

Transcript

Matters of Engagement podcast

Episode: "Webinar Extra: Paula Rowland presenting Dilemmas of Representation"

<https://mattersofengagement.com>

SPEAKERS

Jennifer Johannesen, Paula Rowland

Jennifer 00:07

Hello and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen. It's just me for now, because we have a special feature. But not to worry! Emily and I will be back with our usual episodes soon.

Jennifer 00:25

On October 12 2021, Emily and I moderated an online presentation featuring Paula Rowland. Paula was a guest way back in Season One, discussing a paper she co-authored with Arno Kumagai, called Dilemmas of Representation. We wanted to post the session here because it revisits but also builds on the themes in the original paper.

Jennifer 00:45

This presentation was part of a series called Best Practice in Education Rounds, co-sponsored through the Center for Faculty Development, the Wilson Centre, and the Centre for interprofessional Education at the University of Toronto. Because we were moderators, we introduced ourselves at the beginning and then hosted a Q&A at the end. But for the podcast, we've cut those out. If you want to see the full session, you can check the show notes for a [link to the video of the online presentation](#). I'll share Paula's formal introduction and her lecture will follow right after.

Jennifer 01:20

Dr. Rowland is a scientist with the Wilson Center and the Institute for Education Research at UHN. Having started her career as an occupational therapist, Paula later graduated with a PhD in organizational studies in 2013. In her research, Paula studies dynamics between professions, professional learning and healthcare organizations. Her research on patient engagement practices explores questions of power, identity and knowledge within these programs. This line of inquiry has implications for educators interested in workplace learning and continuing professional development, particularly within changing workplaces.

Jennifer 01:59

And now here's Paula Rowland, presenting Dilemmas of Representation: Patient Engagement in Health Professions Education.

Paula 02:06

All right, so thank you to the Center for Faculty Development, to the Wilson Centre, and the Center for Interprofessional Education for inviting me today for Best Practice and Education Rounds. So I'm going to talk about this notion of the dilemma of representation and patient engagement programs. And when we talk about the dilemma of representation, we often talk about it like this: We worry that people who are coming to participate as patients in these programs tend to be rather homogeneous. And so depending who you're talking to, we will often hear a worry that people who are coming tend to be white, relatively affluent, or at least financially secure, tend to be retirement age, and depending which part of the healthcare sector you're talking about, we might say they tend to be women, or we might say they tend to be men, dependings where you are. And of course, this is a bit of a generalization, but I think you get the general idea.

Paula 02:57

And the reason we consider this to be a problem is because the kind of patient activities I'm talking about are things like: trying to shape health professionals education, to participating in committees, curriculum committees, admissions groups, competency committees, or participating in health services, design and delivery, trying to shape policies and programs, participating in evaluation, how well are services working, participating in health research, shaping the kinds of questions we should be asking, what we consider to be important. And the worry is, if the people who are coming to participate in these programs are relatively homogeneous and relatively powerful within society, by participating in these programs, will we continue to create systems, structures, forms of education, that continue to work for a relatively small but powerful subset of the population? And that is worrisome in that we might be recreating the kinds of gaps that we care about, and recreating some of the dilemmas that we're actually trying to solve.

Paula 03:56

And so often when we talk about the dilemma of representation, we offer these kinds of proposed solutions. And they often hang out in what social scientist Epstein called "recruitmentology", the science of ever-better recruitment. And so it looks like more outreach, more accessibility. And of course, that is a good thing. Of course, we should be thinking about where we're creating these kinds of programs, who has access to them? Are there any barriers to access that we should be able to try to change? And I can't imagine a time when we wouldn't want to think about accessibility and increasing access. And yet, there's a story. And the story sits with me whenever I think about the dilemma of representation.

