

Matters of Engagement podcast
Episode “Evaluating Patient Engagement in Research, with Julia Abelson”
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Hello and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. This is Jennifer Johannesen.

00:12

And I'm Emily Nicholas Angl.

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Jennifer: This episode looks at evaluation. This has become a topic of increasingly urgent or pressing concern as organizations and funders tried to quantify the value of patient engagement, measure the successes of their programs, and figure out a way forward that aligns with healthcare's goals of continuous quality improvement. As we're going to see, evaluation encompasses much more than, say, surveys — and getting a clear picture of it is neither a simple nor easy task.

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Emily: We thought a good guide for this exploration would be Julia Abelson. She's a Professor in the Department of Health Research Methods, Evidence and Impact at McMaster University.

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Jennifer: Julia's research encompasses a wide scope of practice which includes public engagement in health system governance, and evaluation of innovation, funding and delivery of health services. In recent years, Julia's work has included research on evaluation of patient engagement, as well as framework development and consulting. We first approached Julia with the idea of looking at more technical aspects of evaluation, like frameworks and methodologies, and using one of her papers as a jumping-off point. But as we got into the discussion, we discovered there was so much more to talk about, and we didn't quite get there. So we'll head straight into our conversation. But if you're looking for a bit of background on Julia's work, we've included some links in the show notes. We started out by asking Julia how she connects her work in public engagement to this relatively new space of patient engagement.

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Julia: But I'm also a professor who does a lot of work and has training in health policy, and I'm trying to understand how health policy making works. And I think the link to patient engagement — or even more broadly, public or citizen engagement — is how do we understand how citizens and also patients understand policies, contribute to policies, are informed by and really, you know, have a chance to make a difference in healthcare, in the health policymaking processes in healthcare, because — to the extent that it's publicly financed — we are all shareholders?

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Jennifer: An interesting aspect of Julia's work is that she's not just interested in engagement from an academic perspective. She's also immersed in it herself as a researcher.

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Julia: I've been fortunate because throughout my career, a lot of the emphasis of my research has been very collaborative and in partnership to some extent, with policymakers, decision makers, and now increasingly with citizens and patients in partnership and advisory roles.

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Emily: Regardless of what a researcher is studying, it's still often experienced as a significant shift, even a culture shock, to adjust to this new role for patients, originally as subjects or participants, and now as partners. It's a whole different kind of relationship. But Julia didn't really experience this as a shift. She commented about how she was thinking of patient collaborators as partners long before it even had a name. While she herself didn't think of patients as subjects, it's taken a while for the academic structures around her to catch up.

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Julia: I never really thought about it that way, because most of the work I was doing was to elicit their values, their perspectives, their opinions, their viewpoints about a policy process or some set of decision making process that was designed to inform and maybe even, you know, be taken up by decision-makers. So I felt like it was more than the classic "they're just my research subjects", but I think in the way that our REBs — Research Ethics Boards — understand it, and we would be going and seeking, you know, ethics approval for that work. It was viewed very traditionally,

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Jennifer: Julia has been partnering with stakeholders, and now patients, for a long time, and has experienced all the joys and challenges of working in collaboration with others. We were especially keen to hear what she's learned about dealing with conflict.

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Julia: What I have always tried to do was actually not try to avoid that or ignore it, or sweep it under the carpet, but actually embrace it and recognize it and try to achieve some kind of level playing field or at least understanding that we probably have different views about how the world should work, how this research should work, how we should be working together, so let's try to be as open in terms of communication with each other, and if we have real areas of disagreement to try to work towards resolving them.

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Jennifer: Julia's approach to working with others is to keep lines of communication open, which is important for keeping things moving forward. But how can you tell when something is off, or needs addressing? How do you become aware of issues that might not be readily visible?

