

Patient and Community Advisory Committee Meeting

September 14, 2019

Friday 13th September

Many of us traveled to Toronto for the first in-person meeting of the Patient and Community Advisory Committee. Some spent much of Friday travelling: leaving Whitehorse, Thunder Bay, Vancouver, rural British Columbia, Calgary, Winnipeg, Charlottetown, and rural New Brunswick to arrive to skyscrapers, torn-up sidewalks, and the bustle of Toronto's International Film Festival on a warm Friday night. CADTH staff from Ottawa joined staff in Toronto. Dinner at the hotel allowed members to match biographies to real people. Stories, excited hopes, secret fears and not so 'silly' questions were shared.

Reflection: This was CADTH's first advisory meeting held on a weekend. The July teleconference was CADTH's first after business hours. CADTH's two other advisory committees are composed of ministry of health staff, academics and clinical specialists who keep office hours. We learnt (and are still learning) how to ask about members' requirements, how to find venues with appropriate accessibility, and how to explain / adapt our travel policy, expense, and honorarium forms. More ideas on how we can improve our processes are welcome.

Saturday 14th September, morning

We could see the sun reflecting off Lake Ontario as the meeting began. One by one, members described their motivations for joining, and goals for, the committee. We heard of lives 'reformatted by illness' and sharpened awareness of what works well, and what does not, in our healthcare system. In the growing stillness, we admired 'the breadth and depth of experiences in this room'. One member described, with a laugh, the need to 'infiltrate, then subvert' rather than forcing change head on. Another member **imagined this committee 'as like the senate'**, existing to make the house seriously consider the consequences of its actions.

Reflection: It was humbling to listen to members' stories and insights forged by experience. We felt honoured that members were willing to share so opening – that they trusted in the group and us to do so. It was an emotional and powerful beginning.

The diversity of intersectional experiences and professional skills the members can contribute goes well beyond CADTH's expectations. Within the 12 members experiences, we're able to explore: inequitable access to healthcare, rural living and inner-city living, poverty, ageism, invisible disabilities, stigma, gender diversity, providing and receiving health as a First Nations person, and what inclusive healthcare looks like.

Short presentations on health technology management (HTM) and CADTH's approach for medical device and drug assessments, followed. On yellow sticky notes and in groups, members noted surprises arising from the presentations, concepts that should be shared widely, and ideas for further exploration.

On a sticky note, surprise was expressed at the number of groups in Canada (44) that do health technology assessment (HTA) with concern for potential duplication and burden on those contributing feedback. Conversely, surprise was expressed (on another sticky note) that provincial authorities accept implementation guidance from a central body.

Understanding HTM as providing a more wholistic approach to HTA was helpful. The question was asked: **how will moving to HTM change how drugs and medical devices are used in communities?** And if, assessment happens multiple times, or after wide access, **who is responsibility for gathering the evidence** and what parameters are used to do so?

Reflection. These are questions that CADTH and other HTA agencies continue to explore through the pan-Canadian HTA Collaborative, and internationally, through INAHTA and HTAi. It is not immediately clear if there is a role for the Patient and Community Advisory Committee to explore these questions, although worth noting, they are of interest to a wider audience than HTA bodies.

That **all drugs approved by Health Canada are not universally available in Canada** was news to some. Once a drug has received Health Canada's notice of compliance (NOC), private insurance companies choose to cover a drug for their members (fully, partially, or for a subset of members). Publicly funded drug programs and cancer agencies typically use a recommendation from CADTH, with a price negotiated by the pan-Canadian Pharmaceutical Alliance (pCPA), to determine if, and when, to add a drug to their formulary (group of drugs available for use) and under what conditions.

Health care is the single largest budget item for every province in Canada, ranging from 34.3% of total program spending in Quebec to 43.2% in Ontario in 2016. We face a 'perfect storm' of a robust pipeline of promising drugs, devices and procedures, less evidence than before on these technologies when they come to Canada, and many drugs / devices with very high price tags. The challenge for federal / territorial / provincial governments is how to best provide good and equitable healthcare without taking more funds away from social services, education, and all the other services citizens need?

Many members were surprised by the **volume of new medical devices**, surgical procedures, screening tests, medical interventions and equipment available for use every year. CADTH does not assess a technology (medical device, procedure or drug), unless there is interest from a federal / territorial / provincial health authority, hospital, regional health program, or publicly funded drug plan for CADTH to do so. Assessments are used to inform policy decisions. So, there needs to be a 'receptor' - a publicly funded body able to make policy decisions – to 'receive' the findings of a CADTH assessment.

