


Creating a patient and community advisory committee at the Canadian Agency for Drugs and Technologies in Health

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Perspective

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Abstract

In recognition of patients' roles using, and contributing to, a publicly funded health system, the Canadian Agency for Drugs and Technologies in Health (CADTH) created a Patient and Community Advisory Committee. Twelve members bring lived experiences of chronic illness, progressive illness, mental illness, trauma, traveling long distances for treatment, and caregiving to an ill child, parent, or spouse. Members contribute their own insights and ideas but do not represent specific organizations or viewpoints. This paper explores how CADTH determined the committee's role, whether to have individuals or organizations as members, and how to recruit for diversity. The creation of this committee is changing how CADTH engages with patients.

Introduction

The Canadian Agency for Drugs and Technologies in Health (CADTH) evaluates the value of drugs and other healthcare interventions. For Canadian hospitals, health authorities, and health ministries, CADTH finds, critiques, and synthesizes published research to help develop policies on the use of medical devices, procedures, and drugs. For publicly funded drug plans and cancer agencies, CADTH evaluates new drugs to recommend if and how the drug provides value and warrants public funding. CADTH typically involves clinicians, patients, researchers, economists, information specialists, and methodologists to complete an assessment. Involving patients in this process improves the relevance of assessments and supports the fairness and legitimacy of the process (1).

Let us step back from individual assessments to consider the organization that prepares them. CADTH relies on advisory committees with health ministry, health authority, and drug plan members (i.e., customers) to guide its strategic direction and prioritize assessment needs (2–4). Advisory committee members do not have decision-making authority; rather, they provide important advice to ground CADTH's work to the health system it serves. However, what if the priorities of those using the healthcare system differ from those who administer health care? What role might patients have in prioritizing assessment needs or exploring how different perspectives shape the use of evidence? This paper describes the creation of CADTH's Patient and Community Advisory Committee and the underpinning rationale for the decisions made.

Need for Advice

The CADTH 2018–2021 Strategic Plan promised to better identify patients' needs, prioritize technologies to meet those needs, and to better incorporate patients' experiences and values in CADTH's work (5). Priorities for CADTH are improved understanding of the needs for mental health and addictions services; home care services and services for seniors; First Nations, Metis, and Inuit communities; and Canadians living in rural or remote areas. The strategic plan also promised the creation of a patient advisory committee.

In August 2018, SB met with leads of nine CADTH directorates and members of three expert committees to explore what a patient advisory committee needed to be to achieve the goals articulated in the strategic plan. Senior leadership and expert committee members sought diverse voices from patients, observations to support equitable use of resources, and ideas to support the appropriate use of drugs and devices.

To explore the feasibility of building a patient advisory committee, SB hosted a series of telephone meetings with leaders of twenty-eight patient groups who often contribute to CADTH assessments. Ideas from earlier conversations were built upon by each patient group. Some leaders sought patient involvement in the governance of CADTH. Others focused

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Box 1: Advisory Committee Roles and Responsibilities

- Help CADTH understand how its policies and activities will impact patients, families, and communities, and raise awareness of the needs of all who use the Canadian healthcare system, especially the vulnerable and disadvantaged
- Provide advice on approaches to enhance the transparency of CADTH processes and their performance
- Provide patient and public perspectives to CADTH in the development of initiatives to improve the appropriate use of drugs and devices across the life cycle of health technologies
- Provide guidance on initiatives to strengthen engagement with patients, families, and communities across all CADTH programs
- Provide input into CADTH strategic plans
- Participate in internal and external evaluations of CADTH activities

on individual assessments, seeking interaction with CADTH researchers and expert committees. Regardless of focus, leaders emphasized meaningful engagement.

Leaders agreed diversity was important for an advisory committee. Despite efforts, few of the national patient groups consulted had good insight into the healthcare experiences of individuals who identify as First Nations, Metis, and Inuit, or the needs of those groups and remote or underserved communities. Transparency and accountability in the creation of the advisory committee and its activities were essential to patient group leaders. Some encouraged CADTH to cast a wide net to recruit members who met pre-established competencies. However, others felt members should be nominated by, and be accountable to, patient group membership.