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Julia: Well, certainly some things happen that make you acutely aware. So you may be trying to do the best that you can, but then all of a sudden, something will happen, and you'll have to take... you know, sit back and say, "Wow, that I was not prepared for!" So, and as an example, this wouldn't have been a particular, you know, tension in how the work was being done. But it was an effect that a particular engagement process had on someone, so [they] waited to the end of a meeting, and then came forward and said, "You know, I'm really concerned about how I'm going to be able to make a difference. You know, this was great. This was a really good experience for me, I think, I feel like I was my perspectives were valued and taken into account. But where do I go from here?" And there was a sense of... This is all? Is this it? You know — what else can I do? And so that has caused me to reflect a lot more on the impact that the work I'm doing. And again, often in a short timeframe, because we're going from grant to grant and I can't necessarily ensure a longer time frame or time horizon for engagement work beyond "the grant." That's unfortunately, how the structures are in a lot of the work we do. And so it has definitely caused me to reflect on the impact of the work and how to mitigate risks in those situations.

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Jennifer: As a longtime health policy researcher, Julia has a lot of experience in public engagement. Her interests have expanded to include patient partnership, but it wasn't necessarily a seamless transition. As patient engagement started to become more of a focus in her field, she encountered some fundamental misassumptions about the scope of her work.

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Julia: People started asking me to help think things through in that realm and I said, "Well, actually, I don't work in this realm." They said, "What do you mean? You... everything you do is about this." I said, "Well, no, actually, it's more about broader publics, citizens, taxpayers, voters..." — not those who are thinking about things from the perspective of their own lived experiences, or experiences with health issues, conditions, whatever. So that was a bit of a, I think, a shock to some people because they assumed that I would just take all the skills and you know, expertise I had and just shift it over. I think there is some shifting over that can happen, but I don't think it's as smooth as people think it is.

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Emily: Julia's experience in both public and patient engagement has given her a nuanced understanding of how we should think about what exactly it is we're asking people to bring to a project.

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Julia: What is the perspective that we're interested in? Is it a broader societal values perspective? Or is it individuals who are actually living with, coping with, issues you know, every single day and want to make a difference in the care that... so that does suggest it's levels, but it's more about that perspective that we're interested in, if that makes some sense. You have to be really clear and careful in what the ask is. So are you asking someone to come and contribute to something based on their, you know, ideas, background, expertise as a member of their community, however that community is defined, as somebody with expertise in a particular condition that they have or caring for somebody, as a member

of particular age group, someone with a particular educational background, so much more purposeful in why we're asking people to contribute and what we're asking people to, to contribute.

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Emily: Clarifying what sorts of perspectives and contributions you're looking for is clearly important. But these alone don't inform how to proceed with evaluation, so we asked: How do we get to an appropriate strategy for evaluation?

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Julia: First, we maybe want to talk about goals for engagement, right? And again, this is rooted in a lot of theory that's been around for a long time about goals around the legitimacy, goals around accountability, goals around rights, you've asked about and or suggested as well, or even kind of competency or activation. Many people who become, you know, heavily involved in... whether they're on boards, whether they're in involved in more ad hoc kinds of engagement processes... talk about how much they gain in terms of knowledge, skills, building development to go on to do other things.

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Jennifer: Julia mentioned a potential vector for exploration I hadn't heard much about before, and it's to trace how patient partners utilize their newly developed skills in projects or pursuits outside the boundaries of a particular project.

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Jennifer: Something I've always been interested in is actually trying to do some work to see what happens as a result — how do people take the knowledge, the skills, them, you know, all of the things that they build up through their engagement practices, experiences, and actually move on? We're looking at this in the health space and health research in particular, with respect to OSSU's work, but imagine people, you know, having all of this expertise that they go off and do all kinds of great things in their communities, right, that we never hear about?

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Jennifer: You know, it's possible and I'd say even likely that patient partners feel they gained something valuable from the experience of participating in research as collaborators or advisors. But of course, there's more to it than that. In Julia's experience, patient partners are looking for something more:

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Julia: But increasingly, I hear, "I want to know that the time I give to this the commitment, the effort, all of that makes a difference. You're going to do something with it." So it's that accountability loop again, right? Show me that what I've contributed has, if not, you know, *made* the decision — because it's very rare that we could ever possibly track, you know, retrace, you know a contribution from an engagement process to making a decision — but it's to inform right? The whole that's the whole point. If it's not, that's a huge problem.

