

Matters of Engagement podcast
Episode "Reflections, with Lorraine, Maureen, Keith and Jess"
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Jennifer: Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

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Emily: And I'm Emily Nicholas Angl.

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Jennifer: Well, this is the final episode of our first season of Matters of Engagement. We're busy putting together another series that will start releasing this fall. But we thought we'd take this moment to check in with our listeners. We connected with four of them. Three patient partners with experience in both health system improvement and research, and a general practice physician from the UK who is working on a PhD in patient involvement.

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Emily: This was such an interesting episode to put together and I think a really important one for us. Because at least for me, it helped remind me why we're approaching these topics the way that we are. People are really invested in the work that they do. They really want it to be impactful. And they want their contributions to be recognized. So it's important that their interests be taken seriously. And that we asked some of the tougher questions that just aren't getting a lot of airtime.

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Jennifer: You know, I actually found it really moving to hear from, well, all of them, about what motivates them, and also what concerns them. It was moving because the patient partners are just really giving it everything they've got. And honestly, I'm not sure that the systems they're participating in have really earned it. Now, we're going to keep a low profile throughout this episode until the end. We'll introduce the voices you'll be hearing from, and also indicate where we're shifting topics. But we just want to get out of the way for now. The main thing we ask is that, right now, you pause, pay close attention, because what you're about to hear is impressive, and I think moving, and definitely interesting. And maybe will help you see what's happening in patient partnership in a new light.

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Emily: You're going to hear introductions first from Lorraine, then Maureen, then Keith. All three are deeply experienced patient partners in many areas of healthcare. And we asked them, "What brought you to patient partnership?"

02:22

Lorraine: I'm a diabetic and I have been a diabetic - type one diabetic - for 48 years. I was an educator as a school administrator, and I'm still called back to do that role. I was told initially by a doctor that I had a very poor chance of having normal healthy children because of my diabetic background. And I

went back to my GP and she said, "I think you need a new doctor." She has been somebody who really and truly has given me a quality of life. That I never believed was possible. I have two healthy children. When I retired from teaching, I wanted to really give back.

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Maureen: I'm relying on the healthcare system. Like, I can never get away from that. I need them to survive. I need medication. If I don't take that medication, I would die in three days. So, so you're not as independent you'd like to be. When you engage like that it's very fulfilling, and you're taking a negative and you're turning into a positive. To be honest, there's a lot of self-fulfillment in that work. I mean, I hope it's not just that! I really hope that I'm able to, you know, do it for all of the other reasons, too. But I would be dishonest if I didn't say that I get a lot out of it too.

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Keith: Well, I'm a sick guy, I guess. You know, it's funny. It's funny when you're doing a resume and part of your sicknesses is a benefit. But I've always had issues and I've been a busy guy, I've always worked and I'm a family man, all that standard stuff. But I felt I needed to help if I could. If my poor health could be a benefit to anybody, Hallelujah! And I thought, well, I'm gonna start off helping and it's, you know, like, I think most journeys, it was a slow process. I didn't understand what they needed me for at first. And then I got passionate about it, and it just took off. I mean, they started sending me all over the province. You know, I have very little education. And, you know, being a patient partner... it's not required. It was just the passion, I think, that kept me interested, kept me going. But it was my own poor health - I think every patient advisor or partner, we feel like we owe the system I guess, maybe. If we can, you know, if we get asked for help, we should help. That's just a human emotion. And so that's probably why I got involved. I wanted to give back for all the misery I caused the healthcare system.

