



## PARTICIPATING IN RESEARCH: ENGAGING WITH “PHARMA”

With: Tim Turnham, Karen Sachse, and Nancy Lindsey



### Question and Answer

#### **Nancy Lindsey:**

Thanks so much, Karen. We really appreciate you sharing your personal experience along with your experience as a patient advocate. We'll now entertain some questions and I would like to start with a question for you, Tim. **When companies are looking, pharma companies are looking to incorporate patient advocate opinion, are they looking for people who have been patients or caregivers very recently? Are they looking for people with hindsight experience? Are they looking for people who maybe more recently have gone through bladder cancer treatment and or surgery?**

#### **Tim Turnham:**

Yeah, I think that's a great question. Most of the time, companies want to know what's happening now, right? They want to know what the current experience is because 10 years can make a large difference. But simply because your personal experience was 10 years ago, doesn't mean that you don't have anything to offer. But sometimes people who have come in groups like BCAN and really gotten involved are in touch with other patients. Maybe you've mentored other patients, maybe you've been a peer support person for other patients. Maybe you've stayed active on your online community and things like that. If you have current information about what patients are experiencing, I think that can make a real difference. Most of the time, that's the situation, is if they're looking for what's going on now. There may be some exceptions, but they would be less common I think.

#### **Nancy Lindsey:**

Right, great. Thank you, that helps a lot. Karen, as you were speaking, **I was wondering, was participating as a patient advocate really emotionally difficult? Or maybe was it cathartic for you?**

**Karen Sachse:**

Well, certainly there were times when I was overcome with emotion. But mostly it was just a really great experience and feeling that I could really take my sadness and really put it somewhere, and direct it somewhere that it was going to do some good.

**Nancy Lindsey:**

Okay, great. Thank you. Tim, **are other companies other than pharma ever in touch with you? For instance, ostomy supply companies or manufacturers. Are they looking for patient advocates to come in and give some kind of help with product evaluation?**

**Tim Turnham:**

I love the way whoever is asking this question is thinking. I wish I could say that it's true, yes. We have occasionally had those kinds of things happen, but it's not happen. I mean, I haven't... I know a person who is part of a big company that does CAT scans. I said, "Have you ever talked to patients about their experience, about having a CAT scan and what that was like, and ways it could be improved?" They just had zero interest in this. I wish that device companies, supply companies and things like that would talk more about the patient experience. But it's a hard sell, we can't seem to get their attention. But if you know somebody in those companies, tell them they should do this because it's important.

**Nancy Lindsey:**

Karen, **did you find that you had to do a lot of preparation before you would either go to a meeting or be part of even an online meeting, to be prepared as a patient advocate?**

**Karen Sachse:**

Well, I will say that my experience with Merck, with their PR company, was that they actually prepared me. They would send me questions and topics that were going to be discussed. Really, it's just communicating your perspective. There wasn't really any research or things like that that they had to do.

**Nancy Lindsey:**

Tim, I wanted to ask too, there's a question about, **do you find that more men or women are willing to be volunteers or patient advocates?** Or do you find that pharma companies are more interested in either a man's perspective or a woman's perspective?

**Tim Turnham:**

No, I think it's pretty balanced. Maybe a few more women than men, but it's just an accident of who has been impacted or things like that. What's kind of interesting though is when you... is the mix not between male and female, but the mix between patient and care partner. I love bringing groups together that has both because sometimes the patient's experience and the care partner's experience can be quite different, and even priorities. I do an ad board with a disease that's congenital, and we had three or four people who were in their upper teens or early 20s and their parents. The patient perspective about one key issue was completely opposite from the parent's slash caregiver's perspective.

**Nancy Lindsey:**

Tim, the last question that I have had here is, **how do you identify people who might be good candidates for patient advocacy?** I know that we can go through BCAN by letting BCAN know about an interest in that. But are there particular characteristics or a skillset that you recognize in people when they're volunteering and identifying them for a specific pharma company?

**Tim Turnham:**

We generally do interviews or screening interviews. We're not trying to screen out opinions, for example. But what we are looking for are, do people have the relevant experience that helps in this particular need that we have right now? That's one thing. Number two, are people... we do it, I mean, you guys know this because you see it. There are some people who get involved in disease areas who just have ideas that are way outside the norm. "I drank goat urine and it cured my cancer." There are those people. We don't want people who are so abhorrent that it's not really reflective of the broader group of people. But I will say that I'm always interested in finding what I call real world patients, right? The patient who has had a real kind of experience. Because it's fairly easy to find the patients who have gone to the big cancer centers, the MD Andersons and the Sloan Ketterings and things like that. Their point of view is valid and important and valuable. But what about the person who lives in Montana and travels an hour and a half away to the only oncologist who is even that close? That oncologist may or may not know anything about their particular kind of cancer. I want to hear what their experience is as well, so we're always looking for well rounded, broad experience that helps us understand the real life of real patients.

**Stephanie Chisolm:**

We do, and we'll have time to maybe get to one of these final questions. This question is directed at Dr. Turnham. As you mentioned, there's a stigma felt among dermatology patients worldwide concerning their diagnosis. You've now spoken to a number of patients through BCAN and through the work that you do. **What is your assessment of the level of stigma concerning bladder cancer among those diagnosed in relationship to those who have colon cancer, for instance? Do you think the bladder cancer is still keeping people from seeing specialists, their urologist, when they first present the symptoms?**

**Tim Turnham:**

I think denial is a big part of all of us. We don't want to believe that something is wrong. We are still embarrassed about anything that's in the genital area or the urinary area. I mean, all of this just kind of makes us a little bit, we're a little bit prudish about this. I think that those are barriers to people getting care when and how they should. It's a barrier also to, I think, getting the support sometimes that you need. I suspect that many bladder cancer patients have friends and family members with whom they have not really been honest about the impact of bladder cancer on their lives, and what that has meant for them. I certainly know that's the case in colorectal cancer, especially if you have an ostomy or something like that. That's just something people are kind of reserved by. Because of that, you don't always get the support that you need and you don't always seek out the help that you need. I think also, sorry, you had a soap box here. I'll say this very quickly. I think that physicians often do not fully understand the impact of these kinds of cancers on your quality of life. They can be dismissive and I think cystoscopy is an example of that. Well, it's a simple procedure. You may feel some discomfort, right? It's up to patients to advocate for themselves to say, "This is a problem. I need you to pay attention to this. I need you to listen to me." But that's not easy to do, especially when your life is in the hands of the person you're pushing back against.

**Stephanie Chisolm:**

Absolutely. I think that really what you're doing for your group and connecting patients to pharma, and again, the volunteers that we've had that we tried to help share what I call their lived experience. I think it's a win on both sides because knowing that you're helping the people that might not see more than a slide with some tumor cells on it. To really understand what it's like to live with bladder cancer, can be very empowering for a patient. As well as really informative for a company to really get that feeling of what exactly do we want to say having this treatment will do for you? How can we change your life for the better? That's really the most important thing.

**Tim Turnham:**

Exactly.

**Stephanie Chisolm:**

Thank you all for sharing. We do appreciate that. **Now I just want to say thank you again to our speakers, to PCORI for funding this program so that we could really help to engage and develop BCAN research advocates.** Thank you, Nancy, for your excellent job moderating this program. I really appreciate it. Dr. Turnham, thank you. Karen, thank you for sharing.