



Meaningful patient representation informing Canada's cancer drug funding decisions: views of patient representatives on the Pan-Canadian Oncology Drug Review

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ABSTRACT

In this interview with the patient representatives on the Expert Review Committee (pERC) of the Pan-Canadian Oncology Drug Review (pCODR), those representatives offer their views about how to be a valuable contributing member of Canada's national cancer drug funding recommendation committee. The article seeks to inform readers, and especially clinicians, about pCODR from the perspective of the patient representatives.

KEY WORDS

Oncology drug funding, pCODR, health economics

JSH: Why did you want to serve on the Expert Review Committee (pERC) of the Pan-Canadian Oncology Drug Review (pCODR)?

CM: I respect pERC's process for incorporating patient values into funding deliberations. Once I understood [that process], I realized it could be meaningful participation for a patient. I also thought my experience working in a committee-structured environment and my academic background would be helpful qualifications, in addition to my experiences as a caregiver and as a cancer patient.

JN: I first heard about pERC just as I was completing treatment for breast cancer, and I thought that this was a good fit for the skills and experience that I had in other areas. I was attracted by the scientific focus of the work that pERC was doing. I wasn't aware when I began the process that the patient representatives had as much input as they do, but it has certainly been a very valuable experience.

MBB: When our son was in treatment, we received a lot of support, from not just the cancer medical system, but from friends and family and from colleagues. And I felt very grateful for that support,

which made it easier for us to get through what was a truly horrific experience. Professionally, I have interests in methodology and philosophy of science, and when I saw the description of the committee, I felt I might be well qualified as a patient representative, with the combination of our personal experience and my background. I jumped on the opportunity to make whatever contribution I could to the process of improving cancer care.

JSH: How do you explain what the pCODR¹ is?

Response: I think many Canadians, particularly people who have experience with health issues, have begun to understand that everything can't be paid for. People who are interested in what we do on pERC probably already understand that there has to be some process that decides how money gets spent. A deliberative process allows for a broad range of perspectives to be heard in helping make those difficult choices.

Response: I try to emphasize the synergy that you get by having a pan-Canadian committee, as opposed to having nine committees in nine provinces, particularly for provinces [such as] Saskatchewan and the Maritimes, [which] cannot bring the expertise to the table that B.C. or Ontario can, [and] so we benefit from having that greater degree of expertise. I think from a fairness point of view, having one set of information that goes out to the provinces to make their funding decisions is more equitable than having nine slightly different sets of information.

Response: When I'm asked about it, I usually explain that we talk about patient values, medical questions, economic questions, delivery system questions, and [we] make recommendations. The provinces would like to have a recommendation from an independent body, which is important for the fairness question for people. [The] pCODR provides the provinces with a basis, informed by scientific evidence and patient perspectives, for how to proceed.

JSH: As non-clinicians, how do you understand your role there?

Response: I feel an enormous responsibility to learn a lot about what the interpersonal experience is in having these various types of cancer. I carefully read the patient advocacy group's Web site, and then I'll jump to the other Web sites that they flag. I feel that I have a real responsibility to get as much information as I can about that experiential part of what this disease is. I'm not going to be an expert in how to treat it, but I need to find out what it is like to have it.

Response: Our experiences are all with cancer, but they're different in significant ways. The patient advocate reports are important too. While our experiences help us to effectively represent patients, we also do need the insights in the specific input from patients with the relevant type of cancer. I think the combination of being informed by our own experiences with cancer and by the patient advocate reports, and of being informed by regular participation in committee meetings, is very helpful to incorporating the patient perspective [into] PERC's deliberations.

Response: There is this kind of natural conservatism on the part of physicians with respect to established treatment. And as a result, there's a tendency for them to be more sceptical about the promise of a new treatment. And, part of the difference there, between the patient's perspective on these things and the physician's, is that what physicians know they can achieve is, from the patient's and the family's perspective, often unacceptable, given the situation and the condition that they're faced with. But the physician is going to be reluctant to trot out a treatment that is not well-tested, that is brand new, that she might have doubts about; while on the other hand, the patient and the patient's family may well feel, "If we know that the treatment you're offering us can only achieve this, we're prepared to take risks here."