CADTH's Device Advisory Committee and Drug Policy Advisory Committee help shape policy questions. CADTH then finds, critiques and synthesises the related evidence. Our expert committees (CDEC, pERC, HTERP) provide recommendations to answer to policy questions (such as should this technology be adopted in Canada) based on the evidence. Assessments are shared publicly on CADTH's website so interested organizations and individuals, can read the evidence found, critiqued and the conclusions drawn.

Reflection: Slide diagrams and phrasing used to broadly describe CADTH's assessments gave a clear big picture description of CADTH that is missing from our website and other introductory materials. Those using CADTH's assessments often know us through the specific program they use (for example, oncology drug recommendations or evidence search and appraisal). It is challenging (if not impossible) to rapidly (within 4 hours) orientate intelligent, motivated individuals on CADTH's place within the healthcare system and all our activities. We'll repeat information, offer information in different forms, and continue to dedicate time to questions.

A member commented on an observed **disconnect between CADTH and clinical stakeholders**; those turning policy into practice. Traditionally HTA is oriented as top-down policy driven. Now we emphasise engaging clinical and patient communities to support action on policy decisions and to learn how technologies (drugs / devices / procedures) are used in Canada and identify realistic alternatives or standard of care (comparators).

In discussion of the evidence examined during HTA and the deliberative process to make recommendations, members wanted to understand **what constitutes evidence** and the weighting of different forms of evidence. How can different forms of knowledge, with their different chains of reference, not just be 'folded in', but allowed to reform basic principles? Surprise was expressed that **ethical considerations** were not explicitly discussed by all expert committees.

Reflection. Across the HTA landscape, different deliberative frameworks and approaches are used, for practical, historical or methodological reasons. As members want to understand how policy recommendations are made (epistemology not process), those we're asking to trust the outcomes of the recommendations may also benefit from explicit description of the deliberations and clear identification of the values that underpin the assessment process (for example, improving health, fairness, and quality evidence)

Saturday 14th September, afternoon

After lunch, the group turned from orientation to identify and prioritize areas of focus for the next 18 to 24 months. Four major workstreams were identified arising from needs expressed by CADTH staff, expert committee members, and patient groups who regularly contribute to CADTH's work. Each workstream aligns with key area of responsibility as set out in the committee's terms of reference.

1. **Workstream 1:** *Help CADTH understand the needs of those who used the healthcare system (information in)*

Several different communities were identified in the afternoon brainstorm, in addition to suggestions shared in small groups in response to 'what perspectives should be included in assessments?'

Regular stakeholders in CADTH's work are: Health Canada (who regulate healthcare and fund CADTH), federal / provincial / territorial governments (who deliver healthcare and fund CADTH), publicly funded drug plans and cancer agencies, pharmaceutical and medical device companies, organizations of healthcare professionals, and patient groups.

Advice: It would be valuable for CADTH to learn the perspectives of: individual patients / families; most vulnerable end users / underserved populations / those living in poverty; Indigenous communities / non-band affiliated Indigenous communities; youth; social workers/ community agencies; and those living in northern, rural, and remote areas.

These perspectives are needed to better understand broad barriers to care and the supports needed by families to carry out treatment plans and use health technologies appropriately. To also learn of patient borne costs (including travel for treatment) and the experiences of those excluded from trials.

Importantly, ask 'should CADTH be doing this work?' To confirm CADTH assessments align with community priorities and reflect the perspectives of the communities involved.

2. **Workstream 2:** *Strengthen engagement with patients / communities for all programs (information exchange)*

Foreshadowing the afternoon brainstorm, members at one table noted CADTH passively accepted patient group input and stakeholder feedback, rather than actively seeking out perspectives. The passive approach excluded underserved communities who were not able or motivated to contribute. However, ideal engagement can take weeks / months to appropriately identify sources, build trust, and respectfully listen. CADTH seeks to balance scientific rigour with providing timely advice / recommendations.

Advice: Build the cultural and structural competence of CADTH staff and expert committees. (Cultural competency focuses on identifying bias and improving communication. Structural competency explores the economic and political conditions that produce and racialize inequalities in health.) Look to Canadian Charter Rights.

