

July Teleconference Meeting Summary

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

Reflections on COVID-19

Members shared their personal reflections on how the virus and the ensuing lockdowns have affected their communities. One member described the pandemic as “we’re all in the same storm, but not in the same boat”.

Several members mentioned how deeply affected patients and caregivers are by the shutdown of services – this includes but is not limited to access to non-pharmacological pain treatments, service animals, and various therapies. At the outset of the pandemic, individuals with disabilities found themselves unable to secure grocery deliveries and other essential goods. Seniors, individuals in long-term care, and children with developmental delays were particularly disadvantaged, as “good care exists in an ecosystem, where the whole system can get thrown off by one event (e.g. COVID-19)”.

COVID-19 has had a devastating impact on health charities and patient groups including funding cuts and staff layoffs; this will affect their ability to do advocacy work and provide patient feedback for CADTH’s projects for years to come (anticipated).

Some positives to come out of the pandemic are the switch to virtual care (long championed by patients and caregivers) and the number of ongoing medical research projects and attention to medical needs from unlikely sources. It is a boost to patient-centred care, but so far, is inconsistent across jurisdictions; many members noted how wildly varied experiences have been, depending on where in Canada they live.

Feedback on Perspectives

Remote Perspectives

The definition of “remote” currently used by CADTH and others (a minimum of four hours away from hospital services by ground transportation) is lacking. Most of the Yukon wouldn’t be considered remote, for instance. Geography is not the only aspect. Consider instead a region that has substantially different social determinants of health outcomes that directly lead to health inequality (e.g. access to broadband internet, distribution of clinicians, language).

Additionally, most evidence is collected from clinical trials in urban settings, which leaves out the unique experiences and perspectives of individuals living rurally or remotely (note: not interchangeable terms). Remote perspectives may inadvertently be silenced in decision-making. That absence may further health inequalities. In a similar sense, committee members noted that clinical trial participants are most often cis-gender white men; we need trials to engage beyond these parameters to be able to understand diverse experiences that better reflect the population in Canada. There should be more effort to engage patients living outside of urban centres to contribute to evidence.

Rural/Context Matters

A central tenet of this discussion is that context is extremely important, and all too often overlooked. For example, the distinction between living rurally and living remotely is important to individuals and communities but can be poorly understood by researchers.

Context is important when offering public health advice (as seen in COVID-19 pandemic), as it is unhelpful to recommend handwashing etiquette to individuals without easy access to clean water or suggest distancing in overcrowded homes, institutions, or schools. There is a need to actively explore the context of an individual's life (or a community's reality) before providing advice. For researchers and healthcare providers, it is crucial not to make assumptions that the resources readily available to them are the resources available to everyone in Canada.

Individuals

CADTH does not typically engage with individual patients, who are not associated with a specific group or disease area. Individuals come from a variety of sources and have a lot of lived experience to share. It is worth noting that individuals who get involved are most often those who have post-secondary education. Also, some individuals (especially from underserved groups) are uncomfortable with institutions such as CADTH because of past trauma.

Within the system, Patient and Family Advisory Councils in hospitals, long term care, mental health and health authorities involve individuals in system change. Can CADTH be an enabler of collaboration and build relationships with Patient Engagement staff in institutions and agencies across the country? What if there were a pool of patients across disease states that CADTH and other stakeholders (such as other pan Canadian Health Organizations) can draw on for a variety of involvement opportunities, pooling their resources to create a large, diverse cohort of people across the country who are ready, willing and able?

Outside the system, are the independent groups springing up on social media, in particular on Facebook, where the bulk of disease specific conversations among individuals is taking place? CADTH can develop a social media engagement strategy and related policies and develop criteria to distinguish real vs fake news sites. It would be important to establish guidelines for interacting with influencers.

It is important for CADTH to be aware of the patient stories that are not being heard, and why. To encourage more diverse voices to get involved, CADTH should write all communications in plain language and avoid using jargon and acronyms whenever possible. Language matters. A single word can unintentionally act to bar individuals from participation.

Youth

The definition of "youth" is quite ambiguous and could apply to a range of individuals from teenagers to late twenty-somethings. This is noteworthy because medical care shifts abruptly from the pediatric to the adult system at age 18 – often without a clear transition plan.

Several committee members mused over CADTH's relevance to young people – do they know about CADTH? Why should they care? Most agreed that it would be up to CADTH to cultivate a relationship with youth, perhaps by reaching out to existing Youth Councils at hospitals and research institutions. These organizations are natural partners for CADTH and working in collaboration with them provides a safe entry point for CADTH and a safe place for youth to meet CADTH.

Another approach would be to consider a Youth Ambassadors program, as youth tend to listen to other youth. One member stressed how the method used to communicate information to youth matters (e.g. videos, comedy, music) as it will impact willingness to collaborate. Another urged CADTH to always have at least one young person on the Committee to represent youth voices.

First Nations, Inuit, and Métis

Many committee members were troubled by the lack of feedback in CADTH reviews from Indigenous patient groups or individuals. One member recounted their frustrating experience trying to understand the relationship between CADTH and the Non-Insured Health Benefits (NIHB) program for First Nations and Inuit individuals. Members felt CADTH needs to make a concerted effort to raise awareness of CADTH among underserved groups and underscore that their input is valuable (“We want to hear what they have to say”). For CADTH, it may take a greater effort in reaching out to Indigenous health authorities and informing them of the role CADTH has in determining the funding of drugs by NIHB and the importance of having input from Indigenous providers. CADTH needs to do reconciliation work with Indigenous groups.

As an example of missed engagement and the impact that has on a community is CADTH’s recent glucose monitoring review. Given the prevalence of diabetes in First Nations communities, committee members felt that CADTH should have consulted with Indigenous clinicians and patients. One member was troubled by the evidence cited in the review, which did not match up with their experiences in the community.

Several members suggested CADTH should have a strong Indigenous presence in its decision-making bodies and expert committees. Committee members asked CADTH staff to investigate cultural safety and decolonization training for future sessions.

Evidence

The committee feels that CADTH needs to consider its own approach to evidence and how it may be lacking. The committee encourages CADTH to “evolve the feedback model” currently in place, to one where the onus is on CADTH to seek responses from stakeholders – known as a “duty to consult”. Members stressed that there is a power imbalance when individuals and patient groups interact with CADTH and other health organizations, in that individuals are required to adapt to the organizational culture, not the other way around.

It must start with trust, honesty, and respect and uncomfortable conversations. Start with just hearing their stories. Listen with your heart, not your head and stop trying to solve their problems until we ask them what they want and need from CADTH.

Is there a way for CADTH to enable these changes, rather than trying to do it all? The committee is mindful of limited capacity.

Actions

1. Chair will send notices confirming receipt of any emailed documents
2. Committee members will review past meeting summaries at start of each meeting. Approved summaries will be posted on CADTH’s website.