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Emily: So that was Lorraine, Maureen and Keith, sharing with us why they're involved as patient partners. Our conversations quickly turned to some of the topics we've discussed in the past season, and one of the more compelling episodes seemed to be Compensation, featuring Zal Press and Dawn Richards. We wondered what parts of the discussion resonated with them. And, well, here's Maureen:

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Maureen: Well, I was really intrigued by the Compensation podcast. So that's a huge issue. And I've had some very negative experiences with compensation where I found out later that, you know, the person in the room next to me or at the same meeting as me, was getting paid and I wasn't. Because they had asked and I hadn't. And that, I have to say that rocked me. Like, that was something that you know, was really difficult. The lack of transparency about it is the worst part of it. I've only had the discussion twice in all of the projects that I'm in and where I've raised it. And it's really difficult to have it. I'm not shy, and I'm experienced. And even with that, oh man, it just feels like it's a terrible feeling to have to bring it up. I only was able to do it with support from a researcher, kind of thing. But what really intrigued me about the discussion was about Zal's comment about being faith-based and the charitable roots. And I just kept thinking, "Wow, I wonder if we'd having this same compensation discussion if patient engagement was dominated by men!"

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Jennifer: In case some of that was hard to hear: Maureen said she was intrigued by Zal's comments about health care, volunteering, being faith or religion-based, and having charitable routes. And she's making the connection to patient engagement being populated primarily by women who usually do the volunteering. So, she's wondering, would we even be having this conversation about money if engagement was primarily done by men?

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Emily: My own guess is no. Or at least not to this extent. But having said that, the topic of compensation was also a difficult issue for Keith. He feels perhaps more conflicted than Maureen, but I think Zal's comments really got him thinking.

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Keith: I've done a lot of Boards, other Boards and different charities and stuff. And I always say that I get more out of it than I give. And that's the truth for me. I just believe it, and it's true. It was in that episode, about how can we possibly ask for money from a system... and I think as a public, we're conditioned that the health care system is always broke and the hospital here is scraping every dollar to keep us healthy and there's never enough. So that always weighed on me that, how can I possibly say, you know, "I should be paid"? When we're, you know, we're sitting around trying to figure out how to get money for another MRI machine, you know, that kind of stuff. So the average person would feel guilty about saying, you know, I deserve to be paid. And, you know, sometimes it would cost me money. Even though my expenses were covered. You know, I go to Toronto for two, three days, sometimes. I'd be out of pocket, I try to convince myself that, oh it's for the good of the community.

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Jennifer: Keith told us a story about how he used to run into the Minister of Health at the time, at some of the events or conferences at which he would have been invited not just to attend, but to perform a role - as a moderator or as a speaker or a facilitator. Often out of town. Sometimes from multiple days. And there was a running joke between Keith and the Minister which Keith took us entirely good-natured, where she would always say, every time she ran into him, "Keith, I'm doubling your salary!" But knowing, of course, that he wasn't being paid at all. Here's how Keith tells the rest of the story:

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Keith: But it was the truth. I'm the lowest paid guy in the room, doesn't matter what room I'm in. And she said, "Well, I'm going to double your wage." I mean, we all chuckled, and that's great. And every time after that, I see her, she would say, "I'm giving you I'm gonna double your salary again". And it was all in fun. But after a while, I thought, you know.... There are only so many pieces of artwork... you know, \$50 artwork that you can hang up at home, right? Every hospital would give me something - a hat and a shirt... I wish they wouldn't even have done that. It was somewhat of a, I won't call it an insult but... don't give me a hospital t shirt, and a hospital hat and a \$25 gym bag when I just spent two to three days presenting to your senior leadership and your Board of Directors. I would have rather just have a thank you. I've traveled probably 100 times. And I think one time I got \$100, which was the best hundred dollars I ever got. Like, for my work it showed that... it's not a lot of money, but it was enough to make me say "Wow, they appreciate what I do." And I don't if even the thought crossed their minds

to pay a patient advisor even though I chaired the event. They may have – may have - been taking advantage of the whole philosophy about patient advisors, you know - they're just doing it to give back. We can have this guy stay for three days and come chair this event and it doesn't cost us a penny, so maybe there was a bad vibe on my side, I think.

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Jennifer: So does that change how you... Can you imagine, looking forward, that you might broach the subject, for the next opportunity?

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Keith: Well, it certainly crosses my mind now. Every time. I actually think that... you know, I don't travel as much as I used to, but when I do travel, I do the math. Kind of. I look at the organization that has asked me to come. You know, now I'm very sensitive business. It does cross my mind. Is this a job where I should say something? Should I say, you know, what are you going to give me? And it's hard to say those words. It's really difficult to spit those words out. "What's in it for me?" Because we're so used to just... I'm just happy to be helping out

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Jennifer: [sigh] I'm dying to say something here.