Starting from existing CADTH committee terms of reference, NV and SB defined the committee's role (Box 1) with an emphasis on diversity (key for CADTH leadership and supported by patient groups), supporting underserved communities (as identified in the strategic plan), and transparency (key for patient groups). Stakeholders were informed of the committee's development and patient group feedback on plans during the 2018 annual CADTH Information Session. However, a public consultation on draft terms of reference would have allowed additional stakeholders to comment.

Patient Groups or Individuals?

There are public or patient members who serve on CADTH's Board and multi-disciplinary expert committees; otherwise, CADTH typically works with patient groups. For 5 years (2013–2018), CADTH ran a Patient Community Liaison Forum to share information and collaborate on topics touching both CADTH and patient groups. This was a voluntary group with members from four umbrella patient organizations and CADTH. In the past 10 years that CADTH invited contributions to specific assessments, 180 patient groups, across many disease areas, have responded. However, no civil society organizations or those involving First Nations, Metis, or Inuit peoples have ever responded. Organizations with a mandate to advocate for new treatments are the ones most motivated to develop relationships with CADTH, and their contributions to the assessments are essential. Opportunities to interact remain open at CADTH. However, to collaborate more broadly, additional approaches were needed.

Patient advisory groups that support organizations like CADTH differ in their composition. In Europe, the Scottish Medicines Consortium has a Public Involvement Network

Advisory Group, made up of agency staff, expert committee members, and three patient groups, to discuss and shape process changes (6). In Germany, four patient organizations (German Disability Council, the National Association of Patient Advisory Centres, the German Association of Self-Help Groups, and the Federation of German Consumer Organisations) identify and request assessments on topics they deem useful (7). The National Authority for Health (HAS) in France created a Service Users Advisory Council, comprised of individual patients, citizens, and healthcare professionals to ensure that the authority's work is relevant to those using the healthcare system (8). In Canada, the Canadian Medical Association created a patient advisory group in 2018 with individuals from across Canada to bring new insights into the association's policy work (9). Individuals with lived experience participate in Canadian regional hospital Patient and Family Advisory Councils (10).

An advantage of working with patient groups is that leaders represent a broad patient community and are accountable to their membership, who often gather around disease-specific advocacy goals. However, CADTH needs to hear additional voices to understand barriers to health care in underserved communities and explore appropriate technology use (needs identified in the strategic plan and by CADTH leadership), and to identify new engagement approaches to achieve these goals.

Individual advisors can share deep experiential knowledge and offer solutions without advocating for specific causes. Individuals with lived experience of the healthcare system were sought to create the advisory committee to give advisors the freedom to express their own insights rather than represent an organization or an interest. This would support the building of trust, willingness to engage in honest and challenging conversations, and result in meaningful engagement between staff and patients.

"Community" is included in the committee title to create space for seniors, those with multiple health concerns, and those living in rural or remote Canada or in other communities who face unique challenges to access care. "Consumer" would be an alternate term (11) but not one used at CADTH.

Deliberate Diversity

CADTH assesses drugs and devices in many disease areas. Healthcare delivery in Canada is a provincial and territorial responsibility, with needs and resources driven by different demographics and geography. Healthcare priorities vary substantially in a country of 38 million people, who are unevenly distributed across ten provinces and three territories. If CADTH worked with individuals, rather than representative organizations, how could this diversity be reflected in an advisory committee small enough to fit around a table?

The authors found inspiration from the Canadian Foundation for Healthcare Improvement (12). Rather than imagining each committee member as offering a sole perspective (i.e., experience with breast cancer or as an immigrant or living in western Canada), we embraced the concept of intersectionality. Members could bring multiple perspectives at once (experience with breast cancer *and* as an immigrant *and* living in western Canada). We understood that people are shaped by interactions of different social categories; for example, race, ethnicity, indigeneity, gender, class, sexuality, geography, age, profession, and health (13). With careful recruitment, an advisory committee of a dozen members could contribute more than a hundred different perspectives.