Paula 04:34

And it was relatively early when I started researching this, and I'm speaking to a colleague who was not engaged as a patient in any way. And I was telling her about this research that I was doing, and this worry about representation. And she said, "Well, you know, of course it makes sense." And I paused for a moment, and she just quietly and very thoughtfully said, "As a black woman, as a lesbian. I have never expected the healthcare system to be a safe place for me to be. And so when I go there, I'm preparing for how I will present myself. I'm preparing for how I'm going to tell what my symptoms are like. I'm preparing for how I'm going to come across as a rational individual who's worth paying attention to. Because I never expected the healthcare system to treat me differently than that. And so maybe the people who are coming to patient engagement programs are coming because when they were a patient was the first time they really experienced vulnerability. And they're mobilized

by that vulnerability to want to make it to be different. Where I never expected anything different. And I'm going to put my energy elsewhere, instead of into these patient engagement programs." And that gave me an enormous amount of pause. And it's something I couldn't unsee in my later research, when I was interviewing people who had healthcare experience as professionals but later became patients, they would talk about this vulnerability. And they would talk about how surprised they were that they felt vulnerable. And I would see it again and again in my other forms of research. And it led to this proposition that maybe these dilemmas of representation that we're seeing will not be solved through more and more recruitment, through more and more outreach, maybe there's something far more fundamental going on that we need to consider and address.

Paula 06:14

And that using what led to this paper that Emily and Jennifer already introduced, and it was the topic of the podcast that they invited me to join. And it was this notion of... we need to wrestle with the dilemma of representation. But instead of thinking about more and more outreach, maybe what we need to wrestle with is the foundations of how we think about representation at all. And so I was turning to the political sciences to try to understand this phenomenon, with a lens that I didn't yet have access to. And I partnered with Arno Kumagai because he was able to give me access to thinking about patient engagement within health professions education. And so I rely primarily on the work of Hanna Pitkin, and she is a political scientist who wrote this incredible piece of work back in 1967. And it was a whole concept analysis of the concept of representation. And she said, there's three main ways that we tend to talk about representation.

Paula 07:04

And often when we talk about representation, we have this implicit idea that we're talking about democratic representation, this practice of speaking for or acting for others. And in democratic societies, we fulfill these ideas of democratic representation through processes, like nominations and elections. And we have systems of accountability in place to make sure that representation is working the way we aspire for it to work. The problem is when we think about this within health professions education, and we think about representation in health professions education, we very rarely have those practices that we would consider like a democratic practice - like nomination, election, and forms of accountability. And I'm not saying that's true in all the domains of health professions education, but I think this is one of the places where we run into some kinds of tensions.

Paula 07:54

Another concept of representation that I think is very alive and well, within health professions education is the notion of statistical representation. And it's alive and well, because it's very familiar to evidence based practice. And it's the idea that we can generate knowledge about particular kinds of groups through surveys, through measurement strategies. And if our data collection tools are sufficiently sophisticated, we can get to a true understanding of an average idea of patients' needs, wants and preferences. But this kind of representation runs into different kinds of trouble within health professions education practices of engagement, because very rarely are we actually talking about enormous groups. When we're talking about engagement practices, we're talking about people joining committees. We're not talking about people joining decision making spaces. We're talking about people joining as educators and teachers. So we don't have these large groups to be able to make these kinds of statistical representation claims. So we get into other kinds of thorny dilemmas of representation when we have an implicit model of statistical representation in our mind.

Paula 08:56

And the third form of representation that Pitkin talks about, she calls it symbolic and I recognize that word has some problematic translations. Because it's relatively easy to slip from saying symbolic to saying tokenistic. Particularly with the way we talk about patient engagement right now, it's anathemic to say something like tokenistic engagement. But that's not what Pitkin was talking about - she was talking about representation into the foundations of the word and thinking about: to represent is to re-present. So to bring something into a conversation that was not physically or creatively available before, to make something knowable, to re-present it in a new kind of space. And this was a completely different way of talking about representation, because this was not claiming to speak on behalf of others like democratic representation. It was not claiming to give access to some kind of representative average like statistical representation. This was more like art, and the way art can bring in and represent an emotion and experience an impression This might be the kind of representation that's acting in places like Narrative Medicine, when we're talking about engaging with patients in order to inspire critical thinking, humanism, compassion, empathy, and insight. And so what's at stake here isn't necessarily the fidelity of the representation, it's the authenticity of being able to relay a particular kind of experience. But it's less clear about how this kind of representation could possibly work within decision making spaces.