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Emily: Me too! But we'll wait until the end. Another topic that came up was Evaluation. Maureen wants to see some evidence that engagement is effective. And she connects this with being accountable.

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Maureen: You're asking people to give their time. I'm coming from the rare disease world where people have very serious illnesses that, you know, have a heavy burden of caregiving and they have to keep jobs because they need benefits. And we're asking them to get engaged. And if somehow we can't give them evidence that this engagement is making a difference...? It's kind of Pollyannaish to think that people are still going to really want to be involved. Middle-class, white, educated women are dominating this. If we really want to open it up and get all the voices that we need... well, I think we should be prepared to come to come with some, you know, tangible evidence that if you do this, you know, it's been proven that research will be better. And outcomes will be more relevant. And here's some examples of how that's been done. We have some examples, but we don't have a lot. I mean, I keep using the same one over and over and over again about rheumatoid arthritis - that when patients got involved, they found out that you know, it's not the pain that's the most important outcome. It's the fatigue! People learn to live with the pain, but the fatigue is the quality of life, you know... But I mean, how many times am I going to use that same example? Where are the other examples? And so, I think it's a matter of accountability. Like, if you're going to ask people to be involved, then you're accountable to them.

14:00

Jennifer: This is a good moment to introduce Jess. She's a primary care physician in the UK, and is in the final stages of writing a PhD, which looks at the use of patient participation groups in general

practice. In the UK, general or primary care practices have around eight or nine thousand patients. And every one of them is required to have a patient group advising the practice. And the only mandated requirement is that the group somehow be representative of the patient population for that practice. Now, Jess already had an interest in participatory research methodologies, and found that this sort of involvement...? The kind that falls under the umbrella of what they call PPI or public and patient involvement...? Well, the implementation of it is pretty inconsistent and hard to evaluate. So her PhD is looking at how patients and GPs in the same practice can work together, and to see whether the work of these groups can be made more meaningful. Jess had similar comments to Maureen, regarding lack of evidence.

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Jess: And the idea of these groups is that by involving patients, you will lead to more patient-centered services. But actually, when you look at actual evidence of whether that actually happens, it's very hard to find the evidence. So a lot of things that came up in in your podcast at various points, like, why are we doing it? Is it because of moral obligations? Is it sort of like this, holding the practices to account? Is this something about increasing competition? So patients kind of knowing more about the practices and being able to improve them like a governance so that the standards go up? Or is it about the whole patient feedback agenda, and if we collect feedback from patients, then services will magically improve? I'm interested in what the links for all of that is and how and whether it actually makes any difference and, how that would be. Some of the things that come out of the PhD are interesting things about how you do involvement work with your own patients, when there are all sorts of things about how a doctor is supposed to behave, and hierarchy and power, and what patients can and can't say to doctors.

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Emily: Let's bring Lorraine back. She was the first patient partner we introduced. Lorraine spends a lot of time in the role of educator or trainer, and designs and teaches communication workshops that focus on what she calls the Art of Listening. For Lorraine, the patient partner's role is to be helpful and it's less a question of power and more of a question of creating the right environment for collaboration. And for patient partners to become skilled at listening for where they can be most effective.

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Lorraine: I think that there is an awful lot of time spent on the negative aspects of, you know, "Well, I don't feel that my voice is being heard. I don't feel that this is happening. I don't feel that this group is representative enough. I don't..." You know, my emphasis is on what are the skill sets necessary to listen to the voice of each other and to work in a productive environment, and the building of trust. But certainly working with groups that are active listeners and groups that inspire me to give my best, you know, that are supportive and positive and educate me in those areas that I'm not familiar with, and I feel that I'm a real partner. Listening is so powerful, listening to what the researchers are saying, listening to how you can add to that conversation, in hopes of improving the outcomes for those whose illnesses or whose conditions are being addressed, you know? You use encouraging words that kind of set the stage for taking a risk, building that climate where you feel comfortable asking questions that that sometimes may cause you to say, "Should I really bring this forward?"

