

Patient and Community Advisory Committee Meeting Summary – November 18, 2021

Attendees: Anabele, Beth, David, Devan, Heather, Helen, Jonah, Julie, Kathleen, Laurie, Lilian, Marlee, Marney, Marilyn, Michelle, Nicole, Paula, Sarah B, Sayako, Suzanne, Tamara, and Zal.

Welcome

This meeting began with reflections on the devastating flooding in British Columbia.

pan-Canadian Framework for a Prescription Drug List

Two CADTH staff members from the pan-Canadian Framework for a Prescription Drug List team came to present their work to the committee and seek guidance on best practices for reaching historically marginalized communities. Details on the project are available on CADTH's website:

<https://www.cadth.ca/pan-canadian-advisory-panel-framework-prescription-drug-list>

Different committee members responded, beginning with the idea that any engagement must be intentional and mindful of potential barriers; for example, rural and remote communities do not have access to the same highspeed internet as urban centres, making it difficult to participate in webinars or virtual meetings. Members encouraged CADTH to consider alternatives to meetings like quick social media polls or allowing letters from patients and patient groups. They also recommended longer deadlines for greater participation, particularly around the winter holidays.

A member reflected on the different Indigenous communities across the country and cautioned that "participation isn't one size fits all;" they strongly encouraged CADTH to reach out to multiple communities.

As a post-meeting update, in addition to a discussion paper, CADTH held an [open information session](#) on January 18, 2022. Alexandra King and Allen Lefebvre, co-chairs of the pan-Canadian Formulary Advisory Panel presented on the interim work of the panel in plain language. They identified areas for feedback and answered audience questions. In addition to the 6-week consultation, CADTH staff also proactively reached out to First Nations, Metis, Inuit, rural, remote, and underserved communities, holding 4 focus groups.

Real-World Evidence Activities at CADTH

Two members of CADTH's Real-World Evidence (RWE) team returned to this committee to report back on their progress. CADTH recently held a *Best Brains* exchange with patient co-leads focusing on rare diseases; additionally, CADTH is exploring building a database of patients to "reach the right people quickly" and asked this committee for advice.

Various committee members urged CADTH to focus on reaching communities (low income, Indigenous, rural), rather than individual patients and cautioned that it may not be the easiest approach but is necessary. One member reflected on the different experiences faced by patients with a low-income. Some suggestions were to create a toolkit to engage patients (explored more below), to invite participants to

come to the table as people rather than job titles or community representatives, and to include patients on project steering committees.

Post-meeting update: Information about CADTH's work in RWE is now available on our website: <https://www.cadth.ca/real-world-evidence-decision-making>. The Canadian Organization for Rare Disorders (CORD) is a member of the Real-World Evidence Steering Committee, chaired by CADTH and Health Canada.

Update on CADTH Strategic Plan

CADTH's CEO, Suzanne McGurn, joined the meeting to listen in on perspectives shared and give an update on the new strategic plan. Members offered ideas on direction for CADTH, and challenges and opportunities in health care during our February 2020 meeting and again offered feedback on emerging themes in June 2020.

A member highlighted the value of being "seen as allies in this process." Another member asked how engagement is measured.

"How do you plan to measure that? That it's not just words and not just sounding nice but is actual, meaningful action."

Suzanne invited members to contribute to identifying metrics to measure meaningful involvement of patients throughout CADTH's work.

Post-meeting update: Read our [2022-2025 Strategic Plan](#) and [watch the launch](#), including reflections by Marney Paradis, Chair of the Patient Community Advisory Committee.

Collaborating With Patients

A committee member congratulated and thanked members who presented at the CADTH Symposium this year, representing this committee's work on the Learning Series last year. Another member reflected on the importance of strong relationships to disrupt bias. We need to move from "transactional relationships" to meaningful interactions as "harmonious partners" to advance patient engagement throughout CADTH.

"Think about our stories, how we tell our stories, and how our stories change depending on who's listening. The fact that the listener shapes the telling is really important here. Think about your story that you've told so many different times to different people and it comes out differently every time depending on who's listening, whether it be a doctor, a friend, a journalist – it's always different."

In September, several CADTH projects using new approaches to involve patients were highlighted including Internet-Based Cognitive Behavioral Therapy for Post-Traumatic Stress Disorder, Minimally Invasive Glaucoma Surgery, and Phosphodiesterase-5 Inhibitors for the Treatment of Secondary Raynaud's Phenomenon and Digital Ulcers.

To continue to support greater involvement of patients in CADTH's work, resources and approaches were identified from other health technology assessment (HTA) agencies internationally and health care organizations in Canada. Although there is much for CADTH to build from, gaps included resources co-created with patients and approaches with a community focus rather than disease-specific focus. Members were invited to help CADTH co-create a tool kit for use by CADTH and patient collaborators to advance engagement throughout the organization.

Discussion About Member Participation in CADTH

In addition to regular, all member meetings, a discussion took place on how individual members might work more closely with CADTH staff on broad, non-technology specific, CADTH projects such as use of RWE and building a corporate strategy for diversity, equity, and inclusion. A committee member reflected that this committee is often asked about surface level engagement and would prefer the opportunity to offer deeper insights with time to reflect and reach out to their own networks.

Updates Related to Your Advice to CADTH

New this year, CADTH is publishing examples of how CADTH uses patient perspectives in its products. Examples from March, June, July, and August 2021 are available on CADTH's website. For more details see: <https://www.cadth.ca/impact-patient-involvement-0>

Additionally, CADTH is proactively engaging patients and caregivers for 2 upcoming projects, 2022 Tech Trends to Watch and the CADTH panel on people with lived experience of dementia. CADTH is working to find and amplify diverse voices and experiences.