Paula 10:28

And so here, we have these three different ways of thinking about representation. And they're all imperfect. And they're all fragile in different kinds of ways. What's problematic potentially, and when we think about the dilemma of representation is when we mix them together, and particularly when we mix them together without being entirely explicit about how we're thinking about representation, what's considered legitimate knowledge in the kinds of spaces where we're working, and how we would know that we're engaging in the way that's consistent with the way we're thinking about representation.

Paula 11:00

So going through this conceptual analysis led us to this conclusion that there is no one right group of patients to be engaged in these kinds of activities. There's no essential essence of being a patient that makes for this perfect match between the kinds of experiences that you have, the intersectionality that you have, and a particular kind of patient engagement activity. And we ended with this really kind of pithy statement at the end of our paper, that there is... to be the right person for a patient engagement activity is not an intrinsic quality of the individual. It's a function of the match between what is being represented. To what purpose. And to which audience. And the remainder of this talk... I'm checking my time... is going to try to work through each of those three claims. What is being represented. To what purpose. And to which audience. And my hope is that in working through these ideas, we can end with some thoughts about implications of this argument and what this might mean for us going forward.

Paula 11:57

So this notion of what is being represented... Here, I'm drawing on another social scientist, a political scientist, Michael Sayward, who's written two really interesting books about this notion of representation. This one I'm drawing from his 2010. And he talks about the representative claim. And the essence of his argument is that you

don't represent just by showing up. Representation is not just about pure presence in a room. We each try to make some kind of representative claim. And so to say that we're representing something requires a few things. You have to be able to say "who I am" making that claim - there's a subject there. And you're making a claim about "something" - there's an object that you're referring to. And you're directing that claim to some kind of audience. And thinking about it this way allows us to start unpacking the different kinds of objects of the claim. Because it's a really different thing to say that I'm representing the interests of a group of people, as compared to saying I'm representing the needs of a group of people, as compared to the preferences as compared to the essence of the experience. Those are very different objects of representation.

Paula 13:10

And so the way that this showed up in some of my own research, and this research I conducted before I was starting to pull on Sayward. But we had done a qualitative study on patient engagement practices for quality improvement in hospitals. And what we were doing was interviewing people who are participating from a standpoint of patients, but also people who are staff who are creating the programs and also staff who are participating in the programs, but not actually the champions of the programs themselves. And we're also looking at all the texts and documents like invitations, advertisement, materials, minutes, evaluation materials, how do we talk about these programs. And we started thinking about, there's three different ways people could show up as patient advisors, and they were quite different.

Paula 13:50

So one way we're calling it the process informant. And the notion here was to be a good patient advisor in this particular program, was to be able to relay the details of a particular kind of process, how it was working, where it was potentially failing, what could we do differently in order to improve the process. And so here, the patient advisor had knowledge inside their head that the organization wants to extract for the combined purpose of making things better. What's being represented here is a process. Accuracy matters. Being able to relay that process in a way that's current, and that's currently relevant, mattered for this way of being a patient advisor.

Paula 14:31

But there's this whole other way of being a patient advisor. At the same time in the same program, we started calling this being the idea being a vessel of meaning. And so here to be a good patient advisor meant that you could relay your patient experience, you could relay your story in a way that was fit for purpose for the room that you were in. That you could tell your story in a way that was evocative and emotive when the timing called for it. Or you could tell your story in a very rational, clipped linear way when the time called for it. Either way, the skill set sat with the person who could tell their story in a meaningful kind of way. And here it was less relevant whether the story was even accurate or current. You could tell your story from 25 years ago, talking about systems and processes that no longer exist. But if it created the kind of emotive call-to-action within your audience that you're going for? That was considered being a legitimate and credible patient advisor. So what was being represented here was an experience. And what mattered was the authenticity and the delivery of that experience.

