

Patient and Community Advisory Committee Meeting Summary

April 7, 2021

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

Reflections on the Pandemic

The meeting opened with a roundtable discussion on the COVID-19 pandemic. Several committee members proudly shared their vaccination stories (or upcoming appointments) amid a conversation on vaccine reluctance, while others spoke of their experiences on the forefront of the vaccination effort. While most members describe feeling optimistic and hopeful, some shared their mental health struggles, particularly in this latest wave. A member reflected on the parallels to the HIV epidemic while another member shared their personal lived experience with contracting and recovering from COVID-19. Several members expressed frustration and concern that patients with disabilities and their caregivers are not higher on the vaccine priority list in their provinces, citing their heightened risk for severe illness. Overall, committee members expressed *“tremendous thanks and gratitude for health care workers.”*

Not Representatives

To begin the discussion, CADTH staff unpacked decision-making, advisory, and advocacy. The Patient and Community Advisory Committee provides advice to CADTH Executive and its Board, but it does not have decision-making authority. Separate to the committee are patient groups. They advocate to further the work of their own individual mandates and are accountable to their membership. Each member of the Patient and Community Advisory Committee offers insights from their own experiences and does not represent any community, disease area, organization, or viewpoint. A recent article, [Creating a patient and community advisory committee at CADTH](#), explains why CADTH chose to involve individuals with broad intersectional experiences rather than representatives from patient groups for this committee. CADTH will continue to host consultations with patient groups and seek their involvement in specific assessments. The committee does not replace any existing engagement activities.

CADTH Executive stressed that committee members are not expected to represent CADTH and its activities, but rather represent themselves. Several committee members agreed, describing the ways they declare their relationship to CADTH: *“the other key piece I say is that I am on this committee to represent me. My lived experience, both personally and professionally, but I only represent me.”*

Learning Series Update

As discussed in previous meetings, the Learning Series for CADTH staff was suggested by a committee member who had previous experience with a mentorship program for health care providers. The objective of the series is to provide an opportunity for CADTH staff to hear the personal and professional stories of committee members, ask questions, and reflect on the story in their own lives. The sessions are open to all staff and senior management encourages staff to sign up. To date, there have been 6 sessions on topics such as living with chronic disease, living with pain and disability, providing culturally competent care to people in the LGBTQ2 communities, living with migraines, issues of poverty and health inequity, and experiences as a pharmacist and father in a First Nations community. Several more sessions are in the works.

Committee members were given the opportunity to reflect on the series and its goals:

“Staff learning to not be defensive when they hear patient stories that reflect negatively on the health care system is huge. As someone who has shared my story, it is a concern that someone will come up to me afterwards and push me on my experience or why decisions were made, etc. from that defensive standpoint. It’s so important to be heard and accepted.”

Committee members and CADTH staff will need to consider the next steps of the series, including how to evaluate its impact and how to expand (if intended).

Creating a Network of Patient Collaborators

CADTH works with individuals with lived and living experiences in our Scientific Advice program and in some device assessments. As we, at CADTH, expand the number of projects that involve patients, we can work more efficiently by building the knowledge infrastructure to easily identify potential collaborators and have resources ready to support staff and collaborators working well together.

Committee members commented on how CADTH can support patient collaborators. Building on the earlier discussion, members cautioned that CADTH would need to be mindful of creating a safe environment with healthy boundaries and necessary training for would-be applicants — including why you are enlisting patients and how it will benefit them and their communities. Committee members also strongly urged CADTH to reach out to members of the public who are not already engaged in this work, noting that young people, seniors, individuals experiencing poverty, and those in underserved communities tend to be missed in this type of work. This is another reason using plain and accessible language is crucial.

One suggestion to expand patient involvement would be to create and sustain an online database of patients. Another suggestion was to learn from and partner with health care organizations who currently work with patient advisors and patient collaborators. Staff resources would be required to support potential collaborators and maintain records. Members also noted that there would need to be a focus on building an equitable system and building trust; also, that more vulnerable populations would need added support (for example, childcare, IT assistance, etc.):

“I always remind people that when developing health care ‘solutions,’ you must build it based on equity for the most vulnerable persons.”

“You can’t claim to be inclusive until the most vulnerable, marginalized people are at the table.”

CADTH staff and committee members agreed that trust building will be an essential first step in this process.

Updates on Past Advice to CADTH

The Learning Series is a great example of advice coming from this committee being actioned by CADTH, leading to staff appreciating the richness of the stories coming from patients and a higher comfort level interacting with patients.

CADTH Executive truly appreciated the committee’s input into the new strategic plan and are looking forward to returning to a future Patient and Community Advisory Committee meeting to provide an update.

Upcoming Opportunities

CADTH is currently recruiting for new patient members for the 3 expert committees and encourages committee members to explore the opportunity and share it with their networks.

The HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) are sponsoring patients from around the world to be delegates at the HTAi Virtual Conference, June 19 to June 23, 2021. CADTH staff are happy to provide recommendation letters if committee members are interested in attending the conference and learning about how patient involvement works in other HTA bodies.

CADTH's 2021 Symposium will be virtual again this year, hosted on November 2, 3 and 4, 2021. The theme will be "Uncertain Times, Imperfect Evidence, and the Imperative to Act".