

Transcript

Matters of Engagement podcast
Episode: "Expertise Part 2"
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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.

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Emily: And this is Emily Nicholas Angl.

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Jennifer: This episode is part two of a two-part miniseries on expertise. In the first part, we explored why calling patients experts seems to be a hot topic. And we spoke with Frank Gavin about his article in Healthy Debate. Here, in part two, we speak with Francine Buchanan, who wrote her own article in response. If you haven't already, please do go back and listen to part one, so you can have a fuller context for this conversation.

00:46

Emily: Before we carry on, we'd like to briefly reintroduce our guests. Frank and Francine are 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. He's also on the Steering Committee for the Drug Safety and Effectiveness Network. Francine 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.

01:26

Jennifer: As we heard in part one, Frank Gavin feels we don't necessarily need to be seen as experts in order to be seen as equals. He wrote about this in an opinion piece titled, "The Risks of Equating Lived Experience with Patient Expertise," which was posted on healthydebate.ca. For Francine Buchanan, this didn't quite hit the mark. She penned a response which was published a month later titled, "How do Patients Attain Equal Status if They're Seen as Non-Expert?" We've included links in the show notes to both of these articles. And just one more quick note before we continue on: we recorded Francine's interview on Zoom and found that occasionally, some of her words drop out or aren't quite clear. We include full transcripts to each episode on the website. So please refer back to the text if you want to be double sure about what you heard. You can find the transcript for this episode at mattersofengagement.com.

02:28

Emily: So we started by asking Francine why she wanted to respond to Frank's article, she described her initial reaction of discomfort and went on to explain the particular nature of that discomfort was not a new feeling. She'd felt it before. A sense that she was being told she didn't belong:

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Francine: When I got into the academic world, I had this sense that was kind of put on me that I was always the other. I was always the parent who saw things differently. I was, oh, that person. She comes from a different background. Oh, they don't understand. All those sorts of things were never said to me outright, but they kind of permeated a lot of conversations that we would have in class discussions. So I think that kind of led to my unease, that kind of pit in my stomach, because I'd felt it before. I felt that feeling before: being the other. Felt that feeling before of being, you know, different or not part of the group and coming in from the outside into a group and trying to understand what that group is trying to explain to me, and trying to fit my knowledge into that group setting.

03:41

Jennifer: So here, Francine is referring to her experience as a PhD student in Health Services Research, where she's frequently confronted with her own sense of impostor syndrome. She knows she's earned the right to be in the class, yet often feels that her contributions and views are seen differently and not necessarily equal.

04:01

Francine: I walked into a classroom where I had the exact same credentials as everyone else who is in that first year class. I may not have had the same background, I may not have been a clinician scientist or, you know, have a background as a technician or pharmacist, but I walked in with the same credentials, I was allowed into that classroom as a PhD student studying Health Services. And still, I was told that my thinking was not appropriate for that classroom because of who I was. And I think that is what pushed me the most to push back on that.

04:44

Jennifer: We think it's possible that a few things might be happening here. One is that Francine's contributions to academic dialogue are being questioned because there may be an assumption that she's speaking from personal experience, not from more accepted sources like research or theory. Or, and possibly more likely, it could be that even when Francine is technically doing and saying all the right things, it's assumed her personal experience is inflecting her thinking in a way that's seen as biased. Now we can't know what the others are thinking, of course, but regardless, she's left with the impression that her own ideas don't count as much as the others' because of her personal experience. And it's against this backdrop that Francine read Frank's article, and realized it tapped into her own pre-existing discomfort.

05:37

Emily: Which brings us to the article. In her response, Francine thinks through the notion of patients as experts from a number of angles, starting from her own personal experience. She describes her own competency dealing with her son's medical equipment, even troubleshooting ventilator malfunctions on public transit. This is a form of mastery gained from hands-on experience that, in Francine's view, few

healthcare professionals can match. She also describes having to manage an entire care team seeking solutions when others say there are none. She's required to speak at a level that is easily on par with medical professionals. She understands the medications, can describe symptoms and complications, she provides detailed case notes and history at each meeting. The message seems to be: if this isn't expertise, what is?

06:28

Jennifer: To be clear, Francine is not saying that because patients become skilled in managing ventilators that they should therefore be seen as experts in ventilator repair or managing respiratory issues. Instead, she goes on to argue that patients have the capacity to develop the skills required to contribute meaningfully in healthcare settings, and that their experience shouldn't disqualify them from opportunities. Patients already have familiarity and personal experience. So why not foster the skills they already have and allow them to rise to their full potential?

