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*Advancing Health Economics,
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WHAT DOES MEANINGFUL PATIENT ENGAGEMENT LOOK LIKE?

The pCODR Patient Engagement Study Part Two

Part 1 output

Original Research

What does meaningful look like? A qualitative study of patient engagement at the Pan-Canadian Oncology Drug Review: perspectives of reviewers and payers

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Take away messages from Part 1

- Capacity building for pt. groups is necessary but not sufficient to address the problem
- Fundamental tension between evidence-based HTA and experientially-oriented nature of patient perspectives
- Divergent notions of what constitutes evidence and how it should be used
- Suggests the value of re-thinking what is being asked of pt. groups and how this info can best be used

pCODR Patient Engagement Study - Part 2

Aim: To explore the experiences of patient advocacy groups participating in the pCODR process with a view to articulating the strengths, opportunities for improvement and future development of patient engagement at pCODR

Study Design

- Qualitative interview study, REB: U of T
- All patient advocacy groups registered with pCODR
- Data collection April-June 2017
- Invitations: N=44
- Participants: N=22 individuals (representing 21 orgs)
- Interviews averaged 40 min.
- Qualitative descriptive analysis using constant comparative method

Characteristics of participants/organizations

	Range	Number
Number of Paid Staff at Org.	0	4
	< 5	8
	5-10	4
	>10	3
	unspecified	2

	Range	Number
Number of submissions to pCODR	0	4
	1-4	8
	5-9	7
	10+	4

Making submissions

- pCODR submissions are a high priority for pt. advocacy groups despite the burden
- Timeframe for submissions is a major challenge
- Requires constant monitoring of Health Canada, FDA, European agencies and industry partners to alert them when a submission may be imminent

Locating relevant patients

- Widely described as one of the most challenging aspects of the pCODR process
- Extensive efforts including surveys, telephone interviews, web ads, social media, outreach to clinicians, searching discussion and Facebook groups locally, nationally, and internationally
- Often very few pts. in Canada with experience of the drug.
- Clinical sub-populations and rare disease groups esp. difficult

Locating relevant patients

It's not difficult per se to find the patients, but it's really difficult to find the patients who've used these drugs for that indication. Depending on the drug, we may have five patients, seven patients worldwide.

I've had experiences where we've actually had to comb the social media trying to find patients. If it's a small patient group, they will not be in Canada. So, we're trying to contact patients that are, oftentimes, in the U.S. or elsewhere.

Resources

- Participating in pCODR reviews places a heavy drain on limited financial and human resources for many groups
- Submissions often rely on volunteer effort or staff “working off the side of their desk”
- Substantial opportunity costs including displacement of core activity such as fundraising or providing direct service to clients

Perceived impact of patient submission

It's meaningful as a patient representative to be able to say to the Canadian patients that we're going to represent your voice, especially the voices of people who've been on clinical trials. To be able to give them meaning for having gone through that is meaningful in a personal way as a patient representative.

Things to consider

- Dedication, resource demands, challenges, and thoughtfulness of pt. groups
- Some forms of inequity can be addressed through capacity building support and facilitating access to resources such as scientific literature
- Universal desire for a direct line of communication to improve the quality of the interaction and make it more nuanced and meaningful for patients
- Participation is meaningful because it fulfills their mandate to represent the patient voice
 - BUT this does not translate into feeling that their perspectives are optimally represented

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