Patient and Community Advisory Committee Summary

November 18, 2019; Teleconference 6-8 pm EST

In attendance: Beth, David, Devan, Jonah, Julie, Kathleen, Lilian, Marilyn, Marlee, Mary, Michelle, Paula, Sarah B, Sarah S, Tamara, and Zal (Chair for meeting).

Regrets: Marney

1. Opening

- A committee member welcomed everyone to the meeting and greeted the new CADTH staff members. He asked for kind thoughts for Marney.

2. Reflections on September meeting/ "Story of the Day" summary

a. One member noted that the term "office hours" has different connotations for this committee: "It's work we're doing as part of our life."
   - Welcomed honorarium and re-iterated the importance of compensating patients fairly as experts.
   - Also, it is important to have meetings during "off-hours" since members have other obligations during standard business hours.

b. Several members reflected on how much they enjoyed the face-to-face meeting and are greatly looking forward to the next in-person meeting in April.
   - "The sense of trust and being able to share stories, you know, in a trusting, non-judgmental environment."

c. Question: Does the Pan Canadian HTA Collaborative direct have patient input?
   - The Collaborative is made up of agencies, not individuals. There is patient input and perspectives through the agencies.

3. Questions about the Committee's role

a. How is this committee involved in product reviews?
   - It is not; rather, this committee will be providing strategic advice and guidance to overall processes and culture instead of delving into individual reviews. More "big picture" thinking than day-to-day tasks.

b. How will the committee provide feedback into CADTH's future strategic plan?
   - The current strategic plan is in place until 2021 (the next one will be from April 2021 until 2024). We will follow the Board of Directors' direction.

c. How will this committee have an impact?
   - This committee is already having an impact! It is creating new pathways, challenging assumptions, and changing CADTH culture. Opinions sought on using Abelson's Patient Engagement Evaluation Tool or alternatives to measure impact, influence, and collaboration. We can try out Abelson's evaluation tool during our April 2020 meeting.
   - Suggestion of inviting CADTH staff to committee meetings and dedicating 10 mins to hear their stories, roles, and interactions within CADTH. Committee members are keen to understand existing CADTH culture and where they can make an impact.

d. What should committee members be advising on? What is our role?
   - CADTH responded: "Tell us the priorities. Tell us the approaches we can use for engagement. We recognize it's not as clear as in other advisory committees, but we're finding our way and we're creating those pathways."
   - While onboarding may seem slow, it has been enormously helpful in setting up the future of the committee and highlighting where we need further clarity to explain what CADTH is/does. "It's a marathon, it's not a sprint for us."

4. Questions about CADTH

a. What is the process for replacing Brian? Will any patients be on the hiring committee?
   - CADTH is using an external agency for finding a new CEO. Board members will be on the hiring committee, as the CEO reports to CADTH's Board. Our board has a mix of jurisdictional members and non-government members, including two public (not patient) members.

b. How long is the process between CADTH approval to provincial/territorial public plan funding?
   - As explained by a committee member, there isn't one answer; 12 months is a reasonable estimate, while 6-8 months would be "awesome". It is up to individual provincial/territorial governments to decide to add new items to their formulary. Wealthier provinces tend to approve first. Also, drugs are sometimes available through private insurance before they are publicly funded.

c. What is a stakeholder? What is a customer?
   - A CADTH customer funds CADTH directly (Health Canada, provincial/territorial governments) or is a publicly funded health organization who makes policy decisions (health authorities; health facilities, public drug plans). A stakeholder is anyone who is affected by CADTH's advice and recommendations.

d. Why are there no CADTH board members specific to NWT / NV Nunavik Labrador?
   - CADTH board members reflect regions of Canada. It happens that the northern board representative is in the YK instead of NWT or NV, like how the western board members are from BC and SK, but not AB or MB. As how our Committee members are spread across Canada.

e. Why are there differences between the programs, especially in how patient perspectives are handled?
   - Each program serves different purposes. Our methods for gathering and using patient perspectives try to best meet the objectives of the program. Time is the biggest factor; different methods (literature review, patient groups providing input, direct engagement) take different amounts of time and resources. CADTH is looking to complete projects to a robust standard as quickly as possible.

f. How rapid is a Rapid Response?
   - It varies, depending on how in-depth the information needs to be. For instance, a list of relevant resources could be pulled together by our research librarians in about 48 hours while a more comprehensive analysis would take about 6 weeks.

g. What constitutes evidence? Does ethnography count? Qualitative research data?
   - CADTH is open about what can constitute evidence. CADTH uses different types of evidence in different ways, and especially with regards to time constraints. Certainly, the use of qualitative evidence at CADTH has grown in the past few years.

h. What perspectives are used in economic modelling?
   - CADTH has produced guidance of economic modeling in HTA assessment on our website. The perspective taken is defined in the HTA research question. Generally, as a base case, a publicly funded health care payer perspective is adopted with a societal perspective as additional information.

i. Is local health authority data used in CADTH programs?
   - For example, data shows that a committee member's local area use fewer prescriptions than the provincial average, but rather than being healthier than average, the truth is many folks cannot afford to fill their prescriptions.
   - CADTH gets context from our regional customers and we hope that the relevant information is conveyed; however, there are limitations in the report structure.

5. Final Comments

a. What happens next with our workplan?
   - We are mapping CADTH's stakeholder relations with regards to patients and communities, to be discussed at our next meeting in February. We're focusing on the perspectives identified in September (youth, elderly, Indigenous, rural and remote, and individuals experiencing poverty). We will be looking to you to help us prioritize 'less heard' voices and offer ideas for engagement.

b. For April, we will spend time on all four work streams and shaping what we will be doing in the future to advance them.

c. Our website will soon be updated with proper links and committee information, including details on upcoming meetings and agendas.

6. Actions

a. Invite CADTH staff to share their backgrounds and personal motivations to work in health technology assessment.

b. Use Julia Abelson's patient engagement evaluation tool during April 2020 meeting.