Paula 15:38

In the last category of being, ways of being, a patient advisor, we're calling critical friend. And here the notion was being inherently disruptive. Now, it wasn't always antagonistic. I like this imagery of throwing flowers [relates to image on presentation slide]. But there was something that was always set apart. And so here was the notion that being a good patient advisor meant that you see the world differently than providers. And by access of seeing the world differently, you have a different kind of knowledge that the organization could not access in any other way. And so here, the knowledge was considered legitimate almost because it was an opposition. And if people were agreeing too much with the organization and sounding too much like the organization, then they were considered to be caught by the organization - institutional capture - just perpetuating more of the organization, what it already says. And that's where somebody here would lose their legitimacy. So here, what was being represented, was knowledge that was considered to be collective. It was pulling from not just my experience, the experience of others. This is where we would see the involvement of patient groups, patient advocacy - seeing things from outside of the organization, other networks. So legitimacy came here from hooking in to other patient perspectives, and being able to pull them forward in a way that called for change that the organization itself wouldn't be able to hear or see in the absence of that kind of engagement.

Paula 16:58

So of course, a person [could] hold each of these roles. So one person could be a process informant, a vessel of meaning and a critical friend. I'm not trying to say people are in these categories. But I could see different engagement activities, the way they were invited, the way they're evaluated, the way that they were run, the way that they were advertised within the organization - they were calling for different ways for people to show their their knowledge and your experience. And so it was the invitations, these practices of engagement, that were creating ways to be able to learn from patients that were not necessarily about the essence of a person's patient experience or patient identity on their own. And there's something powerful here about unpacking this, away from just the people who are in the room, to the kinds of practices of engagement and what that allows us to be able to say, know and think within those roles.

Paula 17:52

And it requires us to ask questions about power. The kind of power within each of those rules is quite different. The kinds of opportunities for conflict within each of those roles is quite different. There's also lots of opportunity here to realize how often people coming in for these activities have to read the frame. They have to understand: when you asked me to come tell my story, are you asking me to be a process informant - tell it with accuracy in a way that can be validated by somebody else? Are you asking me to be a vessel of meaning, and it's less about the accuracy and currency and more about the experience and what we can learn collectively? And there's also all kinds of opportunities here for misalignments. So when somebody thinks they're being invited to do one thing, and they realize maybe partway through the session that they're actually being invited to do something quite different. And I think unpacking some of these practices of engagement and how they relate then to how we can be in these spaces together is important. So that's the piece about what is being represented. What kinds of knowledge is being represented, and to what particular audience.

Paula 18:56

Then the next part of the argument is this notion of to what purpose. And this is now...I'm going to go kind of broad and overarching... I'm going to pull from some critical theorists, and they'll talk about patient engagement programs and public involvement programs tend to organize themselves around two different kinds of purpose. Sometimes these programs will talk about themselves in a way and say: it is the right of patients and publics to be able to shape, in our case, health professions education. In our country in particular, we think about education as a particular kind of public good, and it's oriented to the good of society. And given that.... society in this case that we're particularly concerned about is patients and publics...then we talk about patient engagement as a way to fulfill some of the democratic promises, where it's the right of patients and public to be able to shape these programs.

Paula 19:50

But other times we talk about these programs and will say things like this: Patients have specialized knowledge that will make education better. And it's a subtle shift here. But the argument being put forward now is less about the right to be able to shape things that are public goods like education and health care. And it's instead more about the skill. The specialized knowledge that patients have access to, and being able to use that knowledge in service of this thing that we care about together, which is improving healthcare and health professions education. And so you have these two different arguments. A democratic argument for why we're doing patient engagement activities, and a technocratic argument for why we're doing patient engagement activities. And they can coexist. And again, the trouble comes when we're not necessarily articulate about some of our purposes, why we're doing some as an engaging activity - and we mix them together. And they create really predictable tensions.

