

# Patient and Community Advisory Committee Meeting Summary

May 16, 2022

**Attendees:** Beth, David, Jonah, Julie, Lilian, Kathleen, Marilyn, Marlee, Marney, Mary, Nicole, Paula, Sarah B, Sarah G, Sarah S, Suzanne, Tamara, Zal.

## Introduction

This meeting opened with reflections from a committee member about their recent experiences as a patient partner beyond this committee. This member mapped their experiences onto the [HEADS UP](#) tool by Vanessa Andreotti, which examines working with systems that control power and how they engage with underserved populations.

The tool allows institutions to explore questions such as: Whose knowledge is perceived to have universal value? How are persons identified as marginalized represented? What analysis of power relations have been performed? How is dissent or disagreement addressed?

A dynamic discussion ensued. For patient partners, key questions are:

*“Am I valued? Is my time/opinion valued? Am I listened to? Does action come out of it? Do I see my comments reflected in reports/outcomes?”*

Another useful resource identified is [Healthcare Excellence Canada’s 2022 Engagement-Capable Environments Organizational Self-Assessment Tool](#) which can be used to guide partners through a reflective exercise to create and sustain a culture of patient-and family-centred care.

## Expanding Patient Engagement at CADTH

The current approach to patient engagement can be described as taking one of three forms: first, traditional stakeholder input and feedback, where people who are motivated and able to contribute do so; second, direct dialogue between the project team and individuals who have specific experiences; and third, patients as part of a steering group or committee.

There was a presentation by the Manager of Patient Engagement at CADTH to discuss the vision to expand patient engagement work at CADTH.

Additionally, there are many CADTH projects about general health where patients and families offer useful insights and delve into health equity considerations. Families and communities have unique knowledge that can help make CADTH reports more relevant and robust for everyone in the healthcare system. Opportunities for expanded patient involvement includes Health Technology Reviews, Horizon Scans, and real-world evidence pilot projects. We have resources in development to support CADTH teams and patient partners in their interactions in partnership with committee members. The input highlighted the need to build a community of patient partners and create the processes to link partners with CADTH teams.

## Roundtable

The next phase of this meeting was a roundtable discussion about members' experiences as patient partners – within and beyond CADTH – and what steps CADTH should take in expanding patient engagement.

This rich discussion involved members unpacking what makes or has made an engagement opportunity “meaningful” for them – or not. Most members agreed that one of the best parts of engagement opportunities is connecting with other patients and caregivers, coming together to share and validate each others' stories. Several members indicated that connecting with others has had a positive impact on their personal health journeys, and that learning from their fellow committee members has shaped their own perspectives on engagement.

Many committee members agreed that the worst outcomes they have experienced are to walk away feeling disempowered, or to not see their own hard work reflected in the result. Several shared personal examples of feeling shut down and deeply frustrated in their engagement work outside of CADTH, suggesting that this would cause them to leave and seek other opportunities elsewhere.

Multiple members cautioned CADTH to be aware of power imbalances in working with patients and caregivers and stressed the importance of strong communications and facilitation skills from the person leading the engagement. One suggestion was to avoid labelling anyone by anything other than their name, thus breaking down perceived imbalances. Another is to be clear on which specific perspectives CADTH staff are seeking and why – it is not enough to want “diverse voices”.

One member suggested CADTH focus on making consultations a “safe space” for patients to avoid retraumatizing them. Another member agreed, suggesting using a peer support model.

*“Being able to disagree with patient partners, I think that's a matter of respect, [to] actually engage in a conversation. I don't think it's a true engagement if you're just saying, ‘oh yeah, thank you for your contributions’.”*

Membership discussed different options and opportunities for patient engagement models at CADTH, including patients presenting directly to CADTH's expert committees in lieu of submitting written input. A similar option could be having patients dial into the meeting with questions for the committee.

Another suggestion was to create a small focus group of patients to advise on therapeutic areas, rather than individual drug submissions. In example, CADTH recently convened a small panel of patients and caregivers with experience around dementia to learn about their lived experience of the disease journey. Another example of expanding engagement is the work with the Real World Evidence team where CADTH is holding multi-stakeholder consultations to explore disease landscapes and needed supports.

A consistent theme throughout these discussions was the need for education, appropriate orientation, and support for patients and caregivers working with CADTH. Part of that support includes our practice of reporting back to patients directly with details on how their efforts contributed to the results of the project or consultations.

## CEO Update

CADTH's CEO, Suzanne McGurn, joined the meeting to give an update on the organization's new strategic plan "[Ahead of the Curve: Shaping Future Ready Health Systems](#)" and [2021-2022 annual business plan](#) as they relate to this committee and patient engagement at CADTH.

## Committee Onboarding and Offboarding

Several members are their terms with the PCAC. CADTH is currently interviewing for new members. Two departing members have agreed to be on the interview panel for prospective members. All committee members whether they will be departing, staying, or joining will be invited to a meeting in September. The meeting will hopefully take place in-person and will allow members to reflect on the past three years of this committee and brainstorm a path for the future.

The next Patient and Community Advisory Committee meeting will be in July 2022.