

## Transcript

Matters of Engagement podcast

Trailer for Meet the hosts!

<https://mattersofengagement.com/meet-the-hosts/>

00:06

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: We're so excited to be launching this podcast and can't wait to share with you what we've been working on. Starting July 1 episodes will be released every two weeks. And if you want an overview of topics, you can visit [mattersofengagement.com](https://mattersofengagement.com)

00:34

Emily: We've put together this short episode to give you a bit of context to this project. And perhaps the best way to start is to introduce ourselves. Okay, Jen, you go first.

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Jennifer: Sure! My name is Jennifer Johannesen. And I have a lot of different roles in my everyday life, including professionally as a website developer. But when it comes to patient engagement, I identify first as a parent and a caregiver. I have a grown son named Angus, and I had a son named Owen who passed away about 10 years ago now. He was 12 when he died and had lived with significant disabilities all his life. Now, when Owen was alive, I certainly participated in my fair share of engagement activities, both in healthcare improvement and in health research. But since his death, I've taken a more reflective and critical turn. I wrote a book called *No Ordinary Boy* in which I reflect on the challenges and absurdities of raising a child like Owen. It's mostly a chronicle of our encounters with health care, pediatric rehab and special education. I then went on to pursue a Masters in Bioethics with a focus on Health Policy. And in recent years, I've done a lot of writing and presenting about patient engagement from a critical perspective. Now, some have said that my research and views are helpful and insightful, and others might say they're just scathing and unproductive! And I'm sure there's truth in both. This project represents for me a real culmination of those experiences, as well as a natural next step - a chance to hear from others and also carry on some of those conversations that never quite felt complete.

02:18

Emily: So I'm Emily Nicholas Angl, and I also tend to have a number of different projects on the go at any one time. But a good deal of what I do professionally revolves around patient engagement. Like you, Jen, I came to patient engagement first due to my personal experience. So I've sampled a good

medley of health care flavors and trips to the emergency room, multiple stints in acute care hospitals for orthopedic surgeries, as well as recovery, inpatient mental health treatment, some private and some public, ongoing care for chronic issues, and most recently, I've gotten a taste of the world of fertility treatments, as well as pre and postnatal care. My son Myles is three now. Throughout much of this, I was also at least sporadically pursuing a degree in medical science with ambitions of becoming a physician, or maybe doing my PhD. But in the end, I realized and actually embraced that this wasn't my path. And so, I looked to other ways to apply my interest in healthcare. And when I learned about patient engagement, actually over 10 years ago now, I was really excited at the idea of being a patient advisor. I tried to bring my perspective to pretty much every conference and committee I could. Over time my approach has shifted and my level of (at least I think) healthy skepticism has increased. I have enough experience now I think that I recognize some of the limits and also the opportunities for improvement. So I'm still on a few boards and committees wearing my "patient hat" as they often say. But these days, I mostly consult on strategy for patient engagement. And also, I'm keen for more ways I can participate in critical and reflective inquiry. Like this podcast!

04:11

Jennifer: The focus of this podcast is to bring forward issues and topics that in our experience, could just use more nuanced dialogue. Many of the conversations you're going to hear in these episodes are perhaps ones you've thought about already, but wish there was a forum to really explore them more in depth. There's never enough time at conferences or in meetings to really dive into some of these complex dynamics. And we're hoping this podcast is a good platform for those conversations to happen,.

04:40

Emily: Each of us bring something different to this project. So Jen, you've intentionally kept yourself at a bird's eye view, commenting on power relations, political agendas, interpersonal dynamics, and yeah, okay, you've definitely ruffled a few feathers! And I've been more on the ground supporting patient partners, researchers, and engagement professionals to work together in hopefully more authentic and impactful ways. That often means wrestling with some tricky questions, including some that we are covering in our podcast. And it even sometimes means saying, maybe this isn't the right project or environment for meaningful engagement. So yeah, we definitely have different experiences, which means we find ourselves grappling with the topic sometimes in really different ways.

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Jennifer: Yeah, that's true. And a large part of the work has been not only figuring out how to present the research perspective and experiences of our guests in a way that's beyond just "here's what they said," but also making sure we don't insert ourselves in a way that's distracting or unhelpful. It really is a fine balance. And hopefully we get better at walking that line with every episode.

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Emily: As they say, it's a process or maybe the journey. Either way, we hope you'll join us. You can listen to each episode at [matteresofengagement.com](http://matteresofengagement.com) or you can subscribe wherever you usually get your podcasts.

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Jennifer: This podcast 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.