

Transcript

Matters of Engagement podcast
Episode: "Expertise Part 1"
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Jennifer: Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. This is Jennifer Johannesen.

Emily: And this is Emily Nicholas Angl.

Jennifer: In developing the initial episodes for this podcast series, we've been thinking about the questions that we hear so often about patient engagement and partnership. Questions like: Should patient partners be paid? How do we evaluate partnership? How should patient partners be recruited? We put a spotlight on some of these issues specifically. But we've been finding that many roads on this journey have led back to one common topic. And that's expertise. We knew we couldn't do a podcast series about engagement without thinking about what it means to call patients "experts." So we thought it would be a good place to start.

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Emily: And we thought the perfect first guests for this topic would be Frank Gavin and Francine Buchanan. They're each parents of children with medical complexity, and both have vast experience participating in committees and projects as patient partners. Frank is a member of the board for the Ontario Strategy for Patient-Oriented Research Support Unit, Chair of the Citizen Engagement Council at the CHILD-BRIGHT Research Network, and is also on the steering committee for the Drug Safety and Effectiveness Network. Francine Buchanan is a PhD student in Health Services Research at the University of Toronto, and is the Patient and Family Engagement Coordinator at the Hospital for Sick Children in Toronto.

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Jennifer: If you've been immersed in patient engagement issues online for a while, you might remember Frank and Francine as contributors to healthydebate.ca. In early 2019, Frank wrote an article titled "The Risks of Equating Lived Experience with Patient Expertise." Then, not long after, Francine Buchanan published her response titled, "How do Patients Attain Equal Status if They're Seen as Non-Expert?" We've included links in the show notes if you want to take a look.

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Emily: Both of us read these articles when they came out. And I think like a lot of people, we felt a mixed response. They both raised such good points, but because their two articles were framed as a "debate," there was a sense of having to pick a side. But taking a step back reading through the articles, and then speaking with both of them, we found that there was in fact agreement on many things, and that both of their perspectives make an important contribution to the discussion.

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Jennifer: When we initially started thinking about this topic, I thought we might head down a different path, that we might explore how classic definitions of expertise are being challenged by not just patients but by the public at large. In these uncertain times, there seems to be a growing distrust of experts because of a perceived disconnect with how so-called “regular” people experience their lives. What alarms me is that in some circles, experts are seen as merely people with opinions, or even as elites with opinions. This potentially sets the stage for a couple of things. One is that experts get dismissed and deemed not credible. And on the flip side, well, anyone can claim to be an expert because they have an opinion. My own discomfort with this, though, is somewhat offset by an equally loud chorus of voices that stands behind science, sound research methodologies, and indeed the advice of experts. But these are perhaps matters for discussion another time. For this podcast, we decided to showcase the perspectives and conversations that are currently being had in patient engagement circles. And these two articles and their authors do a great job of framing the discussion and laying the foundation for future conversations.

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Emily: So we're splitting this topic over two episodes. In this episode, part one, we'll discuss Frank's article and also feature some of our conversation with him. In part two, we'll do the same with Francine and then offer our own final reflections.

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Jennifer: A common refrain we hear both in the clinical setting and in patient partnership settings, is some variation of the sentiment that patients are experts. Now for some, this is one of those “it goes without saying” statements. Patients have been seeking acknowledgement of their hard-fought skills and experience and knowledge for a long time. And the term expert is sometimes seen as the positive result of those efforts. It's a way of recognizing that patients have valuable information and perspectives to contribute, not only, of course, to their own care, but in settings where important decisions get made about healthcare services and delivery. Based on our own conversations with other patients, engaged or not, we suspect this is the prevailing opinion that many patients do see themselves as experts or having expertise in their own experiences. Healthcare professionals use this phrase widely when referring to patients. I was frequently told I was an expert when it came to caring for my son. I've also heard it more broadly stated in educational or professional settings, that patients or caregivers or parents are the “real” experts, and that medical professionals have a lot to learn from them.