Paula 20:44

So this is one.... Some scholars from the UK, wrote about the Catch-22 that seems to permeate so many of our patient engagement programs. And this is the way to describe it. So we talk about wanting to have some people come and be able to speak from their patient experience. And we're asking them in some ways to be ordinary enough to be representative of the kind of average patient experience that we care about. That's some of our democratic rationales. And then we do things like create meetings at difficult times that requires quite a lot of endurance, requires a lot of interest. Yep, often these things are volunteer, and you have to be willing to choose to put your time into this activity, into something else. To be really effective and trying to move really powerful systems you usually have to be relatively articulate, or at least convincing and persuasive. And you need to be comfortable in these contexts. As soon as you're sufficiently articulate, persuasive, comfortable and available - you're no longer considered ordinary. And when you're no longer considered ordinary, you're no longer considered a representative of the average patient. That's the essence of the Catch-22 being described by these authors. And they talk about that we write these things into our engagement activity, again and again and again, where we catch people in these Catch-22s, where we propose mutually exclusive identities, and then say the program's failing when people can't live up to those mutually exclusive identities.

Paula 22:12

And I see this again and again in my own research. I see Catch-22s that we've created. Some of my research participants call that "escape hatches". There's so many ways that organizations can dismiss the kind of feedback that's coming from patients, particularly through a patient engagement programs. And we see other kinds of tension showing up when we're not terribly explicit about what purpose we're doing all this engagement activity towards. And we wrote about this in another paper. This phenomenon of patient engagement is an enormous field that has so many different activities and solutions that are tied to it as a field. And there's a risk of taking solutions that have worked in particular contexts and trying to apply them in new ones.

Paula 22:50

And so for example, taking strategies that have been built within a history of community based participatory action research that has been very nuanced and reflexive about power, and about accountability, and taking those strategies and moving them into organizations that already have very robust and strict ideas about governance and accountability. And then switching some of our rationales partway through and tying solutions that have worked in other places in to new problems spaces, without bringing the whole notion of power, risk and accountability in the way they work, and how they might work together.

Paula 23:29

So we talked about what's being represented, we talked about the different kinds of knowledge and how practices engagement shape what can be represented. We talked about "to what purpose" and I put forward two big purposes - democratic and technocratic - and talked about how they potentially get mixed together in some of these patient engagement programs, and how that can create predictable tensions. Now we'll talk about "to what audience" because that's the idea of a representative claim. Like if I'm just in my room, claiming to myself and making declarations, but there's no audience to it, then I'm not representing anything to anyone other than myself. So when we think about "to what audience", there's a phrase that certainly permeates the patient engagement world, and it's this notion of "nothing about me without me". And when I look at the history of that phrase, I can find it in two places.

Paula 24:14

One is in critical disability studies, but the other is in labour movements, which I found particularly interesting. Because it talks this notion of a collectivity, because this is the other phrase that we'll hear, and sometimes it's a direct translation, or sometimes it's a substitution. But people will also say "nothing about us without us" as a justification for a lot of patient activity, patient engagement activity, that we do. But this phrase comes from community based action research, particularly participant based action research and research with Indigenous communities. And the need to dismantle this idea that research and engagement can happen in an individualistic way. But this notion about "nothing about us without us" really relies on that concept of us. There's an us, understanding of us, that you needs to be encountered.

