

Matters of Engagement podcast
Episode "Dilemmas of Representation with Paula Rowland"
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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 I'm Emily Nicholas Angl.

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Jennifer: In this episode, we're tackling representation. It's such a big topic, we're actually going to do it over a couple of episodes. Here, we'll be speaking with Paula Rowland about some of the dilemmas of representation. And then in the next episode, we're going to speak with Lucy Costa of the Empowerment Council at the Centre for Addiction and Mental Health. We'll learn more about patient councils, what democratic representation actually looks like, and hear her concerns that the current trend towards engagement might be eroding the kind of advocacy work that they do at the Empowerment Council.

Jennifer: So: representation. We hear this word a lot in the context of patient engagement. It's often presented as some kind of ideal that people strive for. But it's not always clear that we're all talking about the same thing. To prepare for this episode, Emily and I chatted about some of the ways we've heard representation enter the conversation about patient engagement and partnership. One of those ways is to think about the idea of the "patient voice." Now as a concept, of course, this is quite complex. But for now, we can say that the patient voice is represented usually by a relatively small group of engaged patients who are included in decision making spaces. And when we think about representation in this way, it almost doesn't matter which specific patients are involved. We commonly think that the requirement to hear the patient voice is satisfied if patients are included in some meaningful or substantial way.

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Emily: And then we often layer on to the idea of inclusion, this concept of diversity. I often hear something like, "We need to hear from patients to represent the diversity of our population" or "... that represent the broader community." And this is really tricky because we don't commonly specify what it would mean to represent a population. We could assume it literally means where the demographics of the engaged patients reflect the wider patient body. So if, say, 20% of the patients of a hospital or in a particular income bracket, then 20% of engaged patients should be from that same demographic. But how do we decide which demographic categories to consider? Is it income, housing status, education level? What are the repercussions of identifying and grouping people this way?

02:38

Jennifer: Yup. And you know, another notion that I think is floating out there a lot is this idea that engaged patients are there to actually advocate for the interests of patients who are not in the room. And this can be explicitly the case when it comes to patients and advocacy groups or patient organizations that focus on specific conditions. But we hear this language used in patient engagement spaces as well. It's often linked to a kind of rights-based argument that in a democratic society, patients should have a say in how things are run. These and other ideas around representation have been kicking around a long time, and as engaged patients, we're quite preoccupied with this question. People very much want to get it right and know that what they're doing is inclusive and also productive and meaningful. In fact, I think sometimes when we say "representative," that's more what we mean. So no wonder conversations around it get really muddled. Sometimes people talk past each other, meaning they're not using quite the same definitions or even talking about the same situations. Or sometimes a form of representation might not quite fit the engagement activity, but nobody can come out and say so. And so then we're left with often confusing and disappointing experiences.

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Emily: And this is why we wanted to talk about representation in this episode. It's so murky, and when it gets murky, we tend to flow focus on the things that we can actually do something about. So we might focus on accessibility or outreach practices... but our feeling is that something keeps getting lost when we focus on actions without probing more deeply into what the underlying murkiness is all about.

04:15

Jennifer: Right. And to help us out we're going to start with looking at a paper written by Paula Rowland and Arno Kumagai called "[Dilemmas of Representation](#)." There's a link to this paper in the show notes. We found it immensely helpful to help us think through some of the key issues surrounding representation. Now as we go through that paper, we're also going to hear from Paula. We had a long chat with her about some of the key ideas found in that paper.

04:43

Emily: Okay, so the paper is "[Dilemmas of Representation: Patient Engagement in Health Professions Education](#)." It's co-authored by Dr. Paula Rowland, a researcher and scientist with the Wilson Centre and an Assistant Professor at the University of Toronto in the Department of Occupational Science and Occupational Therapy. The other author is Dr. Arno Kumagai, who is a full Professor at the University of Toronto and Vice Chair of Education in the Department of Medicine.