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Emily: What's interesting about this debate overall, is that I think many of us, our guests included, would actually agree with some of these basic assumptions. That patient perspectives are valuable and important in many contexts, that patients have a lot to contribute to the improvement of healthcare delivery, that patient experience should not be dismissed as merely anecdotal. The question at hand then is not really about whether patients have something valuable and important to offer. It's whether the label “expert” is appropriate.

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Jennifer: This is really the gist of the debate we see in the two articles. Frank Gavin's article seems to be asking, "What are we really saying when we call patients experts?" And Francine Buchanan's response seems to be, "What are we really saying when we don't call patients experts?" We asked Frank what led him to write the article in the first place.

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Frank: 25 years ago or so, it was not so common for patients and families of patients — caregivers — to be called experts, or, you know, to have something called expertise recognized. It's changed dramatically. So one of the things I've been thinking about especially since I've been involved in patient oriented research: I've many, many times been called an expert. "You're an expert, Frank. We want to tap into your expertise." And it's something which is repeated over and over again, as if... It made me think this is something that's much on the minds of people, and this is an idea that about patients having expertise and being experts that's in the air now, and there is certainly a great inclination, a great desire to identify the contribution of patients as that of experts. As I said in the article, healthcare in general, research in particular, are worlds where expertise is the coin of the realm.

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Emily: At the heart of Frank's article is the idea that by commonly accepted standards of the word "expert," lived experience doesn't equate to the same thing. Usually, experts have a well-defined narrow area of expertise and would have been called upon at some point to demonstrate their knowledge and skills in relation to clear standards with rigorous assessment and reassessment of those knowledge and skills. Of particular importance, says Frank, is a kind of detachment:

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Frank: I think most people in the healthcare system, whether they're administrators or researchers or clinicians who call patients experts, you know, are doing so because they want to recognize something important. That is the knowledge, the important knowledge that patients have the skills they have. But sometimes it strikes me that what you're doing is imposing the terminology and the structures that belong to the academic world, the healthcare world, onto patients. Expertise I think requires a certain detachment. And, you know, we are, you know, we love our children. We have a relationship that comes first. We have a knowledge of them that is *not* to me very similar doesn't seem to me very similar to the relationship that an expert has to, you know, a well-defined body of knowledge. You know, so if someone is an expert in a particular kind of heart disease that requires stepping back a lot of objectivity, a lot of assessment. And I don't think that's analogous to the relationship parents have with their children.

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Jennifer: Now, Frank is referring to caregivers in this case, but what he's saying also applies to patients themselves. He points out that of course, people find individual ways to live with their health conditions that makes sense in their own lives and environments. But even if someone could be said to be expertly managing themselves within the context of their own personal situation, does it follow that they are experts?

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Frank: To say that, you know, because you've, you've managed with a particular condition — with arthritis or with multiple sclerosis and some ways to get around in a different way — that you're now an expert... I would question, "Oh, you're an expert, in what exactly?" You know, I have a hard time seeing that as the same as expertise, which, again, I think involves a lot more detachment than simple competence does.

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Jennifer: Frank mentioned detachment in both the article and throughout the interview. I think what he's referring to is a kind of academic detachment that might allow, say, a researcher to be willing to discover they're wrong, or that there's a better way. For an individual, there may not be that need or desire if what they're doing is working just fine. So in this context, without detachment, or objectivity, this may make it difficult to extrapolate an individual's learning and apply it to the lives of others. And one of the reasons this would be so tricky is because, as Frank asks, how do we know which individual approach is more expert than the other? Of course, there's no need to compare approaches if everyone is just living their own lives. But this dynamic may come into play if a researcher is looking to patients for their expert opinions to help inform a project or a process. If there were competing expert ways of doing things, whose is the right one?

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Emily: Adopting the language of the professional system has other potential consequences as well. Just as there are hierarchies of power and influence within the medical system, Frank has sensed, at times, a growing hierarchy among engaged patients. I've seen this too. Patient partners with more experience may have more influence. Sometimes relationships or friendships form with some patient partners feeling left out. Frank shared an experience in an advisory committee where he felt an undercurrent that credibility was earned by how grave your child's health condition was, which made him feel almost unwelcome.

