Patient and Community Advisory Committee

Minutes July 12, 2019, Teleconference 6-8pm EST

Patient and Community Advisory Committee members: Marney Paradis (Chair), Zal Press, Beth Kidd, David McMullan, Devan Nambiar, Jonah Dupuis, Lilian Hulme-Smith, Marilyn Barrett, Marlee McGuire, Mary Reeves, Paula Orecklin, and Sarah Sandusky.

CADTH Staff: Brian O'Rourke, Nicole Mittmann, Michelle Mujoomdar, Nadine Vautour, Sarah Berglas, and Tamara Rader.

Action: CADTH to share Strategic Plan 2018-2021, Common Acronyms for All Who Are New to CADTH and pan-Canadian Health Organizations external review
Action: Explore use of GoToWebinar with hand raise function for next teleconference.

1. Opening

- Brian O'Rourke, CADTH President and CEO, and Marney Paradis, Patient and Community Advisory Committee Chair, opened the meeting.
- Members are encouraged to bring their authentic self to the table; be actively involved in discussions including holding space for alternative perspectives, adhering to guidelines, and working towards group-based decision making.

2. Introduction to Health Technology Assessment

- Provided by Michelle Mujoomdar, Director of Scientific Affairs, CADTH.
- A health technology is something developed with an aim to prevent, diagnose, or treat medical conditions. CADTH assesses drugs, medical devices, diagnostic tests, surgical and dental procedures.
- Health technology assessment (HTA) is multidisciplinary; synthesizing information on clinical and economic aspects of the technology plus social aspects, ethical and legal issues.
- HTA informs health decision making to achieve the best value and to help develop health policies that are patient focused.
- Other HTA agencies are provincially based or working in hospitals or academic centres.
- Answering a question, CADTH often starts work before Health Canada has made its regulatory decision on a drug. We won't issue a recommendation until the product is authorized to be used in Canada.
- Answering a question, CADTH monitors for emerging evidence or changes in practice to determine whether to re-assess a technology. CADTH advisory committees, including this one, play a role in bringing suggestions to us.

3. Introduction to CADTH

- Provided by Brian O'Rourke, President and CEO, CADTH.
- We are a not for profit corporation, with approximately 250 staff.
- The members of our corporation are the federal, provincial and territorial Deputy Ministers of Health, with the day to day governance of CADTH the responsibility of our Board of Directors.
- Of CADTH's funding ($36 million), 64% comes from the federal government through a contribution from Health Canada; 21% comes from the provinces and territories (apart from Quebec); 14% comes from an application fee charged to pharmaceutical companies for drug reviews and advice program, and 1% from educational events.
- Highlighted the pan-Canadian Health Organizations external review and recommendations, from the advisory council on the implementation of national Pharmacare (led by Dr. Eric Hoskins). CADTH anticipates playing a significant role in whatever model of Pharmacare is implemented following the federal election.

- The work CADTH does has direct impact on patient care and the lives of patients. We need to engage with all crucial stakeholders, especially patients. We want to create opportunities for patient involvement in broader policy issues, beyond single technology assessments.
- CADTH will look to our Patient and Community Advisory Committee to:
  - Engage with our Board and help us develop our strategies moving forward
  - Provide early advice to help us implement what comes out of the pan Canadian Health Organization review and direction on Pharmacare.
  - Give insight as to how we can prioritize technologies for review and use in Canada, as well as how we can be more inclusive of different perspectives in our reviews.
  - Offer thoughts on how to balance conflict of interest when gathering perspectives.
  - Guidance on how we consider ethical, social and legal challenges, especially as we look at non-traditional technologies such as gene therapies, artificial intelligence and digital health.
  - Support on CADTH operational matters, such as greater transparency in our reports and committee deliberations.
- Answering a question, at CADTH, an expert committee makes a recommendation on a technology that goes to a jurisdiction. An advisory committee provides advice to CADTH.
- Answering a question, CADTH and seven other health organizations are collectively referred to as the pan-Canadian Health Organizations. All receive funding from Health Canada to help support the government moving forward. CADTH also receives funding from provincial and territorial governments, in addition to Health Canada.

4. CADTH Governance and Key CADTH Policies

- Provided by Nadine Vautour, Governance Officer, CADTH.
- All CADTH committees report to the CEO, who reports to the board. The board reports to the Conference of Deputy Ministers of Health.
- Provided an overview of CADTH's Code of Conduct, Conflict of Interest disclosure and travel policy.
- CADTH provides all committee members, who are not already paid by the government, with an honorarium. Members of this committee will receive an honorarium as we value the work you do and insights you bring.