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Jennifer: Here's a high-level summary of the paper: Patients get recruited into many different roles when it comes to educating health professionals — that's the realm that the authors are looking at — maybe to share their stories, or to be involved in curriculum planning, or to be involved in admissions and hiring practices. And for each of those roles, there are different reasons or rationales that patients are asked to participate. But there's often this underlying question of whether engaged patients are sufficiently diverse enough to represent contemporary society. And usually, the answer is no. So we turn to a variety of tactics to try and remedy that. But of course, as they're going to point out in the paper, it's not so simple. The authors outline a couple of dilemmas. The first one looks at patient recruitment itself, and the impulse have to focus almost exclusively on recruitment techniques. And

here they use the term “recruitmentology,” which we'll look at more in depth later. The concern here is that patients get recruited into activities that might result in a mismatch of maybe skills or intent or assumptions around representation. And when that happens, the engaged patient might understandably have difficulty establishing or reinforcing their own credibility. The second dilemma looks at forms of representation. In a given engagement experience, there may be several types of engagement at play, and we're not always clear on which ones we're using to justify the engagement. So actually, let's go through those types.

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Emily: All right, so the authors talk about three kinds: The first is a democratic notion of representation. We say that patients have a right to be involved, and that their needs should be represented in decision making spaces. But we don't address the question of who gets to contribute on behalf of patients. We don't actually elect patient representatives to be involved in engagement activities, even though we frame it as democratic. There's also statistical representation, which we sort of hinted at in the introduction. It's the idea that we recruit based on demographics so that subsets of the larger community have a relative amount of presence in engagement spaces. Again, a challenge here is that someone somewhere has to decide what kind of diversity matters. Is it race? Is it gender? Is it age or education level? And if we're looking for a kind of representative sample of the population, then it follows [that] we think this will give us a sense of an average patient perspective. This leads to what the authors describe as a “catch-22” of patient engagement, where the patients who are able to access, who have the capacity, the ability to participate in engagement activities, can then no longer be thought of as average. Okay, so the last form of representation described in the paper is symbolic, where the patient's story or experience is not assumed to be a universal one from which to learn, say, practical tips, but as a conduit to provide a perspective that might ultimately move people or make them feel something. Patient stories do leave indelible impressions and they inspire, they can validate the work of professionals — they sensitize people to the human experience. When symbolic representation is not described here to mean tokenistic: it fulfills a specific purpose, though, that is not often declared and which patients themselves may not be fully aware of. So where does this leave us?

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Jennifer: Let's pause at this point to hear from Paula. She's going to elaborate on some of these ideas, then we'll regroup to figure out what this all means. So first, we ask Paula to let us know where the idea for the paper came from.

08:46

Paula: This is a perspective piece, which means it's not based on a single research study. So it's a... it's a place in the journal where you can pull together some ideas and put forward a perspective, not claiming that it's the only perspective but hopefully, it's a contribution to help give name to certain ideas and that we can think more deeply about it. Because of the years that I'd had already been at various patient engagement tables, and questions I would have, and [how] I'd noticed the way people would position themselves — and I'd find myself both admiring the confidence with which people would say, “I'm speaking on behalf of all patients,” but also questioning, “Do all those other people know?” Like... and how — how do you develop this authority to be able to say. “I'm speaking on behalf of all patients?” I think a real core idea is the dilemma of representation. And people are trying very hard to solve the

dilemma of representation. But I got inspired by other people I was reading who flipped the question around and resisted this idea that we're going to solve this problem by recruiting more people and instead started thinking about what is it that we're trying to represent in these different places and spaces. So I was trying to articulate attention that I think some very committed, passionate people are living, but maybe don't quite have the words for it yet? Because I... I use my words carefully, it sounds like I'm really sure, but I'm not sure about a lot of stuff [laughs]. A lot of this stuff is emerging, complex and nuanced, and I don't know if I'll think about it differently in two or three years.

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Jennifer: Let's take a closer look at this first dilemma about recruitment, which is: how patients are recruited influences who participates. This dilemma really gets to the root of why often, the engaged patient community is so homogenous. Often, we see a group of engaged patients that were all recruited using similar tactics, and from the same demographic pool of people. So when this happens, the solution then is to focus on recruitment tactics, and making opportunities more accessible. A good example would be moving meeting times to weekends so that working people can participate, or maybe providing childcare or reaching out beyond the usual methods of recruitment to find a broader diversity of people. This focus on recruitment has been coined "recruitmentology" by other social scientists. And it's introduced here by the authors.

