

# Patient and Community Advisory Committee Meeting Summary – June 28, 2021

**Attendees:** Beth, Devan, David, Heather, Jonah, Julie, Kathleen, Laurie, Lilian, Marilyn, Marlee, Marney, Mary, Meghan, Michelle G, Michelle M, Nadine, Nicole, Patricia, Paula, Sarah B, Sarah S, Tamara, and Zal.

## Overview of the Pharmaceutical Advisory Committee

This meeting began with a member of CADTH's [Pharmaceutical Advisory Committee \(PAC\)](#) speaking to members of the Patient and Community Advisory Committee and answering questions about the role of PAC, as well as its interactions with CADTH and the provincial and territorial drug plans. There was a rich discussion on this topic. Several members expressed their appreciation for this unique opportunity.

## Update on CADTH Strategic Plan

CADTH is in the midst of developing a new strategic plan for 2022-2025. This committee had provided input into early development of the plan in April 2021 and was asked to give early feedback on the proposed new vision, mission, principles, and the 5 described themes providing high-level strategic direction.

Patient and Community Advisory committee members were pleased with the increased attention given to patients and the Canadian public and encouraged that it be defined how CADTH was going to achieve this goal within 4 years. Members offered alternative language to involve patients and communities respectfully and inclusively in CADTH's work, suggesting the [Canadian Human Rights Commission](#) and [Truth and Reconciliation Commission of Canada](#) as good sources to model.

## Inclusivity: CADTH Corporate Accessibility Policies

CADTH has been working to bring both our website, [cadth.ca](#), and internal policies up to the [Accessibility for Ontarians with Disabilities Act \(AODA\)](#) standards. Having recently relaunched the website, the CADTH Executive team is now looking to update policies and asked the committee members for advice on going above the minimum requirements set out by the AODA.

Some committee members suggested CADTH could include more rest time in travel itineraries, citing the physical challenges of travelling with chronic pain and/or mobility issues. Several committee members urged CADTH to directly involve people with disabilities in the planning process (e.g., scouting meeting venues), as these individuals know the day-to-day realities and can notice things able-bodied individuals might miss (ex. Are accessible restrooms available on the same floor? Are automatic door openers functional?). Organizations can also be contracted to provide accessibility audits, which CADTH may want to look into for future events. This topic will be especially important when large in-person events resume after the pandemic.

## Understanding Systemic Bias

Of the more than 1,000 health related charities that exist in Canada, a small subset of groups (30 to 50) regularly participate in CADTH, Health Canada, or the Patented Medicine Prices Review Board process

consultations. Two committee members shared their observations of recent antagonistic interactions between government-funded bodies (beyond CADTH) and politically active patient groups. Members asked how these experiences might impact CADTH's attitude toward patients, patients' attitudes toward CADTH, and the willingness of both sides to collaborate. CADTH and committee members will reflect on these questions and identify what can be done to prevent, alleviate, or dispel any mistrust that exists.

### **Evidence Gaps: Real-World Evidence**

A member of staff spoke to this committee on CADTH's plans for increasing the use of real-world evidence (RWE) in CADTH's work. RWE comes from the analysis and/or synthesis of real-world data. Real-world data is an umbrella term for data collected outside of randomized controlled trials. It can fill gaps that cannot or have not been addressed by these trials. Real-world data may be collected from a range of sources such as medico-administrative databases, registries, observations of clinical practice, and experiences of patients and health care providers.

Several learning projects are planned by CADTH and Health Canada with focus on collaboration during clinical trial planning (Scientific Advice at CADTH), before regulatory review by Health Canada and following completion of health technology assessment by CADTH. Use of RWE will support decision-making, especially for newer technologies that do not yet have a large body of evidence available.

Many committee members were excited to hear that CADTH is embarking on this work. One member urged CADTH to consider the realities of Indigenous and rural and remote communities.

### **Cultural Competency: Update on Learning Series**

The Learning Series has officially wrapped up, after 10 committee member-led sessions on a variety of topics. This work was above and beyond the roles and responsibilities associated with this committee and CADTH thanks each member who participated and shared their lived experiences with CADTH staff.

While this committee as a collective advises CADTH on a high level, this series was aimed at reaching average CADTH staff members. The goal was for staff to have a chance to reflect on patient and community perspectives as they complete their work, no matter what their role is at CADTH. Now that the series is complete, CADTH will report on its impact - both on the staff attending the sessions and on the committee members leading them. An abstract on the Learning Series was submitted to the CADTH Symposium, proposing a panel discussion.

### **Updates on Past Advice to CADTH**

Committee members have highlighted the need for plain language summaries of CADTH reports and recommendations. CADTH now provides a summary of CADTH Reimbursement Review Recommendations, highlighting key ideas organized around several simple prompts to allow a broader audience to understand the recommendation at a glance.