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Jennifer: You may recall that Julia was talking about importance of setting goals for engagement, which might include ideas around legitimacy, accountability and competency, or what some might call patient partner capacity. But figuring out the goals of engagement is only one layer of the bigger puzzle around evaluation.

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Julia: So just as there are different goals for engagement, there are also different purposes or goals for the evaluation, and I think it's being, again, up front at the beginning of a process — whether it's the engagement process or the evaluation of it — to say, what are we all trying to achieve here? And recognizing that there may be differences, if people have fundamentally different ideas about what they want to achieve from the engagement process, and even what they want to get out of the evaluation, it's not always clear that you could actually come to an agreement, and again, organizations who are conducting the evaluation, or governments, you know, who kind of hold the power in that will necessarily have some influence some sway in terms of you know, which goals, which purposes, will carry the day. It's always quite easy to write in a paper that yes, all relevant, effective stakeholders should be involved in the evaluation and setting the terms, goals... and in the reality, it's much, much more difficult.

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Emily: Julia recognizes that some difficulties can come from circumstances or events beyond the control of the people who are involved in a particular research project. It can be two easy to simply say, "You could be doing things better." For most people, the goal is to be open, but sometimes, for all kinds of reasons and constraints, it can be challenging in the face of fear or risk. Still, it's important, she says, to continue to be as honest as possible:

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Julia: So what I've tried to do is understand that, but also still press, right, as much as possible for that honesty and transparency, because I think patients who are really savvy — those who get involved in these kinds of processes and activities, you know, do so for a reason. They often, you know, have seen a lot themselves, they know, they can, you know, pick up on a closed process very quickly. They... again, you know, time is really meaningful and important to people and knowing that their time isn't being wasted is so, so important. If you actually don't intend, like, *really* intend on using what comes out of this engagement process, you're better off not doing it at all than doing it badly, or in an insincere way. And where I've seen things work very well in these difficult situations, it's usually when that attempt to release very explicit effort to be honest and transparent as has been in place.

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Emily: Even so, Julia says, things don't always go as planned. And there are any number of barriers preventing a project from running smoothly.

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Julia: You can have all of the best intentions for doing things in a particular way, and something comes along — and I've seen that too. I think time, or lack of time, is often a big barrier, and capacity, right?

The level of support for an engagement process to do it well... again, that's another common message I give is if you're going to do this well, you need anytime you need resources for this.

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Emily: Sometimes, lack of support for engagement doesn't show up in obvious ways. Julia shared some patient partner feedback that was submitted as part of an evaluation project.

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Julia: We had people complete our evaluation tool, and one of the text comments, the open text comments was, "I knew there wasn't really anything meaningful in what I was contributing to this committee because nobody ever took a note. Nobody recorded. Nobody wrote anything down. They just listened and nodded their head. And so I knew nothing that I shared was going to go anywhere." I mean, that's a pretty profound observation and critique, and I imagine that was very demoralizing.

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Jennifer: One of the interesting things about this story is that Julia discovered this information because of the open text box, not because of carefully worded questions on a multiple choice survey. When it comes to thinking about evaluation, the instrument or tool being deployed, will influence or even determine what you can learn.

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Julia: I think the survey is, you know, useful — limited, though. And certainly. we heard in the feasibility study of our evaluation, our own evaluation tool, that people want space. So they want the open text comment boxes, right? And so, to the extent, though, that it almost makes, again, from a measurement perspective, it almost makes the survey meaningless. Because if you have to have a text box or a comment box after every question to allow them to really talk about what it is they want, what's the point of the survey in the first place? So really interesting findings that came out of that feasibility study. The organizations though, to reflect their perspectives, they said, "Yes, we understand, and we actually want that that kind of open commentary as well." But it's a lot of work to do a proper qualitative analysis of open comments, right? So their view was, they didn't want to burden the respondents with all of this qualitative material that they knew they would never be able to actually manage.

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Jennifer: There are many considerations when putting together a plan for collecting data for evaluation purposes. And Julia is often considering a range of options and ideas to try to address some of the shortcomings of existing methodologies.