07:03

Francine: So I think there are patient experts that are quite expert [at] rounding up and communicating with other patient partners, right? Really gathering... being those people, "people-persons" that connect people, really get the most out of people, can really be leaders and sort of rallying the troops. There's other experts that are really good storytellers, and if we can get them to teach other people then I think that's a potential pool for expertise. You know, we've experienced in the broader world that all of a sudden, those people that can do really good TED Talks have become, you know, have risen to popularity because they communicate really well. They might not have all the publications that need to be, you know, raised in that sense of academia, but they do really good TED Talks. Those are two different areas of expertise, different ways of communicating: one on paper, one in person. What I want to get across right now is that there is the potential in everyone to affect change. It's how we support those people to affect change.

08:08

Emily: Throughout our conversation, we got the sense that Francine's personal experience mirrors what she sees in patient engagement spaces. Francine indeed has vast lived experience on the patient and caregiver side of healthcare. But that, of course, is not the entirety of who she is. She has an interest in advanced academic training and a capacity for developing research skills that at least matches everyone else's in the room. And yet, she sometimes feels she can't shake the patient persona long enough to be taken seriously. Francine told us that she thinks a lot about when and how personal experience becomes bias. And she feels her experience is automatically seen as bias and as a barrier to recognizing her expertise. Perhaps because of this, she said it seems like it's often only a patient's personal narratives that are of interest, their lived experience. In her view, patient partners have yet to be given real opportunities to move beyond their own stories, or to take their own experiences and translate them into learnings for others. And though Francine is able to draw on her academic training to help guide her through some of the trickier methodological and ethical minefields, she points out no one is explicitly teaching her how to navigate where her personal experience fits in. She identifies this as a gap:

09:25

Francine: The gap is no-one's trained me on how to deal with all that stuff with my personal stories and my lived experience. There's no training for patient partners. There's no-one looking at patient partners and saying, "Yeah, you're doing that right. You're telling your story right, or you're expressing your ideas." Right? Or, you know, "You've really captured that problem that you experienced in a way that, you know, can be translated to others." There's no way to do that, and no-one cares about doing that right now. Right now, we still see patient partners... as much as we try, we still see them as a focus group, where people listen to you, they talk to you. But then they take your ideas and they translate them academically. They take their ideas and they, you know, mold your ideas into what fits into the literature that exists, or contradicts a literature that exists, or matches your idea with someone else's idea to make it, you know, "evidence." No-one's talking to the people that are actually seeing the ideas and utilizing them in a way that allows us to build on them, and have that interaction with people to say, "You are good patient partner. You know, the way you expressed yourself was really, really good." Instead, we still go to people and say, "Thank you for your ideas. I'll see you later."

10:46

Jennifer: Francine agrees with Frank that use of the word expert is defined by the system, whether that's healthcare or academia, and with it comes a set of rules and structures in which patient's skills and experience are not an easy fit. Francine points out that our understanding of expertise is taught and reinforced by the dominant culture, the one that says training and credentials and traditional evaluation methods are the only ways to be seen as an expert. And she's also aware that there's a strong desire to continually engage patient partners who are considered "fresh" and "naive." Francine gets the impression that sometimes patient perspectives are only valuable when they are uncomplicated by professional development as patient partners.

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Francine: The disconnect is from the patient partners who've been asked to come into this world and give their input onto situations, policies, procedures, research — free of any background or understanding of certain things. So that we want "fresh minds" to come and give us a fresh... you often hear the words "fresh perspective on things." And this is where the patient partner comes in handy. People are always asking for that. They don't want the "experienced patient," as they say, or they don't want the "professional patient partner." That gap means that we will never be able to accept someone who we want [as a] patient partner with a sense of understanding of self reflection, or a skill set around methodologies, for example, or a skill set around even statistical analysis of, you know, specific information. We will never recognize them for what their potential will be if we keep on seeking out new people that are "fresh" and "naive" and give that fresh perspective.

12:58

Francine: So we need to have an understanding of where we want our patient partners to be. Do we want our patient partners to be someone who is aware of how things are utilized when they give their opinion? Do we want a patient partner who is clearly trained in being able to express stories in a way that does incorporate a lot of different perspectives? If we want those people, we have to raise those people, we have to support those people, and we have to give them a way to express themselves, where we're not putting them into a box of a non-professional patient partner. But until we bridge that gap and we accept that there is expertise, we're never going to have expertise. So we kind of put

ourselves... it's a self-fulfilling prophecy: we don't want experts we want naive people, therefore you can't be an expert, you need to be a naive person.