Box 2: Core Competencies for Advisory Committee Members

- Extensive lived experience engaging with the Canadian healthcare system
- Ability to use personal experiences constructively
- Familiarity with issues in health care in Canada (at the community, regional, or national levels)
- Ability to provide specific perspectives identified in the current CADTH strategic plan
- Ability to offer a unique perspective that contributes to the diversity of perspectives of committee members
- Awareness of others' experiences and views within a specific community or disease area; for example, experience as a patient organization board member, staff member, or volunteer
- Ability to act with integrity, independent of specific interests
- Ability to work constructively as a member of a team
- Interest in empowering patients, families, and communities to participate in health technology assessments
- Availability to participate in meetings

Recruitment

In February 2019, advertisements using images of people that reflected the diversity of the committee CADTH aspired to assemble ran on the CADTH Web site and social media platforms. Over 10,000 people clicked through social media posts to the CADTH Web site, resulting in 85 completed applications. The authors asked seven broad questions to explore interests and experiences against the core competencies identified in [Box 2](#), such as describe your lived experience engaging with the healthcare system and describe how your experiences can contribute to the diversity of an advisory committee.

NV and SB followed CADTH's established process for expert committee member appointment, with the additional step of involving the patient member of CADTH's independent pCODR Expert Review Committee (DB). All applications were blinded, and four experienced staff ranked the nominees against identified competencies. At least 2 people read and ranked each form. A shortlist of individuals was finalized when consensus was reached. SB and DB, who were not involved in the ranking, interviewed 21 nominees by telephone over 3three weeks. DB's question on the difference between advice and advocacy was surprisingly useful to unearth interviewees' motivations. Successful nominees disclosed their potential personal and financial conflicts of interest. These are shared on CADTH's Web site, alongside their biography and photograph (14). The committee's first online meeting was held on a warm summer evening, 12 July 2019.

Patient and Community Advisory Committee

The twelve members of the committee bring lived experiences of chronic illness, progressive illness, mental illness, trauma, traveling long distances for treatment, and caregiving a child, parent, or spouse. Members come from across Canada and represent a mix of ages, genders, and professions. With their guidance, the CADTH can explore poverty, stigma, ageism, accessibility, gender diversity, how health care is provided and received as a First Nations person, and what inclusive health care is. Members can help CADTH build cultural competence (identifying bias and improving communication) and structural competence (exploring the economic and political conditions that produce and racialize inequalities in health).

In September 2019, the senior leadership of CADTH met with the committee in person to listen and openly answer questions.

An informal dinner held the evening before the meeting allowed members to match biographies to real people and begin to build trust. Budget is allocated for members' travel, accommodation, and their time preparing for, traveling to, and participating in meetings. Sessions are designed with dedicated time for questions and opportunities for brainstorming to encourage active participation by all, with strong facilitation by the committee chair. These actions meet practices identified by Pagatpatan and Ward (15) for engagement to work well. CADTH has also adjusted the advisory recruitment processes, learned to find accessible meeting space, and identified how to plainly explain what it does and why.

Change at CADTH

Inviting e-alert subscribers to provide written input on an assessment and feedback on process change or to review a draft report are adequate approaches to involve stakeholders, but they create barriers for many communities and limit challenges to the *status quo*. In contrast, the Patient and Community Advisory Committee is the result of a deliberate effort to seek out and give space to minority voices. Interactions with the diverse members are honest and ongoing, and involve both senior leadership and teams best placed to change how CADTH works. Eyes have opened to the ability of knowledgeable outsiders to provide insight and to the willingness of patients to pursue excellent and equitable health care.

CADTH's Pharmaceutical Advisory Committee and Device Advisory Committee continue to identify and confirm assessment topics. Testing a new model of involving patients in priority setting, the chair of the Patient and Community Advisory Committee has now joined the Device Advisory Committee to provide insights as someone with lived experience of the health system. In September 2019, committee members articulated the need for plain language recommendations to support understanding by those impacted by the funding recommendation. This is now a task specified in CADTH's 2020 Operational Plan and has been given resourcing to explore. Individual committee members have provided guidance to support accessibility of CADTH's webinars and bolster staff cultural awareness training. An external tool (16;17) will be used by committee members and CADTH to evaluate the first year's engagement and prioritize future activities, in addition to the standard committee self-evaluation. With committee members as guides, CADTH is also respectfully building relationships with new communities. CADTH is supporting health ministries, health authorities, hospitals, and public drug plans by engaging with, and listening to, the people they serve to undertake relevant work and share the results so that they can be understood by all.