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Jennifer: Lorraine's comments are an interesting contrast to what Jess talks about In this next segment, where someone in the patient group actually needed explicit permission to speak their mind. Jess links this to overt efforts to be “nice”, where environments are set up to signal: this is a social interaction rather than a professional one. Part way through she mentions providing food as an example.

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Jess: So we in one of the practices we worked in, one of the practice managers actually gave the patient permission to challenge her. And you could see around the table the patients' eyes lighting up. And they've never been given permission to challenge the practice before face to face. And it kind of gave them all sorts of ideas about what their role could be and how that could be different. We never tend to do that - what we tend to do is be all touchy feely with each other on both sides. So it's a nice, nice process. And, that's the most important thing. And I really think food is important. But it's kind of setting that tone of this is going to be a nice, nice, sort of, not a professional thing, not where you can come and be challenging and, and raise your voice. And I think what Lucy's episode adds is that that is such a key skill and an important skill. And I like what you mentioned before, about in terms of, is this a process? And the process we're talking about all the time is representation, and the outcome that we want is influence - and everyone seems to shy away from the word influence because it has more power. It's actually an outcome rather than just a process of representation.

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Emily: Jess' comments are a good segue to something Maureen said, which gets into the distinction between patient partners and patient advocates.

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What people often will comment on patient partnerships that I've heard over and over again, is that they'll bring someone on, and they can only focus on one thing. And that's really difficult because that one thing could be the thing that's really driving their lives. And so we have to be very sensitive to that. And some of those partnerships are not successful, because that person's experience is basically, you know, they're trying to make that be representative of all experiences with that disease, and that doesn't work. But for patient advocacy groups, it's more complicated. We need advocates to speak on behalf of people with medical conditions, but it ideally, you know, they're surveying their members, they're making sure they're reaching out to diverse populations, and then they're representing them. We wouldn't have advanced without those groups. So, you know, I often hear critiques about you know, “Well, they think they're speaking for the patient, they don't speak to the patients!” Well, what do you think? Are you going to line up 2000 people with cystic fibrosis, and ask them to speak to the government? And so in that case, representation takes on a different meaning, and we need both.

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Emily: While Keith doesn't necessarily make the same differentiations between patient partnership and advocacy, he's committed to the idea of patient inclusion because as Aman said in a previous episode, he's just seen it work.

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Keith: There's a real impact having patients involved. It's, it's the real deal, because if it wasn't, we'd be on to something else by now. We're not even halfway there. Just wait until we can convince the whole culture of research, how patients can help them. It might make the difference between somebody discovering something, the fountain of youth, whatever. It may be that patient input that does that. It is a philosophy. But it's not a fluffy, warm philosophy. It boils down to real numbers, real events, better health care, better outcomes, happier patients. That's the way I see it.

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Jennifer: With the patient partners we spoke to, there's a lot of hope invested in the potential for system transformation. But for Jess, who's seeing things from a different angle, many questions remain about the goals of the whole project of patient engagement.

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Jess: ...and listening to your podcast, the thing that has come out more and more for me has been that we put all this work onto patients to think about their roles, and think about the hats, to challenge us to put in requests for expenses.... And we're really just asking them to fit in with us, rather than the aim of it, which seems to be to change the culture and make the whole culture of healthcare more patient-centered.

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Keith: I've got lots going on in my life, like, too much! But I just love this work. And you know, when we talk about... I'm the lowest paid guy in the room. But the second part to that is it's the best job I ever had!

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Jennifer: Hey, Emily.

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Emily: Hi, Jen.

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Jennifer: I thought it was important that we finish with that last quote from Keith. If nothing else, I'm wanting this episode to reveal just how much people are giving of themselves - and their levels of trust and belief and optimism. On one hand, like I said at the beginning, I find it really moving and impressive. And on the other hand, it's deepened my desire to put pressure on the people and systems that have yet to account for how they're absorbing or utilizing these very heartfelt efforts.