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Julia: I think, from my perspective, an interesting methodology that hasn't really been explored in a lot of detail — and I think, mainly, you and I have talked about this a little bit — is this idea of the tracing, right, of the process tracing and trying to be very logical, and we're talking in this new evaluation framework that we're doing about a "logic model" approach to say, can we actually trace the inputs, the context, the inputs, the processes and activities, outputs, to outcomes and impacts and actually really

do a nice job but that requires good documentation. And if you don't have the good documentation, it's really tough to make these logical links or identify these relationships.

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Jennifer: Emily, you mentioned recently that you tried to do some tracing in a project. How did that go?

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Emily: Yeah, I did. And it was way more challenging than I expected. So some things are straightforward to track, like, where someone suggests changing the wording and a document or something. But when it comes to say, the direction of the research, or whether we end up approaching something differently, because maybe a month ago someone shared their experience or raised a question, or maybe things are discussed differently at a meeting because someone is present at the table? Well, it's tricky, because it's one thing to record the technical decision itself, but to really understand how decisions are made... well, it's so much about context and interpersonal dynamics and even body language and gestures and sometimes very subtle things. Trying to do that would be closer to conducting an ethnography which I'm not trained to do. The logic model that Julia mentioned might address some of this complexity. It's something I'd like to learn more about.

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Jennifer: So much like engagement itself, evaluation of engagement can be hard to pin down. But for Julia, it always comes back to being able to identify or surface considerations that would not have been discoverable or would not have been as relevant without the involvement of patient partners.

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Julia: Scientists talk about this at meetings to say, wow, you know, before we engaged our patients in this, identifying the outcomes or prioritizing our questions, we had no idea that some of the outcomes that we felt were so important, had no meaning to... had no relevance to... so. And often it's the quality of life outcomes, right? Often, the scientists are looking at the mortality, morbidity... you know, very specific clinical outcomes, and these were some other quality of life related outcomes. So...

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Jennifer: Is that not research, though?

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Julia: Right, but it's patient, but it's a...

Jennifer: Is that engagement?

Julia: But it is. well, you'd have to look at the particular studies, but they would talk about engagement, and certainly the SPOR networks, some of them, I think, believe and would be able to show that they're engaging patients in their research more than just as traditional research subjects. So we'll ask you what... so it's a good question, you know, this fine line between: is that not just research versus engagement? I think there's lots of good questions around when is it research and when is it not and

particularly when we're looking at it in the in the research space as compared to policymaking and decision making.

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Jennifer: This has always been a point of confusion for me. I appreciate that from an interpersonal perspective, there's a real sense of collaboration and exchange of ideas. But at the end of the day, isn't it just about collecting more information and data from patients to inform the research process? Isn't engagement still just a form of research? Or is it in fact replacing research with something else? It's a complicated question. And I appreciated that Julia was willing to think out loud about it.

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Julia: To me, I don't think for good engagement to happen, it has to be more... be moved into the research realm. Like I'm really intrigued by your comments, Jen, about isn't that research because I have to think about that a lot myself. When is the work I'm doing... well, it always is really under the broad umbrella of research because I'm a researcher, but I like to think that it's more engaged research with different types of partners, whether they be policy folks, you know, health system decision makers or even potentially patients and family members, but what makes them engaged partners as opposed to the subjects? Well, if they're actually on my, you know, executive or advisory team for the project, right, if they're actually making decisions with me about every, you know, step of the project that we undertake, right, if they're actually involved in that way, as opposed to just the people we want to hear from.

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Jennifer: We've both been on projects and advisory roles, and I don't think either of us have experienced this level of co-decision making. So we asked for clarification about what this looks like.

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Julia: Yeah, the principal investigator typically makes the final decisions but... or certainly makes all the day-to-day decisions about the execution of the study. But when you're making *key* decisions, for example, how we design, how we go ahead and structure our... so who we sample... all the major, major decisions about the design and execution, you would go to your full team. And you would actually, I would like to think, make those decisions together. Yeah — is it full-on, every single person could say I made the decision? No. But could people say: I actually felt like I contributed significantly to the shaping of this research study? I would hope so.