Look to social sciences literature. Learn from social services groups interacting with underserved populations (for example, women's shelters, First Nations Health Authority, SANYAS, Age Friendly Communities, Canadian HIV / AIDS Network, Pain BC). Speak to those at nursing stations, those providing social support on the challenges faced by underserved populations. But do not prevent patients / families from contributing directly. Ask groups in Canada (and outside, such as INVOLVE in the UK) how they are reaching out to different communities.

Be aware, if CADTH asks for input, there is an expectation that those views are listened to and considered.

3. **Workstream 3:** *Enhance the transparency of CADTH process (information out)*

Members, as well-educated, motivated individuals, immersed in the healthcare system, reflected on key ideas that ‘*other stakeholders*’ and ‘*all Canadians*’ should understand about CADTH in the morning, and in the large group discussion, after lunch.

Advice: Themes from the yellow stickies on what should be broadly shared were: Access to healthcare is a collective and shared responsibility; whether you have specific healthcare needs or not, it is precious and needs to be fought for. CADTH exists and contributes to a safe, effective and equitable healthcare system. Patients and public can and should have a voice in assessments. Patients do not exist in mutually exclusive categories – someone can be in a ‘disease group’ but also need other forms of justice to be addressed.

In communicating CADTH evidence (such as Rapid Response), summaries of research studies – at a grade 6 reading level – are needed to communicate to the general public. To avoid over simplification, links to science are needed, as is clear presentation of differing viewpoints. Materials produced by CATIE (www.catie.ca) and NAM (<http://aidsmap.com>) were suggested as strong communication examples.

Exploring whether patients and public are the audience for CADTH advice, it was noted that patients ‘*may not understand the science but need to be able to trust it*’. Another member highlighted that if CADTH asks for input, patients need to understand the conclusion and the results of their engagement.

4. **Workstream 4:** *Contribute to activities to improve the appropriate use of drugs / devices across the lifecycle of technologies*

In Health Technology Management (HTM), CADTH looks to support decisions at all phases of the technology life cycle, from pre-market to adoption, to actual use in Canada and encouraging greater use of the most-effective technologies. How can CADTH access the best evidence of technologies use in Canada?

Advice: A couple of members asked of the responsibility of the drug / device industry to explore patients needs before developing a product and then to explore how well the drug / device meets the needs of users (as judged by users’ parameters). Could CADTH could ask / require the drug / device industry to include patient perspectives / quality of life data in their submissions of evidence to CADTH? How would the picture change if the lens broadens from a single technology to look at the treatment journey undertaken by patients?

How can CADTH prioritize technologies for reassessment? A member of the Patient and Community Advisory Committee (Marney Paradis) has joined CADTH’s Device Advisory Committee to contribute a healthcare user’s perspective to assessment prioritization and question refinement.

5. **Workplan 2019-2020**

After the brainstorm, members were asked to identify key priorities for the first two years of the committee’s work. While there is overlap between the workstreams, understanding the needs of healthcare users and strengthening engagement received the most support. There was also interest in using CADTH policies to greater motivate industry to better gather and share patient quality of life data and patient experiences using drugs / devices.

As next steps, we’ll continue to orientate members during 2019, allowing much time for members’ questions. CADTH will map the extent we’re hearing from different communities across our activities and the approaches we currently use to gather insights. This map will be discussed at our February 2020 teleconference to identify gaps and prioritize communities and approaches for greater engagement. Discussion will likely continue to form part of the next in-person meeting in April 2020. We will continue to return to the ideas shared by the committee in September to identify opportunities for action and prioritize effort.

Before members journeyed home, we shared our reflections of the day. Many offered thanks and agreed it was a good start, that ‘something good happened in the world today’. The honest discussion, without barriers, enabled discussion to grow organically. A sincere thank you to our chair, Marney, and facilitators.

Reflection: Overall, the meeting accomplished two key objectives: to build respect and trust between committee members and CADTH senior executive; and to grow deeper understanding of why CADTH's work matters. Questions asked by members and surprises noted help identify what matters to those impacted by CADTH's work (as patients, caregivers or citizens) and how CADTH can or should describe itself, as a sum of the various programs and processes it runs.

While the workstreams (and the identified requests that contributed to the workstream) are ambitious, members were able to share rich observations and ideas during the series of short brainstorming sessions. We recognize further reflection and prioritization is needed to fully develop a workplan. While a workplan guides agendas and activities, our overarching goal is not workplan accomplishment. Instead for committee members to understand CADTH's role within the healthcare system and be trusted to offer CADTH the best advice possible, from the viewpoint of users of the healthcare system.