Paula 25:03

And the way these ideas have been translators in the patient engagement world is in this phrase of thinking about patient engagement from the bedside to the boardroom. And so we'll often see these frameworks... and

this framework [showing slide], I'm just trying to give you the the visual of the notion of these different levels of engagement that we'll see in many patient engagement frameworks. And we'll talk about patient engagement at the level of direct care. So when we're making decisions about my body, my care, or the care of someone that I love as a family member. I will talk about patient engagement at the level of organizations, when we're talking about trying to shift organizational policies, thinking about evaluation within organizations. So this could be the level of hospitals, this could be the level of faculties. And we also talked about levels of engagement within policymaking. So this could be provincial level policy, federal level policy.

Paula 25:50

And out of these different levels of engagement, I think it's this middle area that we know the least about. So when we talk about patient engagement at the level of direct care, we have this whole body of research to draw from about shared decision making. When we talk about patient engagement at the level of policymaking, we have a whole body to research draw from this about citizen engagement. But when we start talking about engaging with patients and communities at the level of making decisions at hospital units, faculties... I think we have less depth to draw from about some of the implications of doing engagement at that level. And this is where I think I see some of the tensions showing up. Because when we're talking about engagement at the level of direct care, when we say "nothing about me without me" at the level of direct care, all the "me"s are in the room. So we can start talking about things like risk and accountability.

Paula 26:41

When we start talking about level of decision-- [at the] level of organizations, there are bodies, lives and work of people who will be impacted, that are not part of that engagement activity. And I think at that level, we start getting into different kinds of conversations about risks and accountabilities of how we're sharing decision making, when the decisions will have impact beyond engagement activity. So how do we consider the impact of engagement for people not yet in the room, and maybe not yet imagined?

Paula 27:12

So I think that when we start thinking about what audience - and we're moving between these levels - talking about engagement, the level of direct care, the level organizations, the level of policies - I think there are entire conversations about accountability and risk that have not been fully developed or explored. And I think that we're coming to... and I think this last year and a half has really put this into focus... is potential dilemmas of expertise. When we start thinking about whose knowledge can influence what kind of decisions, to what kind of effect. And Jennifer, Emily, Arno Kumagai and Meredith Vanstone and I are working on a paper to that effect. So this all comes to starting to think about these questions of what's being represented, for what purpose, and to what audience, as some of our foundational work to start thinking about why we're doing this engagement activity in the first place. And thinking about the what and the why before we even start worrying about the who. But there's a little orange asterix, because there's a caveat there. Because if the people who are answering those questions "what" and "why" are a relatively small group, they might have some blind spots of their own. So to be prepared to think about the what and the why, as anticipation of your engagement activities, but knowing that your understanding might need to shift as you begin.

Paula 28:28

So some of the implications of all of this conceptual argument: The biggest piece is thinking about representation as a particular kind of practice, not just a presence. It's not just about who we who shows up into the room and how we can have more people show up into the room. And I like this quote by some researchers who are looking at patient engagement and [...] engagement in the UK. And they're talking about the complexity of participating in these programs from a patient standpoint - they said, you know, to become a patient advisor is not just showing up. First, you have to struggle to create some kind of legitimate identity in this space. Second, you have to survive as a lone outsider, a minority in a complex expert system or systems [that are] expert-ridden. Third, you have to demonstrate some kind of agency. You have to be able to adapt to these alternate forms of patient and public activities. And then fourth, you have to cope to various threats to the identity that you're developing.

Paula 29:20

So all of this to say, I don't think we're going to solve the dilemmas of representation through more and more recruitment. And this is scandalous to say in the patient engagement world. I also don't think we need more and more toolkits. I think we need different ways forward to really wrestle with this dilemma. And I'm going to argue that our ways forward are around the notions of reflexivity. I'm going to point to a paper about mosaics but I'm going to end with this idea of humility.