Response: From my own experience, the clinicians see you for relatively brief times, and they don't get involved in some of the psychosocial issues. And so they're not always as cognizant of the issues around caregiver burden, around travel expense, around childcare—issues that may make a huge difference to the ability of the patient to comply with the treatment. One of our jobs is to keep reminding people that those are important issues as well. I think I'm the only person at the table who's had a lot of experience in rural and remote settings, and with aboriginal clients. And, so I feel a certain responsibility to remind people that not everyone is an urban-dwelling, articulate, able-to-contribute patient, and it's important that that perspective be looked at as well.

Response: My experience [of] living in a small, rural community in Ontario tells me that the financial burdens are quite different there. And the support system is quite different. When we consider drugs, we also need the context of not just city dwellers who may have some available support around them. The issues for a person who's isolated, finds it hard to access support, and doesn't have access to the Internet may be unique to rural patients.

JSH: You have "lived experience with cancer" and know "patient values." Do you see yourselves as another type of expert at the expert table?

Response: It's more a matter of having the perspective on the patient experience. That brings a better appreciation, I think, of what it is that concerns patients, and why patients have the kinds of responses they do, for instance, to promising new therapies before there is strong evidence that the therapies are clearly superior to what we've got now. By having three patient representatives at the table, PERC is seeking the kind of input that involves an empathetic understanding of patients which, often, health care professionals don't quite have or can't duplicate, even if they're sympathetic people.

JSH: Do you feel your views are listened to, or do you feel you are there just to make sure PERC has "representation"?

Response: I've been very pleasantly surprised with that. I really worried about it being like the kids' table at Christmas dinner, but it hasn't been like that. I've been remarkably impressed by how much our perspective is valued and very much sought out.

Response: It was natural to anticipate that you might be regarded as not really fully informed, and not really fully at the table, but I haven't felt that at all in our meetings.

Response: I haven't either but I think it goes back to the deliberative process^a, which I find so thorough at incorporating patient values.

Response: The deliberative process has four quadrants: economic, clinical, implementation, and patient values. "Patient values" is one of the four, not a sub-category, no dotted line to the side. In every meeting, time has been set aside for us to present patient values and for the discussion of this in terms of the

^a The *pCODR Expert Review Committee Deliberative Framework* is available on the Web at http://www.pcodr.ca/idc/groups/pcodr/documents/pcodrdocument/pcodr_perc_deliberative_frame.pdf.

drug being reviewed. It's easy to tell that people are thinking carefully about it when they ask challenging questions. I'm happy when I'm asked difficult questions, because it's an indication that the committee is giving serious thought to patient values.

Response: I think the other thing that's unique to this process is that, as patient members, we're given every opportunity to level the playing field.

JSH: What do you mean?

Response: I don't have a scientific background, and the first time we talked about ICERS [incremental cost-effectiveness ratios] and QALYS [quality-adjusted life years], I thought, *I don't know the jargon.... How are these calculated?* But, all of the educational opportunities that we've had, plus the wealth of articles and reference material that pCODR has shared with all of us, has given us the opportunity to be competent members of the committee. That's a steep learning curve, but that we've been provided with all the resources to do this is tremendously enabling.

JSH: Others at PERC may be good at one of the four quadrants in the deliberative framework, or maybe two of the quadrants, but isn't everyone learning together?

Response: It's pretty clear that some physicians are not particularly focused on the economic questions. They understand, broadly, issues of cost and ratios and such, but looking deeper below the hood is a challenge for all of us.

JSH: I want to go back to the patient values quadrant. Some people might cynically say, "They spend time on it, but do you really think it matters?" Can you think of an example [in which] you feel that that quadrant made an important contribution to a recommendation that the entire committee made?

Response: One example for me was when I could see the sense of the table shifting as we focused on the patient reports about their experience with the disease, their experience with the drug and the difference that the drug was making to their quality of life. The difference, in the presentation from the economic guidance report, was a small difference, but I think it became clear to the table, looking at the patient input that, in fact, it was a substantial difference to patients. We were looking at a small increase in progression-free survival, but in the eyes of the committee, the benefit of reducing a very unpleasant side effect was recognized to be more significant in terms of the difference it made in quality of life: more than just applying that small difference in progression-free survival would usually suggest in the decision matrix that we're faced with. It made a real difference to the final recommendation.

