Patient and Community Advisory Committee Meeting Summary

August 25th, 2020

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

Regrets: Marney

Meeting Suzanne McGurn

The committee met with CADTH's new President & CEO and heard about her previous roles, her transition to becoming CADTH's President & CEO and her commitment to this committee and involving patients in CADTH's work. Members highlighted their interest to add patient members to the Board of Directors, to create clearer paths for advice from this committee to decisions being made, to work on inclusion of under-represented communities in CADTH's work and to ensure CADTH's work was understandable by the general public.

Suzanne confirmed opportunities for this committee's involvement in discussions for CADTH's next strategic plan and contributing to Health Canada's five-year evaluation of CADTH. CADTH is also undertaking a review of our processes for generating recommendations through a review of our expert committees' deliberative frameworks. There may be opportunities for the committee here too. ***"Having patient values top of mind will be critically important."***

Feedback on Perspectives (continued from July)

LGBTQ2S+ and Racial Inequity

The concept of "intersectionality" was key to this discussion; specifically, understanding the intersectional identities of patients. An introductory video was shared, highlighting the ways that different oppressive forces can affect a person at the same time (ex. Racism, Sexism, Ageism, Ableism, Homophobia, etc.) and how many would-be helpful policies only address one issue at a time.

During the discussion, a committee member asked each participant to consider their own intersectional identity, asking a series of questions and providing examples of microaggressions (ex. being complimented on "speaking good English") and the resilience required to overcome it. They cautioned against researchers assuming that every patient has the same sex and gender experiences and called for greater diversity in participants in clinical trials.

> *"White privilege is not about socio-economic status. It's that the colour of your skin is not a barrier or impediment to your existence, survival, [and/or] your access to services and health care."*

Healthcare providers must ask the right questions to provide culturally appropriate care to their clients. LGBTQ2S+ youth are struggling with mental health concerns (depression, anxiety, stress, suicide ideation), eating disorders, adverse childhood events, HIV infections, intimate partner violence, and intergenerational trauma.

The discussion touched on how CADTH resources can be useful to communities who are underrepresented and patients. Several members felt that the senior management would have to "buy in" to these ideas to create real change, and that the committee would need to monitor their

performance on these issues. A key message was noting the difference between diversity (having people of different races, sexes, religions, etc. come together) and inclusion (how your voice is embedded in the decision-making process).

Several members expressed appreciation for the frank conversation and the resources provided. Another member noted that many committees, including this one, are primarily representative of the white, middle class voice. They pushed for the committee to establish principles to address this and have more diverse patient representation. Members agreed that diversity should be a key consideration in future iterations of this committee.

Rural/Remote

The pandemic lockdown (and resulting issues with online learning) have highlighted the struggles of living outside of an urban area in Canada. Members from different regions detailed how difficult it has been to continue working and connecting with loved ones using unreliable Wi-Fi and slow bandwidth. As many medical professionals moved to virtual appointments during the pandemic, many patients had to adapt quickly. However, several members were quick to note that the pandemic has led to advanced technology (including virtual healthcare) that has been enormously helpful to patients with chronic pain and/or mobility issues. This format has also helped address some transportation challenges.

Despite technological advances, living in a rural/remote area remains a barrier for clinical research participation. A member noted that rural and remote Canadians are often left out of clinical research because they are unable to easily return to the institution where research is happening (typically in a large urban centre). In addition, there is a burden placed on participants in terms of the time and cost to participation. Patients must cover the costs associated with transportation and plan for time away from work and home commitments.

CADTH staff noted that researchers have worked with patients living rurally or remotely in the past, relying on telephone conversations and physical mail to communicate (as opposed to the more standard email).

Seniors

A member shared their personal struggle with losing eyesight over the last few months and how this has affected their day-to-day life and work – being unable to read previously handwritten notes, for example.

Members expressed concern that seniors have been significantly affected by the pandemic lockdowns and lack of preventative healthcare procedures. The 70+ cohort have experienced significant isolation and deterioration during this period, largely due to the cancellation of in-person fitness classes and social gatherings. Some places have few COVID cases, but regular healthcare is still affected, and visitors are not permitted in most hospitals (and some care homes).

> ***CADTH reflection:*** *It is crucial to understand the "why" in these scenarios – why is it important to understand what's going on in the healthcare system? Why are projects incomplete when we aren't capturing these perspectives? At the same time, we want to move to practical next steps, turning "what should we be doing" into "what can we be doing" and going from there.*

Questions for CADTH Staff

Senior staff from CADTH's Pharmaceutical Review team, HTA and Program Development team, and the Implementation Support team joined this meeting to facilitate a clearer understanding of the ways in which the committee's work and CADTH's work interconnect.

Committee members asked about the type of medical devices CADTH reviews and how CADTH finds and works with patients for device projects. Engagement can vary across projects, with the approach taken described in the methods section of the resulting reports.

Members noted with surprise that stakeholders who contribute feedback do not hear back from CADTH to know they've been acknowledged and/or what becomes of their advice and asked CADTH staff to look into alternative options.

Members were also interested in hearing what 'ah-ha' moments were inspired by patient insights during assessments. It was shared that patient experience is important and can influence reviews by identifying new angles to consider, identifying any mismatch between what we heard was important to patient groups and what was measured in trials, in defining drug recommendation conditions for reimbursement and in creating patient-focused resources.