Having a Patient Perspective in Grant Review as a Research

Bill Russell:

Now, our next and our final speaker for this evening will be Dr. John Gore, who is an associate professor at the University of Washington in Seattle. If you have attended any of BCAN's, annual summit meetings, or perhaps their Annual Think Tank Meetings, you very well may have seen Dr. Gore or even met him, as he is a staunch supporter for BCAN and attends many if not all of them. Besides being an educator, he's also a practicing clinical physician, specializing in neurological-oncological surgery, yet somehow still find time to be a researcher and a reviewer, which simply amazes me. So Dr. Gore, if you will, please. It's all yours.

Dr. John Gore:

Thank you so much for that awesome and kind introduction. It's really great to get to be on this webinar with people that I love working with, whom I have a tremendous amount of respect. So I appreciate your leadership on this webinar, and I'm happy to share my perspective as someone who has been a grant reviewer, and how of each perspective not only influences the grant review process, but it also affects my process as a researcher. What I take away from that process.

I do think that different organizations have differentially recognized the importance of having patients on that review panel. The panel in which I have the most robust experience with integrated patient reviewers is through PCORI, who funded this webinar in our pragmatic trials CISTO, but I've been a part of a number of grant review processes where the patient is an adjunct reviewer who really just makes comments as part of the review process. And what is really striking about the PCORI review process is that they are embedded within the organized review. And what I mean by that is, your scientific reviewers will deliver their review but as part of the itinerary for the review process, our patient reviewers also give an organized detailed point by point review.

Dr. John Gore:

And the content reviewed is somewhat different. The patient reviewers focus on impact, why the research study is important, why it's important to different stakeholders including patients, they review the level of stakeholder engagement with the process. This is like Donna's comment about how are patients involved in this study? Are they just there for the grant or are they actually embedded in the research team? And then patient centeredness. How the grant adheres to core contents of patient centeredness that are important to PCORI's funding mission. And I've found that patient reviewers really have incredible input that guides the grant review process on issues of feasibility, issues of acceptability of the research study and the study design, and on outcomes of interest. Are we actually measuring the things that are important to measure with this research question?

We're nearing the end of the webinar. So I want to focus a little bit on how this has influenced my own personal research program. And I think, in working with this process, it really highlights in so many ways, the critical role that patients have in influencing our research processes and the fact that it's really remarkable that we haven't done this before, that the work of PCORI really revolutionized the integration and how we embed patients into the research teams. And so, a couple of things I've learned. Number one is, engagement is important early and often. So we try to get patients involved in our research teams quite early to validate the importance of the research question and even to make important decisions about the research design.

As an example, this is not a bladder cancer study, but we have a research study that is funded to develop and implement patient centered pathology reports for cancer care. And very early, we included patients in our study planning sessions, to try to figure out what outcomes would benefit from being able to view a patient centered version of your pathology report, and what participants we should be studying, should we be studying just the patient? Or should we also be studying the caregiver or spouse and the provider? And so it had a tremendous amount of influence just on the scope and scale and study design of our study. Patients have really critical input on recruitment and retention, and an ability to really I think, enhance our recruitment activities. But also by retention, we mean, once we recruit patients into a study, how do we keep patients in those studies?

And so I think patients have a terminal to impact on that, and also really dissemination. I think we have all too often adopted traditional dissemination routes. So as a researcher, we typically are trying to get a summary of our research as a scientific manuscript into the most well known journal that we can get it into. But that's not how it reaches the patient population. And so I think having patients really embedded in your research team highlights different ways of dissemination of research products, how you actually get the news of your cool research study out to the patients who are going to benefit from it. And so, I think importantly, it grounds our research in the patient experience, which should be the experience that we're prioritizing. I think it improves the quality of all the materials that our research study is going to include that realize a view by our patient participants. I think it informs how patients access information. And I think it critically changes how we communicate our study findings. And so, through reviewing with patients, it's really impacted how I conduct research on patients. Thank you so much, Bill.

