"

The conversation closed with reflections on the connections between this conversation and previous discussions held with this group about unconscious bias.

Tech Trends to Watch 2022

The top 10 list of technologies, Tech Trends to Watch, was presented. This list examined top 10 technologies that have the potential to fundamentally shift the way health care is provided and accessed in Canada within the next 2 years. The list was developed by collecting the views of people from across Canada about new and emerging health technologies and trends and prioritizing them using a consensus-based decision-making process adapted from the James Lind Alliance . Patients, health care decision-makers, researchers, and industry experts were involved in the prioritization of technologies. The ranking informs the work of CADTH's Horizon Scans program.

[Note: Since this meeting, the report has been released and is available online: https://canjhealthtechnol.ca/index.php/cjht/article/view/er0012/576]

One committee member participated in the ranking process and shared their reflections with the wider team, highlighting the respect they felt as a contributing member of the process. Committee members encouraged CADTH to clearly describe patients' involvement in the creation of the list of technologies. CADTH incorporated this feedback at the March webinar 10 Trends Shaping the Future of Health Care in Canada.

Recruitment for CADTH Committees

CADTH is in the process of recruiting for multiple positions on different committees, including this one. Several members are ending their terms with this committee (extended by one year due to the pandemic) to allow for healthy turnover. So, there will be open positions on this committee. There are also openings on the: Canadian Drug Expert Committee (CDEC); Health Technology Expert Review Panel (HTERP); Device Advisory Committee (DAC); and the new Post-Market Drug Evaluation (PMDE) committee. Of the 16 roles we are currently looking to fill on these committees, 7 are for patients.

More information about each of these committees and openings is available online: https://www.cadth.ca/news/cadth-call-nominations-our-experts-need-your-expertise; anyone interested in these opportunities is encouraged to apply.

Members are welcome to apply to other committees but are cautioned that they would only be able to participate in one CADTH committee at a time.

Updates Related to Your Advice to CADTH

CADTH is working with other pan-Canadian Health Organizations and Patient and Family Advisory Councils to learn from their experiences with patient networks and learn how best to support patients in this endeavour.

CADTH has been working to improve staff's cultural and structural competence through attending conferences, workshops, and an upcoming "cultural competence in health care" event.

In recent months, the Patient Engagement team has expanded the approaches to involve and collaborate with patients and communities. As explained by <u>IAP2 Spectrum of Public Participation</u>, to involve is to work directly with the public to ensure concerns and aspirations are fully understood and considered. CADTH teams working on Scientific Advice and some Health Technology review projects meet with patients and/or family caregivers who: identify patient important outcomes and family-borne costs; describe their experience of illness, the technology, and their health system journey; and identify equity considerations. Recent CADTH projects include <u>Lived Experience with Dementia</u>, Peer Support Programs for Youth Mental Health, and Internet-Delivered Cognitive Behavioural Therapy for Chronic Pain.

Collaboration is another part of the IAP2 Spectrum; to collaborate is to partner with patients in each aspect of the decision. Recent examples include a person with lived experience of multiple sclerosis and stem-cell transplant joining other experts at HTERP to advise on autologous hematopoietic cell transplant for MS, patients on the Stakeholder Panel on Post—COVID-19 Condition, in addition to the Tech Trends to Watch working group and workshop. Following up from a suggestion from this committee, CADTH has begun reaching out to patient groups to let them know about potentially relevant, recently published, Horizon Scans and Rapid Responses. Several patient groups have responded with their appreciation of the outreach.

Finally, CADTH would like to thank this committee for their work on the proposed pan-Canadian Formulary last meeting. The information will be presented to the Advisory Panel.

The next Patient and Community Advisory Committee meeting will be in May 2022.