CADTH Symposium 2019 – Report

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Workshop: Would you Fund this Drug?

Summary

This workshop included all stakeholders. The workshop started with a "Health Technology Assessment 101' to set a foundation: information about the patient input submission and what the role overall is; the clinical data portion of the submissions; and, the economics section of the submission. A theoretical case study and questions provided in advance as a case study. The case study was for an oncology IV-delivered drug that impacts a small population of people (about 600 people in Canada). The standard of treatment of these people currently is various chemotherapies (noting that they will eventually relapse), and one other type of IV drug.

Breakout groups worked through potential sections of how pCODR would deliberate, including: patient unmet need; most important qualities of the medication for patients; clinical data including primary outcome data, side effects, etc.; and, the economic data. Groups reported back: all groups either recommending 'not fund' or to 'conditionally fund.' Most of the recommendations were based on unmet need, economics, and lack of clinical data (only phase 2 data, no direct comparison, etc.). There was robust discussion about the recommendations, with many patients in the room expressing that the process felt somewhat unfair – in a sense feeling as if the process tells people that some people's disease/lives are worth it while others are not, and the rigidity of the system that fails to take in to account a holistic, i.e. whole person, approach.

Key takeaways & Suggestions

- While there are patient input submission opportunities associated with HTA, many patient workshop participants expressed feeling that deliberations leaned towards weighting the quantitative data more than the qualitative data
- CADTH might consider doing this workshop with a mix of case studies (chronic disease, life-threatening disease). It might be interesting to see how thoughts and ideas change based on case study type (if at all)

Patient Networking Reception and Poster Session

Summary

CADTH hosted a networking reception for patients and patient organizations and health charities, in a room that was a dedicated quiet room for patient participants for the

entire symposium. It was appreciated that this forum and type of quiet room was set up from the start of the meeting.

The poster presentation kicked off the symposium formally. It was appreciated that one's poster was dropped off for setup by CADTH staff, and that the posters stayed up for the entire symposium, so that they could be visited at any point during the symposium, allowing for more time to digest, take pictures, etc.

Suggestion

- A 'buddy' or 'mentor' system could be set up for patient participants at the conference. While some patient participants have been to the symposium many times, other patient participants were new to the symposium experience and to health technology assessment. CAPA would be happy to work with CADTH to brainstorm how this could work as well as help with the execution for 2020.

April 15, 2019

Plenary Session – Disruptive Innovation: The Hope and Hype of Transformation

The plenary session was well planned and executed. Panelists included Colleen Flood (moderator, Prof at U of Ottawa), Carole McMahon (former patient member of pCODR), Frederic Rupprecht (Johnson and Johnson Medical Devices), Irfan Dalla (HQO), and Harindra Wijeysundera (CADTH). It was focused on hype and innovation, and how that helps/hurts the public (and other stakeholders). There was discussion about the HTA process and the need to consider reassessing drugs and devices (in France this happens at least every 5 years and is mandated). This does not necessarily mean that drugs/devices will be removed from use, but it does help fill gaps in data that exist when these hit the market, and it reflects better use of these within the system and to best help patients and their outcomes. Carole McMahon and Irfan Dalla re-enforced the importance of patients and the role patients should play within all levels of decision making in health and health care. Panelists were thoughtful and the questions asked were insightful.

Key Takeaways

- The patient perspective was front and centre at the plenary session.
- Health technology management (as presented) appears to be an opportunity to review data that were not available when the drug/technology was originally assessed and is part of continuous diligence and improvement to the health and healthcare system.

Understanding the Burden of Evidence: Cultivating Best Practices in Patient Evidence

Panelists: Connie Cote (Health Charities Coalition of Canada), Mary Sunderland and Chad Andrews (Foundation Fighting Blindness - FFB), Tamara Rader (CADTH, Patient Engagement)

Connie Cote reminded the audience of how and why patient input is important. Mary Sunderland and Chad Andrews reviewed specific details about how FFB has been involved in collecting patient input for their CADTH submissions, and are generally interested in collecting patient input less related to specific drugs and technologies and more about the patient experience. Tamara Rader spoke about patient input at CADTH and its exercise (summer 2018) where they reached out to some patient organizations and health charities (not an inclusive exercise) to gain input and information about the process. I was also interested to learn that CADTH sometimes reaches out directly to patient organizations and/or patients for input in to certain reports. *There was not enough time to ask about specific cases or examples, or when they decide to do this and why, as well as how they determine or find the individuals they reach out to.*

Requests of CADTH

- To make a public report available or undertake a webinar to share learnings and findings of its patient engagement exercise (from summer 2018).
- To share more information with patient organizations about how/when CADTH decides to reach out directly to patient organizations and/or patients for input to certain reports.

Pharmaceutical Policy: The Relationship of Conditional Regulatory Approvals in HTA Recommendation – Outcome and Timing

Panelists: Lawrence Liberti (Centre for Innvoation and Regulatory Science), Frank Lichtenberg (Columbia University), Elena Lugu (PMPRB), Ana Komparic (U of T student)