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Emily: Organizational recruitment techniques are often deemed to be faulty or inadequate, so more work and more resources are put into better recruitment approaches. And that often means trying to include people from what are commonly described as "marginalized" or "hard to reach" populations. Now, as Paula points out, this could be problematic:

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Paula: If we keep focusing on trying to reach the hard to reach, then we keep putting the problem onto that community: "You're hard to reach," as opposed to looking back and saying, "Why are some institutions so hard to trust?" We have this action bias, like we want to do something and then do something... you can easily make that commitment — to doing more recruitment. It's harder to think through [...] "How do you change institutions so [they are] more trustworthy?"

12:06

Jennifer: I think the takeaway here isn't that people shouldn't be thinking about recruitment, but that this recruitment technology mindset may make us miss the point about why certain groups or individuals don't participate. So that was the first dilemma. The second dilemma is described as: choosing among multiple forms of representation. And they're listed here in the paper as democratic, statistical and symbolic. So let's first look deeper at democratic representation, which I think is maybe the more common notion.

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Emily: Yeah, I agree. I hear it all the time. Whether it's meant literally or not, there's a sense of democratic principles at play. We say that patients have a right — or even a responsibility — to participate in engagement programs. But if we look at what the authors call the "apparatus of

democratic activities,” where we nominate, we vote, we elect... and if someone isn't actually fulfilling on their promises, we can remove them from their elected post, this apparatus is pretty much non-existent inpatient engagement programs. Yet we still refer to democratic principles.

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Paula: When we're pulling in the idea of patient engagement in a rights-based language about [how] the patients have the right to influence the healthcare system, we tend to draw upon that same kind of rationale about democratic societies, but what we can't usually draw on is a whole apparatus that supports a democratic society. So that's what we're trying to pull out there with that notion.

Jennifer: And what do you mean, the apparatus...?

Paula: Nominations, votes, terms, opportunities to uninvite somebody if they're no longer acting for, or speaking for, in a way that the people that they are to be represented, feel represented. So that whole apparatus that supports the notion of democracy is part of what's tied in to this idea of democratic representation.

13:56

Jennifer: Paula points out here that we're not voting in patients as representatives in the same way that we vote in elected officials. Even though saying it's democratic to include patients is a very strong moral rationale, we can't actually say that engaged patients are somehow representing a patient group in a collective sense. And I quite appreciated this point because it helped to clarify for me some of my own discomfort with using the word “democratic” when it comes to patient engagement. We may be wanting to hold on to this general sense that the engagement enterprise is inherently democratic, or maybe it's seen as evidence that we live in a democratic society, but there's actually nothing tangible or structural propping that up.

14:39

Emily: Yeah, that certainly stood out for me too. Okay, so if we move on to the next one, statistical representation: this is maybe the easiest to grasp conceptually. This is where we ask, “Do engaged patients statistically or demographically reflect the larger population?” The question is simple. The answer — not so much. The authors drill down into wondering, “What sorts of statistics are we actually looking for?” And more importantly, Who decides? And what is important? Is it age, gender? Is it education? What are the implications of assigning people to categories in this way?

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Jennifer: Right. And not only does this greatly inflect who participates, but this could easily mean that someone who wants to participate is actually not allowed. Paula elaborates on this and shares an experience from one of her research projects.

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Paula: They will never be an entirely representative group, like the feasibility of that like, which... which groups do you decide to represent? Where are the boundaries made? Who gets to make those boundaries? And I would also watch how it would turn into some unintended impacts. One of the

women I interviewed was telling me how she was uninvited from a committee because they already had a white woman with breast cancer. And she said, "How do I make sense of that, and where does my voice show up if there's this other arbiter of what representation means that I can't influence?" So, again, possibly good intentions framed around this idea of statistical representation, which has got deep, deep roots in medicine and evidence-based practice, but some unintended effects of silence, all in the name of creating more voices, but it's just... it's got the potential of creating different kinds of silences.