13:53

Emily: Francine isn't exactly sure what the right path forward is, but she believes that investment in developing the skills of patients partners is required in order for patients to be seen as experts which, in turn, would give them access to roles and positions that can influence healthcare and make system change. Related to that, Francine thinks that part of the equation is to reflect on how we value or compensate expertise:

14:18

Francine: This comes back to the idea of, you know, volunteers and the idea that you do this voluntarily because you want to make the hospital better. Meanwhile, there's people that have been paid to be hired into senior executive roles whose job *is* [getting] paid to make the hospital better. So why does that person's knowledge base equate them a salary, and someone else's knowledge base equates them with a volunteer stipend for paid parking? Where do we want the money to go if we value people's knowledge to make the system better? And to me, this is where that tokenistic idea comes in a little bit, you know. It's much easier to ask for a group of volunteers you might have to eventually change every five or six months because people have dropped off, than it is to make a commitment to one or two people and hire them on as employees. Maybe that commitment to one or two people changes the way they think, does that affect how we see them as patient partners? I don't know. Like I said, I don't have an answer for the future. I just want to make sure that we think about it differently and not in the same framework we've been thinking about it for years.

15:37

Jennifer: Francine is well positioned to think about these issues because of her role at Sick Kids Hospital in Toronto as the Patient and Family Engagement Coordinator. So she's thought about patient partnership from both sides: as a caregiver, and now as someone working as an engagement professional. We asked her if there was something specific she felt she was advocating for from within the structure of her job. What sorts of internal barriers did she feel she needed to push against? Here's what she said:

Francine: A predefined expectation of what patient partnership is. And I think I am, like I said, fighting against that focus group thinking. Even family advisory groups or family advisory committees, a lot of them do exist at hospitals now, and a lot of hospitals want them implemented. But the actual work that happens at a committee meeting could be different to every hospital. We don't know what that actual work is. We don't know the nitty-gritty around, you know, how those people were recruited, how they... what information is shared with them, what role do they have in actually making change? How is their feedback incorporated into the big picture?

16:51

Emily: Francine is expressing a concern here that is shared by others we've spoken to. Regardless of the context in which patient partnership takes place, there can be a lack of consistency, transparency

and accountability. Or at least, if any of this is known, it's not necessarily shared with the patient partners. For Francine, this is part of the work that still needs to be done.

17:20

Jennifer: One of the things we found interesting about each of our interviews, with Frank and Francine, is that although we started out talking about the basic question of whether patients are experts, both seemed keen to move past the semantics to not dwell on the official definitions for too long, and instead think about the path forward for patient partners. For example, you might recall Frank talked about genuine reciprocity between patients and professionals. And here, Francine resists rigid boxes or definitions, and imagines a way forward where patients are supported to develop their interests and strengths:

17:58

Francine: If we start saying that this is an area of expertise that we can grow as a whole, then maybe we start looking at that new person we brought in and say, "Here's the pathway for you. You can start here. But the next path might be to evaluate where your strengths are. And then, if you evaluate where your strengths are, maybe you go here, maybe you go there. Maybe you become a storyteller, maybe you become a mentor, maybe you become, you know, a person who's sitting at the CEOs table." We can't do that if we start to package people right at the beginning and try and compartmentalize where their expertise lies. We're way too new in patient partnership to do that. And to go back to what you were saying earlier, when we start to dwell on the semantics, we may be putting up more barriers and we're actually leaving.

18:46

Emily: Our interview with Francine happened in the early days of the shutdown orders due to the COVID-19 pandemic. And for her, the limitations of how we do patient partnership were becoming increasingly clear: In a crisis, she wasn't so sure that the current model was flexible or agile enough to utilize what patient partners would have to offer:

19:08

Francine: I've learned that patient engagement, the way that it's structured right now... I don't know [whether it] will work in a crisis, you know? Patient engagement takes a lot of manual labour right now, right? We have to get these groups of patients together, we have to get their ideas, we have to collate their ideas, we have to make sure that there's someone at a senior leadership level listening to those ideas. And then we have to translate them and put them into these discussions that are happening on the fly all over hospitals, and making sure that the patient perspective is included. Meanwhile, sitting in an office, being a paid employee, I have access to people where I can share my personal lived experiences and bring those to discussions that are happening on the fly in hospitals. That can't happen as an external group. That on-the-fly thinking doesn't happen unless the people are already at the table. This third-party extended thing that kind of happens on a Thursday night where you invite people to have, you know, dinner and sit around a boardroom table doesn't happen in a crisis. So how do we get those people that have those ideas at the table already, so when a crisis does happen, we're already utilizing [them]. And that's what I think needs to happen in terms of patient engagement. We need the people embedded in the organization, used for their strengths that they have, if it be for, you

know, data analysis, or administrative duties or things like that. And then bring them to the table in the time of crisis and say, you know, "You understand our organization, you understand what we're doing, and you have the patient perspective as well. How can you help us?" And I don't think there's anything wrong with that. I think a lot of people might disagree and think that we need those fresh faces, those external people. But I don't think there's anything wrong with having people embedded in your organization that you're paying constantly for their value.