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Jennifer: Julia went on to say that even with such robust engagement from her team members, she always validates proposed directions with existing literature and evidence.

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Julia: So I gather a lot of information and do a lot of research. How has everybody else carried out studies of this population? You know, we have now really interesting studies on incentives. What are the most effective incentives for engaging, you know, members of the public in a test study that they would otherwise have no interest in? I would always go to the evidence, right, and do that homework.

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Emily: We were both struck by how thoughtfully Julia approached her own sense of responsibility as a researcher who engages patient partners in her work. Which made us wonder: what is it like to be this self-reflexive, while also researching and advising others' engagement practices? Surely it can be frustrating. Julia is circumspect in her answer, and believes that people really are trying to do well:

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Julia: I think it's a bit unfair to say, okay, there are a few people who are doing this well... and then the rest are, you know, not. I think people are struggling. I think some people are struggling and then learning and improving and really doing incredibly thoughtful work. I think there... I think of people in the mental health field who... many people who've been working at this and maybe bringing in more of the community-based participatory research approaches that we've been talking about, who are, I mean, incredibly thoughtful about how they, you know, approach engagement with partners, client partners, community partners, etc. So there's so much variation. And I think that's been... I think that's part of the challenge. I mean, it is a huge part of the challenge in this space, I think we need to call out, you know, and recognize and, as we've been discussing, have a, you know, take a critical stance on this and be reflective and self-reflective, but I think we also have to, you know, try to give people the benefit of the doubt and equip people actually, with good resourcing, good supports to do this. Well, if this is going to be the way, you know, we do business or is, you know... as long as we have major investments in this kind of research, right? I feel like we've gotten into this situation of people thinking, "You just have to have a patient on there," two of them, one of them, whatever, or on the board, or at the highest level and it's about full-on empowerment, and I mean, it is for some people, and I guess it's maybe just having good healthy discussion around this and debate and letting people have the space to do it.

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Emily: As we wrapped up, we did touch on the different ways of thinking about evaluation, which is different than the more practical discussions about establishing goals and selecting tools or frameworks.

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Julia: As I immerse myself a little bit more in the evaluation work, I'm seeing, you know, valuation scientists... the community of evaluators have different views and different approaches to evaluation. So I think this is going to be an interesting new challenge in this space. Whether you're coming from program evaluation, there's even a field of impact evaluation, whether you look at realist evaluation, I mean, there are different actual fundamental underpinnings for evaluation and how we think about it and not, again — not to add more complexity to this — but we'll so stay tuned for that set of debates and dilemmas, then.

Emily: ... next season on! [laughter]

27:02

Emily: Despite all the nuances and complexities inherent in this discussion about engagement and evaluation, Julia frequently encountered the assumption that one can just measure engagement and produce meaningful numbers, and do so in a straightforward fashion. With all her experience, Julia knows this just isn't the case and articulates the issue quite succinctly. When asked recently to quickly produce results that would show impact, here's what she said:

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Julia: Describe patient engagement in your organization! Tell me what it is! Because if you can't actually tell me what it is, clearly, we can't evaluate it. Unless we're clear about what the thing is that we want to evaluate we can't actually move on.

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Jennifer: Hey, Emily.

Emily: Hey, Jen.

Jennifer: I think we have a few things we want to talk about. But I do first want to say that it was so great to cover so much ground with Julia, some of which didn't make it into this episode, unfortunately. She was really game to think through a lot of ideas and entertain some of the scenarios we kept throwing at her. It must be challenging to study patient engagement, and then also have patient partners for your own research projects about patient engagement. That's a lot to navigate and a lot of interest to have to take into account.