16:28

Emily: There's another key point about statistical representation that the authors raise here, and that we mentioned before, and it's about using statistical representation to get a sense of the "average patient." We think of it as a problem when engaged patients aren't quite average enough. Again, the paper refers to it as a catch-22. So a patient with skills and capacity that may actually be appropriate for a given task might actually be deemed no longer suitable to represent the average patient. For most of us, this is not news. It's been an ongoing open question in the engagement space about how skilled or knowledgeable should engage patients be in order to be useful or effective. But then, when we put this question in the context of also thinking about forms of representation, it does get even more complicated, and highlights the need for clarity of purpose or goals in any engagement activity.

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Jennifer: So we've covered two forms of representation. Let's now turn our attention to symbolic which is the third and final form of representation that is outlined by the authors. Now here, it's really important, again, to emphasize that the authors did not mean "tokenistic" when they said "symbolic." Symbolic, in this context, means we're focused more on the authenticity of feelings or experience that are being represented in an engagement setting. This is where we include storytelling. For example, we invite a patient to tell their story, not because we think it's *the one* story that everyone shares, but because it's a human experience that makes helped develop our sense of compassion and understanding and empathy. Stories really help to illustrate what the authors call a "rich tapestry of human experience," which includes all the varieties and possibilities of being. Paula describes it here using art as the metaphor to help us better understand what they're trying to say.

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Paula: The metaphor that comes up here is art. So the notion of re-presenting an emotion or an experience, and that the person in presence of that representation is in some way changed or moved. But whatever change or move they experience is their subjective experience, and there's no judging between whether yours was more adequate than somebody else's. And so then the ideas of "change" that show up here is the way you might experience change in the arts, the way you might experience change when you hear a song that moves you, the way you might experience change in the experience of a play. So it's a very different logic about what's considered a quality representation of a particular kind of experience. And it's a different idea about what constitutes change. Where this one falls into trouble is when you try to take that idea into decision making spaces that hold ideas of democracies.

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Jennifer: This last point is where I think we really get to the heart of the paper. As Paula says, there are different logics at play. And often, it's really just not clear which ones are present in a patient engagement activity. And actually, not only is it not clear, but sometimes there's a mismatch between what is assumed and what is present. Paula is inviting us here to wonder: when we engage patients as storytellers, how do we bridge the gap between the symbolic representation that's used to invoke a feeling, and the democratic notion that patients should be involved because it's their right? And as Paula says, it gets really murky when we bring in the storytelling element into decision making spaces — and assuming that we're all here for the same reasons.

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Paula: Our language uses all three of these ideas, and we move them around and sometimes we move them around within the same meeting, based on what we've invited somebody to do, and then what the meeting actually evolves into. And it was not trying to propose that any one of them is superior. And it was not trying to propose at all that symbolic meant tokenistic. It was trying to hook into different metaphors of representation as they're showing up. And they're particularly contestable, when you try to use one idea that was built in, say, the idea of democratic framing and power, and you try to bring that into an organization that does not experience itself as democratic nor will it ever.

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Jennifer: This paper to me is a bit of a Trojan horse. It's ostensibly about forms or types of representation, but nestled in there, I think, is an underlying critical commentary about the ways that organizations deem patient voices to be legitimate and credible. Here's a quote directly from the paper: "This critical reflection challenges us to question the ways in which individuals' perspectives and life experiences are deemed as credible and legitimate representations, and the possible underlying motives for representing patients and their stories in specific ways."

21:07

Emily: I think a good takeaway here is that organizations should at minimum be sure that their recruitment practices are aligned with the intention of why they're engaging patients. Of course, this presupposes that they know why they're engaging patients in the first place. For patients, I think this paper at minimum gives words to the ambivalence and what we keep calling the "murkiness" of the representation discussion.

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Jennifer: I've often wondered if engagement activities should be populated not with individual patients, but with representatives from the patient community who are selected by patients, and who move things forward towards a specific common agenda. And this is why our next guest is such a natural fit for this conversation. Lucy Costa is with the Empowerment Council at the Centre for Addiction and Mental Health in Toronto. In our next episode, we'll explore what representation looks like in an advocacy context, and think about implications for patient engagement and partnership. We hope you tune in as we continue to build on the ideas discussed here in this episode.

Jennifer: For now, though, thank you to the authors for their work on this paper and especially to Paul Rowland for sharing her thoughts. You can refer to the show notes wherever you listened to this episode or visit mattersofengagement.com.

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