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References

1. CADTH [Internet] Framework for patient engagement in health technology assessment [cited 2020 Apr 6]. Available from: <https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment>
2. CADTH [Internet] Pharmaceutical advisory committee [cited 2020 Jun 29]. Available from: <https://cadth.ca/collaboration-and-outreach/advisory-bodies/pharmaceutical-advisory-committee>
3. CADTH [Internet] Device advisory committee [cited 2020 Jun 29]. Available from: <https://www.cadth.ca/device-advisory-committee-dac>
4. Husereau D, Boucher M, Noorani H. Priority setting for health technology assessment at CADTH. *Int J Technol Assess Health Care*. 2010;26:341–7.
5. CADTH [Internet] 2018–2021 Strategic plan: Transforming how we manage health technologies in support of better health, better patient experience, and better value [cited 2020 Apr 6]. Available from: https://cadth.ca/sites/default/files/corporate/planning_documents/CADTH_2018-2021_Strategic_Plan.pdf
6. Scottish Medicines Consortium [Internet] Public Involvement Network Advisory Group [cited 2020 Apr 6]. Available from <https://www.scottishmedicines.org.uk/about-us/public-involvement/public-involvement-network-advisory-group/>.
7. Haefner S, Danner M. Germany. In: Facey K, Ploug Hansen H, Single A, editors. *Patient involvement in health technology assessment*. Singapore: Springer; 2017, p. 299–312.
8. Haute Autorite de Sante [Internet] Conseil pour l'engagement des usagers at HAS [cited 2020 Apr 6]. Available from: https://www.has-sante.fr/jcms/c_2891593/fr/conseil-pour-l-engagement-des-usagers.
9. Canadian Medical Association [Internet] The Canadian Medical Association announces the make-up of its first-ever patient advisory group [cited 2020 Apr 6]. Available from: <https://www.cma.ca/canadian-medical-association-announces-make-its-first-ever-patient-advisory-group>
10. Ontario Hospital Association [Internet] Patient and family engagement requirements for accreditation [cited 2020 Apr 6]. Available from: <https://www.oha.com/Documents/Patient%20and%20Family%20Engagement%20Requirements%20for%20Accreditation%20with%20Appendix.pdf>
11. Street J, Stafinski T, Lopes E, Menon D. Defining the role of the public in Health Technology Assessment (HTA) and HTA-informed decision-making processes. *Int J Technol Assess Health Care*. 2020;36:87–95.
12. Canadian Foundation for Healthcare Improvement [Internet] Diversity in patient engagement learning exchange 2019 [cited 2020 Apr 6]. Available from: <https://www.cfhi-fcass.ca/NewsAndEvents/Events/diversity-in-patient-engagement-learning-exchange>
13. Shimmin C, Wittmeier K, Lavoie J, Wicklund E, Sibley K. Moving towards a more inclusive patient and public involvement in health research paradigm: The incorporation of a trauma-informed intersectional analysis. *BMC Health Serv Res*. 2017;17:539.
14. CADTH [Internet] Patient and community advisory committee [cited 2020 Apr 6]. Available from: <https://cadth.ca/patient-and-community-advisory-committee>
15. Pagatpatan CP, Ward PR. Understanding the factors that make public participation effective in health policy and planning: A realist synthesis. *Aust J Prim Health*. 2017;23:516–30.
16. McMaster University [Internet] Public and patient engagement evaluation tool [cited 2020 June 29]. Available from: <https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool>
17. Abelson J, Humphrey A, Syrowatka A, Bidonde J, Judd M. Evaluating patient, family and public engagement in health systems improvement and system redesign. *Healthc Q*. 2018;21:61–7.