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Frank: We would go around and let everyone know what our experience was. And for a long time, what happened then was it was almost a kind of one-upmanship. And I always, I've certainly felt myself, you know, "Geez, I don't really don't belong here." And it did seem to me what was happening there was, you know, we're creating our own kind of hierarchy. What's really being said here is that, you know, there is a gradation, a ladder here, and that some people's experience, some people are more experts than others. So there's a kind of contradiction. Everybody's an expert, but some people's expertise is of a different nature.

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Jennifer: Another point Frank makes is that he worries that calling a patient an expert, just by virtue of their lived experience, may place undue pressure on them to perform as expert patients when they may not even think see themselves as such. Over time, the message that "you're an expert" may get internalized, which could compromise how you might see yourself in moments of difficulty.

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Frank: I worry a little bit that that can place a particular pressure on people to say, therefore, if something comes my way that I don't understand, or that I'm having difficulty, I should be able to manage this in some way. It takes some guts sometimes to say, "I don't know what this means I'm at sea." I think sometimes, if you're not managing your illness properly, you know, if you're not navigating the system with skill, and you are meant to be an expert, and you've been told you're an expert, is there a danger there? And I think there is: that what you're going to feel is terribly inadequate, like you've been a failure.

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Emily: So Frank is suggesting that calling patients experts may in fact undermine the value of experiential knowledge that patients possess. We don't need to use the language of professionals if we authentically value the experiences of patients. According to Frank, patients don't need to be seen as experts to be seen as equals.

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Frank: I think there's a difference between when a person who barely knows us, or our work in a clinical setting, or our work if it's in, say, patient oriented research, if very early on, the person says, "Well, you're an expert." I'm thinking that doesn't... "How do you know that? Why are you saying that?" There was once... My son had a clinician who, you know, after many encounters, said to us at one point, "You know, you're doing a really good job." She said that to my wife and me. We really valued that. And we valued that in part because we had known this person for months, if not years, at that point; had had many encounters, had spent hours with this person. Therefore, what she said meant something to us. What she said, though, was, "You're doing a really good job." I think was easier to absorb that. And we thought about that often afterwards. And it was a very valuable thing for her to say — it was valuable to us. If she had said, you know, "You're real... you've become real experts," I don't think we would have valued that as much. It wouldn't have meant as much — it wouldn't have rung as true.

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Emily: In our conversation with Frank, he mentioned a meme that's made its way around conferences and presentations as well as social media. It appears in the form of a saying or a poster or cartoon, and it goes something like this: A patient and a physician are in a consultation, and the physician says something like, "Please don't confuse your Google search with my medical degree." And then the patient responds with, "Please don't confuse your one hour Lunch & Learn with my 20 years of living with this condition." Frank recognizes this is meant to be a caricature, but also thinks it reflects something quite serious, perhaps concerning.

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Frank: And the message always is, hey, the real experts are often the patients. I thought about and I said, wait a second, how likely is it that a patient who's had a serious condition for 20 years is consulting a physician whose only experience with that condition is a one hour lecture many years before? I don't think that's a common experience. Now. I know where it's coming from where it's coming from is too often, patients have their own experience, their own knowledge, you know, under-acknowledged, underappreciated, undervalued, but now we've almost gone to the flipside, where essentially the clinician is the butt of the joke.

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Jennifer: Although Frank thinks particular sentiment may be taking things a bit too far, he understands where the need for patients to be seen as experts comes from. It may be a response to longstanding information and power imbalances, especially in clinical encounters, where patients and caregivers sometimes feel left stranded or feel they have no control. He told us about when he took his young son to a hospital clinic and the surgeon was especially condescending.

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Frank: I mean, I know exactly why people feel a need to respond in some ways after their knowledge and their skills have been dismissed. So, you know, I think many of us have had that experience in the healthcare system. And of course, that can be humiliating. So, when you ask a question, and essentially, you're slapped down in front of your seven-year-old, it's more than discouraging.

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Jennifer: Frank proposes an alternative to this tussle over expert status. He suggests a spirit of reciprocity and earnest and authentic give-and-take of knowledge and experience.