Response: I can remember a time talking about a certain drug and a side effect. The side effect profile wasn't drawing too much attention, and a patient member spoke up and said, "Whoa, I've had that. That's really nasty. And, if there's a drug that has a similar cost and a similar benefit and can avoid that side effect, we should be thinking about that."

JSH: Do you think it's worthwhile considering the economic evidence, or do you find [that] it's not really that useful?

Response: In the system we have, many treatments we're providing are going to be paid for, by and large, by the public purse.

Response: And, every time you pay for x , you can't pay for y . I value the general practitioner's perspective on PERC because of the reminders that there's a world out there besides cancer, and if we spend x amount of money on oncology drugs, it may come out of mental health or heart disease or something else, and we need to be reminded of that, because we're in the cancer bubble.

JSH: So, as patient representatives, do you feel an obligation to vote "yes" for every drug?

Response: I think the difference between what we do and what patient advocacy groups do is that we have the benefit of the economic guidance panel and the benefit of the clinical guidance panel. The recommendations are made by a committee, and the committee has to consider all of the evidence. We really look at all the information that [has been] provided that may make a difference to saying, even though Health Canada has approved this as safe and effective, it may not be the best use of a finite pool of money, given the alternatives.

JSH: What kind of feeling do you have when you vote "no"?

Response: It's always hard. But, I have to take it in the broader context, that we can't fund everything for everybody and, if the evidence isn't strong enough for this particular drug, the funds are probably better spent somewhere else.

Response: Hope has its own power, [and] so in one way, it's tempting to recommend every drug that shows promise. But promise isn't the same thing as evidence, and spending funds on something that may not be as effective as it could be or [that] may not help in the ways promised could be detrimental for patients who need effective treatment, and this takes away funds that could otherwise be spent on treatments that are effective.

JSH: So, you're not hurting patients, you're helping patients?

Response: I'm helping more patients than the ones that might be hurt by not having the drug.

JSH: What's been the most difficult thing about being on PERC?

Response: The learning curve was pretty steep.

Response: Yeah, I would have to say that, too.

Response: And it took much more time than I had imagined.

JSH: Was it just the economics, or were there other things to get used to?

Response: With the clinical studies, you have to acquire a sense of the level of effect and outcomes: Progression-free survival? Overall survival? How long? Today, I look at the studies with a different eye than I did at first.

Response: There's a fair bit of effort getting to the point where you feel like you're processing the information in a way that accurately reflects the right overall perspective on these kinds of reports. And, then there's some emotional difficulty, because it leads me to think a little more than I otherwise might about things that are difficult to remember.

Response: That part is sometimes hard. On an ordinary day, I keep some of my experiences stowed away—not in my thoughts. But here, remembering helps ... to relate to a value in a patient advocate report—to look at the clinical evidence and be able to see the magnitude of difference a certain drug offers.

JSH: What's the most rewarding thing about participating on PERC?

Response: I think a sense that the patient perspective is really valued.

Response: That sense that I've had a couple of times, when I really could see that the patient input is making a difference in how the committee recommends. It might not be the difference between the straight-out "recommend" and "does not recommend," but it has shifted the weight of the decision, I think, in ways that made an impact.

JSH: You are pioneers in this experience in Canada. Is there any advice you could give to people who might be, in the future, participating in committees like this?

Response: Block off a lot of time.

Response: I would say [that] you need to be able to become really well-informed.

Response: At least a little introduction to decision theory would be good, and a short intro to reading clinical papers. The details make a lot more sense when you understand the underlying ideas.

Response: You can be invited to join the committee and be given the time to discuss patient values, but to do the job effectively, you also need to acquire a good understanding of all of the issues on the table.

CONFLICT OF INTEREST DISCLOSURES

The authors have no financial conflicts of interest to declare.

REFERENCES

1. Hoch JS, Sabharwal M. Informing Canada's cancer drug funding decisions with scientific evidence and patient perspectives: the Pan-Canadian Oncology Drug Review. *Curr Oncol* 2013;20:121–4.

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