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Emily: Yeah, for sure. Okay, so I have a few things on my mind about evaluation. And we spoke to Julia a while ago, so our conversation has sat with me for a long time. I'll see if I can explain. In our discussion, we talked about the ways that patient partners contribute to research projects. And we touched on what makes involvement meaningful and consequential, like: did the partners have a hand in decision making? Were they consulted along the way? Were they instrumental in how the research was carried out? And at this point, I think we're actually getting pretty good at process measures and looking at how people experienced engagement. And there's obviously a lot of work being done to move things forward when it comes to measuring outcomes and impact. But I feel this still leaves a lot of unanswered questions, or maybe I feel there are a lot of unstated assumptions. Like evaluation doesn't tell us what would have happened if we'd never done the engagement. It doesn't explain why we're picking *this* way of doing things over other ways.

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Jennifer: The way engagement is currently structured certainly isn't the only way that patient priorities could be foregrounded. I remember Lucy Costa talked about applying for funding for a patient-led Research Institute. I'd love to know why that was rejected.

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Emily: Right, and evaluation doesn't tell us who left patient engagement and why. It doesn't tell us what non-engaged patients and the public think about the overall engagement project. There's so much to consider, but these questions just starting in scope.

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Jennifer: Yeah, and it sort of makes sense. You can't "boil the ocean," as the saying goes. But I do sense there's a lot of anticipation or investment in the promise of evaluation, to demonstrate or to prove the "true value" of engagement. So yeah, I see what you mean. It seems like we're just skipping over a lot of stuff.

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Emily: Yeah, it's like this world of patient engagement and partnership happens in a bit of a bubble. Everything inside the bubble connects and has a certain logic to it, like recruitment or capacity building or evaluation. We can all talk with some confidence about the tactics and even strategy. But we don't talk much about what happens outside the bubble. Like: if we're still trying to figure out how to prove value and impact, there must be other reasons why it's seen as so important. It's almost like we'd need a separate evaluation process that assesses the broader structural components, like how and why patient partnership is mandated in research, or the extent to which funding or publication is attached to it being performed.

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Jennifer: So what about this: maybe, one of the reasons evaluation is so hard to pin down isn't actually because of unspecified or unclear goals — although, I mean, that certainly doesn't help — but maybe it's simply because of the nature of how we have come to define good engagement. What if the point of engagement is... engagement?

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Emily: Hmm, can you expand on that a little?

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Jennifer: Okay, well, Julia's accounts of patient partnership, and what makes them successful or not, are focused on relationships, openness, transparency, and trust. It's all about how people work together. Now, I get that these are seen as the foundation for good engagement to happen, but it seems like we're not really getting past that, given that researchers are working so hard to figure out how else to measure it. It's as though good relationships have become the very definition of good engagement. And on this premise, outcomes don't actually matter — or they aren't the point. If we think back to some of the conversations we've been having, this idea that engagement is about relationships has a real foothold. People thought of engagement as a way to build their skills, as a safe space to talk honestly, and as an opportunity for mutual respect.

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Emily: And remember when Paula Rowland spoke about symbolic representation, as opposed to democratic or statistical? She used the metaphor of art, where people are moved in untold ways because they're exposed to, or are part of, something creative and maybe inspiring. We agreed that a lot of engagement falls into that category, where individual feelings and experiences are "re-presented" for the benefit of both the audience and the storyteller. I mean, what she's describing is literally theatre, which is all about the experience for those who are present.

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Jennifer: Yeah, well, it's not no surprise that all of this stuff is really hard to measure and quantify. You know, it's not that these topics aren't relevant. Certainly they are. Patient partnership is inherently social and interpersonal. But isn't the overall purpose of engagement supposed to be that it's a way to improve healthcare delivery, which could then ultimately have a positive impact on the health and well-being of Canadians? And we just haven't heard much about those goals in any of these conversations. And if we did hear about patient partners wanting to make a difference somehow, it was often related to having influence in a particular project. If we see engagement as primarily having value as a shared experience among participants, then trying to evaluate it using economic or impact yardsticks — you know, "return on investment" — may not adequately reflect what people seem to value. And it may help explain why goals for engagement are often really unclear. We come back again to questions of purpose. Why are we engaging patients in the first place? This evaluation conversation I think, is really highlighting the need to explore these questions further.

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Emily: We'd like to thank Julia Abelson for her participation in this episode. If you have any suggestions 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 and are not to be considered endorsed by OSSU, the Government of Ontario, or CIHR.