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Frank: We I think what we want to get to is a situation where people, you know, can sit together, can talk together, can share ideas, be candid with one another, and try to arrive at the best possible solution. I think if clinicians come in too keen on their own expertise, that can be a big problem, you're not going to get that. Also, I think if patients and caregivers come in thinking, "We are the real experts here. We are the ones who should have the last word in this situation," then that's ... that doesn't happen so much, but it's almost as if sometimes I've seen some evidence of this where somebody... I think that's behind that cartoon with the clinician and the patient. But this is where I think the reciprocity comes in. And I think we get hung up. If the question is who's the real expert, that becomes the focus, then I think that gets in the way of genuine reciprocity.

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Emily: As we started to wrap things up, the conversation shifted slightly from talking about the need of patients to be seen as experts to some possible motivations that healthcare professionals and institutions might have for calling patients experts. Well, maybe we can't know motivations, but what might be some consequences? Frank described an encounter in a meeting when he brought forward some questions.

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Frank: And I had some questions about the process, about what it was, how we should evaluate these grant proposals and so forth. And the response I got a couple of times was, "Well, you're the expert!" and I felt like saying, "Well actually, I'd rather have my question answered, you know how I should assess, how I should grade these applications." Being told I'm the expert is distracting in that case. Being told you're the expert can also be a way of saying, you know, "You figure it out!"

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Jennifer: In our conversation, we considered the idea that perhaps calling patients experts is a kind of a tool or an intervention which might help to move discussions forward more smoothly. If it's important to patients to feel they are seen as equals to the professionals, then calling patients experts may help remove some barriers in the moment. But Frank notes that this may just cause more problems down the road.

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Frank: Patients are told, "You're really important. You're at the heart of this institution. You know, your input is essential. We learn so much from you." And then more recently, you know, "You are experts and we need the expertise you offer to help us... whatever, you know... improve our care processes or, you know, change something about something important about the way this institution runs." And then eventually it seems something happens. And I think it has something to do with power. There's a clash, and somebody feels in the end, well, you've got an agenda of some kind. Something happens. And there were many situations where things broke down completely. And my worry is people then don't learn from that experience. Part of the problem is something deeper hasn't been looked at, you know. What's the real reason we want these people involved? What's the real value in it? What's the point, and how are we going to tell whether we are achieving that value? And who's going to be able to say whether we are getting there? Unless you ask the deeper questions, you're going to be, sort of, well, we're going to try this model, we're going to rearrange the tables, you know, we're going to meet over a meal rather than at the end of the evening. And none of these things are... or we're going to get free parking passes, or we'll give an honorarium of some sort, you know, or none of these... some of these things are in fact important... but they may not be at the root of the problem.

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Jennifer: Between Frank's article and this interview, we covered a lot of ground about expertise. But it also feels like we've barely scratched the surface. Which makes sense: the ways in which we think about experts and expertise is multifaceted. And if we want to make sense of the issues, it really does require us to look at it from a lot of different angles. Our conversation with Frank looked mainly at how the impetus for patients to call themselves experts may stem from patients' interactions with their own healthcare providers, in which they've historically felt that their own knowledge and skills were undervalued when it comes to managing their own care. Claiming expert status for themselves in a clinical setting is one way to respond to this — to level the playing field. This dynamic has carried over into patient partnership spaces where patients want to ensure their own contributions are seen as equal to the contributions of those who are traditionally called experts. So again, here, calling patients experts plays a helpful role in facilitating a more productive relationship between patients and professionals. But for Frank, this may in fact be distracting everyone from asking harder questions, or maybe even preventing us from getting to genuine reciprocity which he thinks should be one of the goals of patient partnership.

Jennifer: Now, not everyone agrees, of course. So in part two, we speak with Francine Buchanan, who wrote a response to Frank's article on healthydebate.ca. She gives us another angle to consider and proposes that patients should be given every opportunity to develop their own expertise as patient partners, which may eventually put to rest any question about whether patients are, or can be, experts. To Francine, that answer is yes.

Jennifer: So please join us for part two to continue the conversation with Francine Buchanan. And a big thank you to Frank Gavin for participating in this episode. If you have a question or comment, please visit our website at mattersofengagement.com, or you can find us on Twitter at [@mattersengage](https://twitter.com/mattersengage).

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