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Emily: Me too, and I think this podcast series is a good start. The topics we're covering are ones that keep emerging as concerns for patient partners, or are raising concerns that people had a hard time putting words to but that seemed to capture some of their discomforts. Keith actually said that it was like we took his thoughts and expressed them directly when he hadn't even formulated the words yet. He also said he thought he was the only one thinking about certain things. And it sounded almost like it

was a relief to know that he wasn't alone. We heard that from a few people, which suggests that there just aren't enough platforms for this kind of discussion.

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Jennifer: I think in terms of getting people thinking, Compensation was definitely a hot topic. And Lucy Costa's episode also had a big impact. That was the one about the Empowerment Council, or at least it was at first, but it became a commentary on how patient engagement is a threat to advocacy. Which is a pretty challenging idea, but hard to ignore. So, Emily, for you, was there anything specific you learned or thought about after talking to some of our listeners?

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Yeah, there were a couple of things. First, I appreciated what Maureen said about accountability - that if you're going to ask people to give their time and energy to this, especially knowing just how valuable that time and energy is, then you owe it to them to provide evidence that what they're doing is worthwhile. Like Aman said in a previous episode, there's sometimes pushback on evaluation because it might imply that patient engagement doesn't work. Or maybe outcomes don't really matter to patient partners. I don't think that's true. I think evidence and impact matter very much. And it goes back to what Julia Abelson said, that patient partners want to know that what they're contributing is going to make a difference. And Maureen is saying, "Yeah, show me." But there's another side to this too. As part of evaluation and accountability, it's equally important to show that engagement isn't also causing harm to those involved. Both Maureen and Keith told stories that someone could experience as quite devastating. And what recourse is there for people who experience harm and what are the long-term effects to their relationship with the healthcare system? As someone who's been engaged in all sorts of different ways over the years, I certainly found there to be risks and consequences of being involved as a patient partner.

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Jennifer: Oh, I'm glad you mentioned harm. I want to go back to the story Keith told about the Minister of Health, joking around with him about doubling his salary. It's not funny. It's belittling and crass. Now, Keith is so good natured, and he shrugged it off. But it even got to him eventually. I personally found it deeply offensive. It reveals just how ingrained it is from the very top, that engagement is seen as a volunteer and middle-class pursuit. You wouldn't make that joke to someone whose work is valued and who is underpaid. In what context is that appropriate? Now, Keith loves what he does and is of course free to make his own choices. He's done nothing wrong here. And I don't want to minimize any of his sense of personal fulfillment. But wow, this particular anecdote, I think, reveals something quite troubling about patient engagement and power and how the work is valued, especially by people in leadership.

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Emily: I felt the same. I have one more thing to comment on - and it's kind of related to that story - and it has to do with how we're collectively looking at patient engagement. Lorraine's ideas about not being negative and being supportive and teaching patient partners to be better listeners. I think this has become one of the 'standard operating procedures' of patient engagement. Patient partners are trained and socialized to be ever more helpful and collaborative. But then thinking back to Jess describing how

the patients were delighted when they got explicit permission to challenge the physician and the practice just made me wonder: do we know what patient engagement has really become? Is that what we want? Aman spoke confidently about inviting dissent and challenge but we're not focused on developing patient partners who really know how to do this. Sometimes we don't even allow those who are seen as challenging through the door. When we're focused on feeling good, it creates a vision of what we want engagement to be. As it stands, I'm not sure that the dissent and challenge fit into that vision.

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Jennifer: Well, I think there's a lot here that sets the stage for our next season. I guess we can't say too much yet, as we're still sorting some things out. But for this next round of episodes, we're going to look more closely at the notion of lived experience, and how the idea of the Professional Patient Partner is gaining momentum. And we're also working on a few fun ideas that I think listeners will enjoy!

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Emily: That's a wrap for Season One. Onwards to Season Two! If you have any questions or comments, please get in touch through our website at mattersofengagement.com.

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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 belong solely to the producers or their guests and are not to be considered endorsed by OSSU, the Government of Ontario or CIHR.