At the start of this session was presentations that included conditional notice of compliance for reimbursement decisions. The original purpose of this conditional notice was to expedite access to treatments for life-threatening illnesses, with the trade off that the manufacturer would bring additional data to the table when it became available. However it appears that many decisions from payers about conditional approvals are negative, which has moved away from the original intent. Elena Lugu of PMPRB talked about biosimilars, and points she made included: Canada pays second highest global price for biologics and has second highest use of them; PMPRB's reflection that Inflectra/Remicade is a lost opportunity (data that were presented included that Remicade had 25% of marketshare in new starts historically, and when Inflectra came to market, it took about 6%, Remicade took about 6%, and Xeljanz (another innovative medicine) took about 13%). While conversations are different in the

oncology space about biosimilars than they were in the rheumatology/GI space (my personal assumption is that this is potentially due to the nature of the time exposed to treatment), PMPRB offered that moving forward, it will work more closely with prescribers. The reasoning provided was that patients generally trust their prescribers in terms of recommendations for medications and treatments. PMPRB is now talking about the oncology opportunity for costs associated with biologics. Ana described the potential models of pharmacare that could be under consideration for Canada – i.e. Fill the Gap vs. One Payer model; her talk was about values related to the pharmacare debate and what people feel overall with respect to this concept and these ideas. There is some form of agreement that pharmacare is important to Canadians, and that it probably will not be a one payer model, rather some form of fill the gap.

April 16, 2019

Tackling the Thorny Issue of Patient Partner Compensation in Research and Health Care

Zal Press (Patient Commando) and Dawn Richards (CAPA)

This was a co-presentation of our publication from PXJ. There were about 40 participants in the session and after presenting key points from the paper, the audience was asked to talk amongst themselves and before opening it up for questions. Questions and comments included:

- How patients always seem to be at a disadvantage: "If you don't say the 'right' thing, you won't get asked back to many tables"
- How some patients feel that any form of compensation is not ideal as they feel that it hinders their ability to be truly independent with respect to their opinions
- Wondering how to go back after the fact to ask for compensation for a project moving forward on which you had not been compensated to date
- The topic of industry funding overall and how this is currently viewed, and what to do about it. How can we start to talk about other funding models, or what suggestions are there for new or other solutions?

Incorporating Patient Input in CADTH and INESSS Drug Reviews: How is it Included and How Does it Inform CDEC, pERC, and CSEMI Deliberations?

Panelists: Sarah Berglas (CADTH), Allen Lefebvre (public member, CDEC), Virginie Landreville (INESSS), Elizabeth Lye (Lymphoma Canada), Amanda Cresswell-Melville (Eczema Society of Canada), Cameron Lane (patient member, pERC)

This panel included a number of interesting perspectives. The health charities reflected on their practices for patient input, which generally includes a survey and in some cases,

putting the submission back to the community for comment, and submission to CADTH. They also discussed the outcome of a negative recommendation – how they need to communicate this to their respective community, and how they then try to continue to advocate for and help their stakeholders. This is likely not easy when in some cases this may seem like the only option for patients. The patient and public representative perspectives were informative. The public representative saw his role as also being responsible for reviewing clinical data. He offered advice for patient input submissions including: not being overly excessive in the use of quotations from patients, providing a 'balanced' perspective of both good and bad effects of medication use, and being cognizant that his role is to make a recommendation based on the overall package of the medication under review, not just the patient input. He indicated in some cases what he saw in patient input submissions were strikingly different from what the clinical trial data reported. CDEC and the Expert Committees receive the entire patient input submission that patient organizations provide, whereas the 2-page combined submission that CADTH asks for patient organizations to review and agree to is actually for the CADTH team that will put together the final report. INESSS had interesting comments about how they work with patients and patient groups, including that they are still 'new' at this and are forming their processes (e.g. in some cases they reach directly out to patients/patient groups and talk to them for input outside of the formal process).

Questions for CADTH

- *Why are there differences between how CDEC and how pERC operate (e.g. in terms of public vs. patient members, patient input, etc.)?*
    - *Why does pERC have a patient perspective while CDEC has a public perspective? Are the roles of these perspectives meant to be different (e.g. are their Terms of Reference or Role Descriptions available publicly)? How long do the patient and public members serve in their roles?*
    - *Why does the pERC process allow for formal input from patient groups after a recommendation is made while the CDEC process does not?*

Closing Thoughts – Including Kudos and Suggestions

- For someone completely new to HTA or CADTH, this symposium could be overwhelming. See the suggestion above about a buddy-system for patient participants at the symposium.
- There was a range of patient representatives at the symposium, which was good to see. It was also appreciated that CADTH could provide resources for so many patient representatives to attend.

- The quiet room for patient representatives is a welcome idea.
- It was unfortunate that parallel sessions occurred about how patient input is used in HTA and a fireside chat with the CADTH executive. Perhaps CADTH would consider hosting the fireside executive chat over a lunch so that everyone could attend.
- There is an opportunity to drive towards innovative and new solutions. Areas in which discussions and real conversation could occur at future symposia might include:
    - Introducing real conversation of what health technology management should or could look like in Canada
    - What disclosure and conflict of interest mean in patient input submissions (and other processes here)
- As a #patientsincluded supporter and general champion of patient engagement, CADTH should also promote best practices related to patient engagement. Any sessions about patient engagement at the symposium should include at least one patient speaker and/or co-presenter, and CADTH should be proactively encouraging this of all panels, sessions, and speakers.
- The online interaction via twitter of the symposium was appreciated. It was great to meet people in real life from twitter conversations. Would CADTH consider a tweet meet up during the poster session or during one of the breaks early in the conference? Or a webinar in advance of the symposium on best practices in sharing information from the symposium (e.g. CAPA would be happy to participate in it and a prolific tweeter such as Pat Rich could also be approached)?
- The conference registration covering hearty and decent meals was really appreciated - it's nice to be able to count on good options for meals and snacks (especially in case you miss a meal or snack due to a meeting).
- The conference is small enough (~750 people) that there are lots of impromptu networking possibilities, including at the opening poster session.