21:16

Jennifer: Hey, Emily.

Emily: Hey, Jen.

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Jennifer: So remember when we were putting together these two episodes, we knew going into it, we might have some trouble pinning down definitions. And now that we've put together the interviews and can reflect back on it, what do you think? Are we any closer?

21:34

Emily: Yeah. And no, I have a lot of thoughts about this. How about you?

Jennifer: I don't know, maybe a bit closer. But you go first, how are you thinking about experts and expertise now? What did you take away from the conversations?

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Emily: Okay, so one thing I noticed was that Frank and Francine seem to focus on different forms or levels of patient engagement when they talked about expertise. So Frank talked a lot about expertise in the context of clinical encounters, like his reference to the cartoon with the patient and doctor, and then his examples with his son's medical care. Now Francine seem to focus a lot more on the idea of patients and their role as patient partners and, say, quality improvement or research.

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Jennifer: Yeah, I thought so too.

22:22

Emily: She seems to feel patients have the capacity to become experts and just need to be given opportunity and support in order to contribute beyond their own stories and realize their expertise. Well, they both seem to agree then that, while experiential knowledge should be deemed valuable and should be respected, people aren't automatically experts just because they've spent time as a patient or caregiver. And both also seem to agree that patients have potential to become experts. So maybe rather than a debate, it's like Frank's ideas about patients as experts triggered Francine to think more about patient partnership. More of a multi-pronged exploration rather than a polarity or a disagreement.

23:06

Jennifer: Yeah, you know, they were thinking through aspects of the same topic, but it's almost like they were having different conversations. And because it was a more free-form discussion, we did veer into different territory with each of them. I thought Frank made an interesting connection about how using the label "expert" can be distracting. And Francine had interesting comments about embedding patients in organizations, so that when something like a pandemic hits, there's this different kind of expertise ready to be engaged.

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Emily: They're both thinking about ways for patient voices to be heard and patient partners to have meaningful impact. And maybe there's just not "one way" or even the "best way." Francine said it's too early to put people in a box, and maybe she's right.

23:59

Jennifer: So I think it's fair to say it's not as though we solved anything, but we did get to explore a couple of ways that patient partners are thinking about expertise. But you know, in future, it would be great at some point to think about some of the other angles on this. One of the things which we mentioned at the beginning of Frank's episode is that there's a trend now to question expertise and the credibility of experts themselves, and to bring forward a more populist voice. And I think there's an element of that in questions of whether patients are experts, or whether patient experience should be seen as equivalent to professional training.

24:38

Emily: And another idea worth exploring is the notion of patients being experts in their own experience. So Frank referred to this at one point, and he's skeptical about equating experience to having a PhD, which is something we hear a lot. I think there's a lot written about this, particularly in anthropology, this question of whether individual are reliable translators or even communicators of their own experiences?

25:04

Jennifer: Yes, exactly. And it's why I think ethnography is such a valuable research methodology. The ethnographer is both a participant and a trained observer. They're skilled in capturing and describing people's experiences and their interactions and their perspectives in detail, and then connecting those findings to a wider cultural, social and political context. But of course, this is part of a much broader discipline of study, and I'm just not sure how feasible it would be for patients to become "auto-ethnographers." I think this question is relevant here because I remember at one point, Francine was wondering if patients could actually build the skills that allow them to take their own stories and extract the meaning, and perhaps even teach or share that meaning themselves. Now, I know she was just thinking out loud, but if this is on the minds of patient partners, it's worth thinking about whether there are appropriate contexts for this.

26:04

Emily: Yep, lots to think about for future episodes. And with that, let's wrap it up here. Big thanks to Francine Buchanan and also to Frank Gavin who joined us in part one. If you have thoughts or comments about this episode, please visit us at mattersofengagement.com.

26:32

Jennifer: This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl, with generous financial contribution from the Ontario SPOR SUPPORT Unit, or OSSU, which is jointly funded by the Government of Ontario and the Canadian Institutes of Health Research, or CIHR. The views and opinions expressed in this episode belongs solely to the producers and are not to be considered endorsed by OSSU, the Government of Ontario, or CIHR.