5. Working with CADTH Directorates

- Provided by Sarah Berglas, Patient Engagement Manager, CADTH
- Introduced patient engagement colleague, Tamara Rader
- CADTH uses a range of engagement methodologies, in addition to patient input and identifying patient and caregiver perspectives in the published literature. CADTH also has well respected, fully involved patient or public members on all our expert committees.
- Using the spectrum from the International Association of Public Participation (IAP2), we're expecting to use a very collaborative model with this committee. While CADTH will gather data and perspectives, we imagine members, in small groups, also gather resources, open doors for CADTH, suggest solutions, prepare materials and present to others on the committee.
- To develop the committee's terms of reference we spoke with CADTH directorates, expert committee members and 24 patient groups who regularly contribute to our work.
- We're aware that in some areas of CADTH we have little engagement such as our Rapid Response Service, in priority setting and process development. We generally inform and consult rather than work in collaboration. Another challenge is how to incorporate social values, not only patient values. Patient groups are also seeking greater interaction with CADTH researchers and committees, plus support to contribute to CADTH.
- In addition to topics the committee identifies, eight broad areas to explore are:
  - Identify opportunities in our project priority setting to incorporate patient and community views
  - Explore efficient ways of gathering these perspectives
  - Identify principles and practical approaches to enable greater understanding by those impacted by CADTH's recommendations and advice
  - Identify solutions to improve ease of access to information on our website for a wide range of audiences
  - Identify processes, partners and best practices to work with CADTH's implementation support and knowledge mobilization team to support the uptake of CADTH's advice

- Explore approaches to integrate societal values into resource allocation decision making.
- Explore and advise on how CADTH engages with communities and identify alternate approaches
- Provide input into CADTH's strategic plans and annual business plans.

6. Reflections and Comments

- CADTH is open to revisiting the committee's terms of reference, once the committee has had some time to work together. We want a level of consistency across all CADTH advisory committees.
- The work plan (to be developed at the September meeting) will also define specific roles and responsibilities. As with other committees, there will be opportunities for self-assessment and new modes of working.
- One member saw opportunities for the advisory committee to go beyond collaboration, to become an equitable partner, a human resource within CADTH. The member reflected on the challenges of crossing the divide between being an advisory committee and participating in a variety of activities that might compromise the advisory position.
- Another member asked about the tensions between being evidence-based and patient-centred, with their vastly different kinds of knowledge systems. How might this committee find ways to move through that tension.
- CADTH tries to reconcile patient evidence or expert opinion through our multidisciplinary approach. Patient engagement officers are part of the project team. The patient engagement process is part of our larger assessment process and in our expert committee deliberations.
- Maybe there are other ways, and we're open to hearing them.
- Asked about the role of patient groups representing individual patients, CADTH explained that program restraints and the questions to be answered drive how we engage patients. For some projects, we work with individual patients and caregivers, for others with patient groups, and sometimes with both.
- CADTH answered a question on the role ethics plays in HTA.
- There is an ethicist on the Health Technology Expert Review Panel, and specific ethical considerations are explored in larger projects within the medical device and clinical interventions portfolio. For example, our CAR T cell project, where ethical, social, implementation issues and patient perspectives interwove. For other programs, ethical considerations are part of the deliberative framework.
- Again, we're open to improving how we do this.
- CADTH does not imagine this committee will be identifying societal values. Good quality research on Canadian societal values already exists. We're looking for new ways to integrate these values.
- For example, we often hear directly from those who stand to gain, should a new drug be funded, but we do not hear directly from those who will lose out if resources are redirected to pay for that drug.
- From a health economics standpoint, the payer perspective is recommended for the reference case in CADTH's economic guidelines. The payer perspectives include costs incurred by the Canadian public payer for the treatment and management of side effects and the outcomes of meaningful health effects for patients and their families. A societal perspective includes treatment costs, plus patient out-of-pocket costs, travel time, lost productivity, and includes both health and non-health effects to patients and their families.
- If CADTH owners are the Federal, Provincial and Territorial governments, why might they have their own HTA agencies?
- CADTH explained that some provinces have committees to translate the evidence or recommendations that we've given them into funding or practice. We collaborate with l'Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec, Health Quality Ontario, the Institute for Health Economics in Alberta, and the B.C. Health Technology Review as part of the pan-Canadian HTA Collaborative.
- We're trying to build the capacity of other HTA agencies through a collaborative model.
- One member reflected that it is important to recognize we all have implicit biases. To make HTA more equitable and inclusive for all Canadians it is important for members to give their authentic selves and give voice to those not represented.

7. Thank you to all. Meeting closed at 8:03 pm EST.