PCAC September 2021 Meeting Summary

Attendees: Beth, David, Devan, Jonah, Julie, Kathleen, Lesley, Lilian, Marlee, Marney, Mary, Michelle, Nicole, Paula, Sarah B, Sarah S, Suzanne, Tamara, and Zal.

Regrets: Marilyn.

Medical Devices and Clinical Interventions

This meeting began with a presentation from the Vice President of CADTH's Medical Devices and Interventions Directorate, who gave an overview of their team, the types of products they produce – Rapid Response, Horizon Scans, Environmental Scans, Health Technology Assessment, and Optimal Use – and some examples of the topic scoping process. They outlined the roles and responsibilities of the 2 committees related to this work, the Device Advisory Committee (DAC) and the Health Technology Expert Review Panel (HTERP).

Health Technology Assessments and Optimal Use projects are typically used in decision-making and involve stakeholder consultation facilitated by CADTH. Committee members expressed a general concern of when CADTH products, such as Rapid Response reports, are used in policy decisions made by federal, provincial, and territorial health ministries, without stakeholder consultation or patient involvement.

It was also highlighted that insights and experiences absent in the literature and clinical trial data can become available to CADTH if there is respectful, proactive engagement with patients and communities. A member highlighted that patients and communities offer:

"[Members of Indigenous communities] have evidence that is difficult to obtain or impossible to quantify. That's why it's important to have patient perspectives."

An opportunity identified by committee members was the potential for CADTH Horizon Scans to be proactively shared with patient and community groups, as they could be a useful resource for potential users of the technology. As an update, in November 2021 and February 2022, staff proactively reached out to 32 patient groups to share 4 relevant Horizon Scans. Several groups expressed their interest and appreciation.

Proactive Engagement With Patient Collaborators

Based on advice from this committee, CADTH is making deliberate and careful efforts to improve diversity and inclusion in health technology assessments that inform policy decisions in Canada.

"The challenge for CADTH is you have such a broad scope and need input and advice on an incredibly wide range of topics."

Recent examples include engaging patients in projects on Internet-Based Cognitive Behavioural 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 (which was the first CADTH Rapid Response to include patient engagement). Staff use the "GRIPP2G" framework to track engagement in new projects.

Committee members recommended BC's Patient Voices Network, Aboriginal Patient Navigators, and Patient Family and Public Advisors Council in Ontario as examples of organizations who have good engagement with patient advisors. A member cautioned CADTH to make the process simple to ensure accessibility for a wide range of communities. Another flag was related to compensation – specifically, ensuring that patients are treated equally and at the very least, are not the only unpaid members of the team.

"And there's a big psychological difference in being literally valued that isn't always considered. Working with CADTH was the first time I felt like I truly had something of worth to say, that my lived experience was actual, real, experience and not just a buzz word."

Exploring Systemic Bias

Continuing a theme from the last meeting, a member of the committee met with other interested members for one-on-one conversations about the systemic biases relating to patients in our health care system. The committee member spearheading this initiative expressed deep appreciation of their fellow members' honest and thoughtful reflections.

Participating committee members explored personal experiences of bias, what influences bias, experiences of bias with CADTH, and considerations for improvement. Several themes emerged, including disease, condition, and provider bias; socio-economic bias; literacy bias; clinical trials; patient groups; policy; industry; professional training; epistemic bias; employer loyalty; media and research influences; temporality; and ableism. CADTH-specific topics included advisory panels and drug review patient input.

Members urged CADTH to continue engaging and educating both staff and expert committee members in activities such as the Learning Series and projects enabling patients to directly interact with staff. Several members reflected on the changes they have witnessed around valuing patient feedback and insights, arguing that CADTH is making progress, with further progress needed.

CEO Remarks

Suzanne shared her observations on the growing role for patient and citizen engagement in shaping compassionate public policy. In listening to the earlier discussion on proactive engagement, Suzanne was excited about the new ways CADTH is involving patients and promised to include regular updates to the board on our new engagement initiatives, in addition to sharing advice from this committee. Recognizing that relationships only matter when there is trust, it was noted that the work being undertaken around systemic bias demonstrates a level of trust by this committee with CADTH and Suzanne looks forward to seeing that continue to grow.

Several committee members recommended cultural sensitivity training to CADTH last year and were encouraged to hear that this work is under way and is directly tied to CADTH staff performance objectives. CADTH's recent board member appointments were undertaken with a diversity and inclusion lens, again something this committee has encouraged CADTH to action.

Updates on Past Advice to CADTH

Two of our committee members worked with CADTH's Corporate Services team to update CADTH's corporate accessibility policy; based on their expertise, the overall tone was adjusted, and the policy was expanded. Committee members will be asked to collaborate again in a few years when the policy needs to

be updated. Another policy – Equity, Inclusion, Diversity, and Anti-Racism – is currently in the works and will be another opportunity for this committee to contribute.

The Learning Series – an idea arising from this committee last fall – has officially wrapped up; the purpose of the series was to use stories to enrich staff appreciation of patients' lived experience, with a longer-term goal of influencing CADTH culture to consider patients as collaborators and be more comfortable with the messiness of real life. The upcoming CADTH Symposium will feature a panel of committee members and CADTH staff to talk about the series and its impact. As a post-meeting update, the abstract BS4. Patient and Community Advisors Co-Produce Program to Instill Person-Centred Principles Across CADTH, is available in Proceedings of the 2021 CADTH Symposium

Finally, this committee advised CADTH to take action to increase diversity on our expert and advisory committees, and to build relationships with First Nations, Metis, and Inuit communities. CADTH reached out to patient groups, Patient and Family Advisory Councils, and community organizations for the most recent round of expert committee appointments. Candidates were asked to describe their background experience and what prepared them to be effective in an environment that holds diversity as a core issue.

"It is hard to change, and we're not going to do it well at the beginning. But we're going to keep moving forward to improve inclusivity, accessibility, and diversity at CADTH."