Paula 29:46

So first, reflexivity: look at our programs and look where are we catching... where are we actually creating Catch-22s? If we really look at some of the inconsistencies we're creating in our practices, would that solve some of the dilemmas that we're encountering? I think we need to sensitize ourselves to some unintended consequences of our engagement work. So just like that first story I told you, engaging with my colleague and she relayed her experience with engagement that really shifted my mind. There's this quote from one of my studies that's sensitized me to a potential unintended consequence involving engagement work. There's becoming so much effort and visibility around patient engagement work and the kinds of patient engagement programs that faculties are creating, that hospitals are creating... that it's becoming... the first reaction is to engage with those programs. And I wonder to what potential effect to things like community engagement? Are we looking only to the programs we're creating? And are we actually starting to sidestep some really meaningful community engagement?

Paula 30:47

I think we need to build some better understandings of how our proposed solutions align with our hoped-for impacts. So this is my rough formula about how I think a lot of the patient engagement work is being written about right now. Not all of it. But often there's this idea that patient engagement is going to lead to something better. Otherwise, why would we bother. And very often, we're pulling from policy directives to talk about why we think this would work. But thinking about how our patient engagement activities actually lead to something better we're less articulate about. So I think we need to really start digging into how we think this works. And there are so many theories within the domains of social science in particular, to try to unpack and understand why we think these patient activity engagement activities will lead to something better.

Paula 31:35

And so this is kind of an overriding theme throughout all my research, is this notion that patient engagement is not a singular program. There are so many different activities being held under the singular umbrella of patient engagement. And similarly, "patient voice" is not a singular phenomenon. We have this temptation to talk about the patient voice. But of course, there are many, many voices. So how can we be more intentional for how we map together patient engagement activities with many kinds of different patient voices. And I'm giving this visual... it's from a paper co-written with Kinnon MacKinnon and Nancy McNaughton. And we tried to give a visual to this idea of mosaics. And it's recognizing that there are many kinds of involvement. There's direct involvement with individuals. There's direct involvement with patient groups. There's indirect involvement with individuals through things like data collection surveys. There's indirect involvement with patient groups. There are so many different areas of health professions education where there could be points of intersection with patient voices, community voices. And so thinking about, and zooming out, and looking at all these activities as a whole, and start mapping where these different points of contact and interaction are, allows us to be more intentional and looking for where we might have blank blind spots in our programs in our curriculum that would benefit from different kinds of engagement and being intentional about what we're asking for, when, why and who.

Paula 32:56

So this is the summary of the critical reflections in terms of ways forward. There's no direct advice, there's always these... this invitation to critically reflect. So I think the first one that I'm pulling forward is: what are our practices of engagement creating for participants? And that's pulling from, what are we asking them to represent? What are practices of engagement creating for people not in the room? How do we think about risks and accountabilities and the impact of all our work?

Paula 33:24

How are our practices engagement situated in broader landscapes that zooming out and taking a look at how all these activities fit together? And finally, what are theories and views about this work? And how we might deepen our understanding of how this actually working. So I'm going to end with a shout out to some of my favorite scholars. And when I started doing this research in 2013, this book was really influential for me. This is by Ruha Benjamin, a sociologist from the States. And this is her first book, and it's about stem cell science, particularly in California that was emerging. And she has a whole thread here that's around community engagement and citizen engagement and whose body science is being built upon and who benefits from that kind of science. And she put forward what I think is a really foundational commitment. So: commitment to how can we create opportunities to elaborate our collective understandings of important issues? To ensure that there's a full range of identities, hopes and concerns may gain a genuine hearing. And I appreciate that commitment to this idea of having a genuine hearing, which is a bit different than an attachment to the current practices in patient engagement that we have.

Paula 34:31

And so finally, I'll bring it back to the story that really prompted a change in my direction and how I think about dilemmas of representation, and a story that gave me pause about why people engage and why more outreach may not be the answer to the dilemmas of representation. And so this again is the thread that Dr. Benjamin pulls through her work. And she argues that there might be really important, really rational, really protective reasons why people are choosing not to engage and instead of pathologizing that and saying "why are some people so hard to reach?" Maybe it's more fruitful to turn our gaze, turn our lens, and start asking "why are some institutions so hard to trust?"