Bill Russell:

Thank you so much, Dr. Gore. It was a very informed presentation. We certainly appreciate it. Well, we've come now to our question and answer time of the webinar, and I'm personally interested in case any of you have any questions you may want to bring forward.

Question and Answer

Bill Russell:

Dr. Gore, if you would, please. I think we all know now, how you feel about the advocates' point of view regarding your experiences and all, **how do you think that your research colleagues feel? Do they feel the same as you do regarding the value that say a patient advocate would bring to the table as a reviewer?**

Dr. John Gore:

That's a really great question. And I think one of the benefits in our working relationship together with Dr. Angela Smith, who's at the University of North Carolina has, as we really started working on our process for engaging patients and research activities about six years ago, and I think we've come up with a way to embed patients and research teams that enhance the patient centeredness, but also the quality of the research we're doing. But it is not universal. And one of our goals with programs like this, it's to increase really our population of patient research advocates, because we recognize that this benefits all modes of research, clinical trials, pharmaceutical research, and grant funded research.

And so I think that that recognition is increasing. A lot of people in the bladder cancer domain are really more focused on clinical trials. But I think more and more, in a clinical trial context, they're also realizing the importance of embedding patients into those protocol teams. But it's not quite caught up to where we're at with our Patient-Centered Outcomes Research Program.

Bill Russell:

All right. Thank you very much, Dr. Gore. We really appreciate the time you've given us this evening.

Stephanie Chisolm:

Yes, we do actually have a couple of questions. **How do we get involved with the project? Do we reach out on the PCORI side or there's something that BCAN is overseeing?**

If you are interested, please reach out to Morgan Powell and she will be able to help you get involved in the BCAN Research Advocate Program. We have lots of varied opportunities, whether it's being part of a research review process, or being part of an advisory board, say for one of our pharma partners who really want to understand the lived experience, but if we don't know that you're interested, we can't suggest that you be considered for those particular opportunities. So please do reach out to Morgan so that we can add you to our database as people who have a direct interest. We also send out notification when programs like CDMRP are looking for reviewers and you do have to apply and you do have to know BCAN and we have to write a letter of recommendation as Dr. Kimbark had explained. So we would love to have everybody who is interested get into our program and Morgan can help you out with that. So that answers that question. And then there's another question we have time for. I think we'll just finish up with this last question.

Stephanie Chisolm:

Are most grant applicants from academic centers? Is human subjects review process completed at their institutions rather than being addressed by the DOD PRCRP reviewers? So I'm not sure who might want to answer that. But Dr. Kimbark, are you getting most of your applicants from academic centers?

Dr. Donna Kimbark:

Yes. Most of our researchers come from academic centers. We do once in a while get some researchers who are from industry, small biotech companies and so on. And as far as regulatory review and all of that, that is outside of the scope of what is done at the peer review. You will have some questions in review criteria that will be centered on clinical strategy for those that have pilot clinical trials or clinical trials, but you will not be looking in depth at the review of the human subject ethical points and some of the recruitment and consent forms and so on and protocols, you will not be looking at that per se.

Ralph Ullman:

I just like to chime in that even though the proposal is certainly going to have had to go through the local or institutional IRB with respect to formal requirements for human subjects, the treatment of human subjects, as a patient advocate, it's certainly an area that you're probably going to want to take a look at. Even if a proposal satisfies formal requirements, you may have some issues about it as a patient who is a patient advocate with respect to privacy, security and so on, safety with respect to the human subjects. So it's an area that I always look at as a consumer and reviewer or a patient advocate.

Dr. John Gore:

I just wanted to make one comment that, even though most of these come from academic centers, that doesn't mean that they take place at academic centers. In fact, most industry sponsored clinical trials occur at community sites, community clinics, places like that. But most of the grants do come from the academic centers, but more and more we recognize the need to actually convene our research where most patients get their care?

Stephanie Chisolm:

Thank you so much, Dr. Kimbark and Dr. Gore, Ralph Ullman, and Bill Russell for your amazing leadership in pulling this program together. And thank you to PCORI for helping to support this program.