

Transcript

Matters of Engagement podcast

Episode: "Discussing failures in participatory research, with Lori Ross"

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SPEAKERS

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Lori 00:00

Through that lens, then, we were able to see that, you know, regardless of how committed an individual researcher or research team might be to the values of participatory research - when it's happening in an academic institution, at least in some respects, it's kind of doomed to fail.

Jennifer 00:24

Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement in partnership. I'm Jennifer Johannesen.

Emily 00:33

And I'm Emily Nicholas Angl.

Jennifer 00:37

We're excited to bring you this episode about peer researchers and participatory research, featuring Lori Ross. Now, because this discussion is not really centered on patient engagement, we decided to replace Patient Partner Reflections, which is the new OSSU-sponsored segment, with a separate episode that features the experiences of people with peer work and peer research experience. So that episode will be next. It features Jenn Broad and Paula Tookey of the South Riverdale Community Health Center in East Toronto. Okay, let's jump in. Here's our episode featuring Lori Ross.

Jennifer 01:18

We've noticed that the scope of what counts as partnership and research seems to be expanding. From the perspective of CIHR and OSSU, pretty much any type of health research or engagement activity that involves patients - beyond just being subjects - is broadly counted as being on the spectrum of patient partnership. At one end, we have simple consultation or feedback. And all the way on the other end, we have full partnership, or even leadership, where patients define and shape the research project from the very beginning.

Emily 01:50

Right. And there are some methodologies and approaches that get included in this partnership spectrum that have been around for a very long time, much longer than the more contemporary idea of patient partnership that we see today. These include participatory research, participatory action research, community based research, or some combination of all of those. And these methodologies often include tools and frameworks

related to social justice change and impact. They're also typically initiated or led by communities or stakeholders, not by institutions or organizations. Or at least they're ideally driven by community goals and not by institutional agendas.

Jennifer 02:31

So even though each of these methodologies are distinct and utilized in specific contexts, the lines between them can seem less distinct when we put them all under the same umbrella. Sometimes terms like participatory or community based are used to describe health research projects, where in fact patient partners were recruited to join an existing research team. And those projects may not be at all rooted in community priorities.

Emily 02:59

Which makes understanding some of the dynamics and challenges related to involving patients more difficult. Participatory and community based research projects are often complex undertakings that are highly context specific and come with their own set of challenges, including the fact that they don't fit easily into institutional bureaucracies and processes. Perhaps if we better understood some of the challenges in these methodologies, it would help explain some of the challenges that persist when partnering with patients in health research.

Jennifer 03:32

Which brings us to our guests Lori Ross. Her work is centered on community based and participatory research projects. And the idea of partnership is just inherent to the work. A recent project of hers caught our attention, and it led to a fascinating discussion about, well, as she puts it, the failures that she and the project team experienced. Lori is the principal investigator on a research project called PEERS, which stands for Peers Examining Experiences in Research. The project looks at the experience of peer researchers who engage in community based research projects.

Emily 04:07

We're first going to talk through some of the complexities of assembling a team that includes peer researchers, and then move on to the project, and how the research team identified and describe the failures. Here's Lori Ross:

Lori 04:21

I work as a faculty member in the Dalla Lana School of Public Health at the University of Toronto. And so my program of research for many years has had pretty deeply embedded in it a commitment to participatory research. And so for this particular project, what we wanted to do was to actually research the practice of participatory research. So kind of a meta project, you know, to study the way that we study basically. So PEERS stands for Peers Examining Experiences in Research. So that was the name of our project. And it was a two year study, it was federally funded. And it was to study specifically the practice of hiring peer researchers - so people who have lived experience of the thing that you're studying - in research staff roles. So we wanted to basically understand like, what are the benefits of doing that, but what are also the risks or potential harms of that practice. We focused in this study specifically on four different communities of identity or experience that face structural oppression in the Canadian context, communities that are often engaged in participatory research. So those were mental health service user - consumer/survivor, mad communities - communities of people who use

drugs, trans and non binary communities and racialized communities. And of course, those communities are inherently intersectional as well. And the project itself involved interviewing 34 people who had themselves worked as peers on various research projects, to talk to them about their experiences - kind of the good, the bad, and the ugly.

Jennifer 06:06

So that was the research focus, studying peer researchers who had experience in particular communities. But the project itself also had its own peer researchers. And we just want to note that for this project, peer researchers were designated as "research assistants" for funding purposes. You'll hear Lori use the terms interchangeably.

Emily 06:27

We asked about how they were selected. And whether it got complicated because of intersecting or overlapping experiences.

Lori 06:34

We made sure to hire one research assistant who was connected to or had experience working as a peer for each of those four communities. But at the same time, we really valued all of the identities and experiences that people brought. So just because someone was hired as the peer for a particular community, for example, didn't mean that we weren't also, you know, interested in valuing the experiences they had in relation to other communities - both those that we were explicitly researching and those that we weren't. And definitely what we found was that people's experiences that they brought to peer research for our staff, but also in the study, they weren't linked to one specific community or experience, right? In the way that you experience, let's say, for research projects that were looking at homelessness. So the way that you experience homelessness as a white person is necessarily different than the way you experience homelessness as a person of colour. They're not equivalent experiences. So we were very aware of that both in the context of our own projects, but also in the research itself.

Lori 07:46

You know, we hired the folks that we hired not only because they they were connected to these specific communities, but because they had worked as researchers, like they had specific research skills that we valued. So you know, what's more important than...or, like, can you give greater importance to one of those types of experiences over another? Like that's a very tricky question. And I think it's really contextual, right? It depends on the specific thing that you're trying to figure out. Like, I think if I'm trying to figure out what's the best way to recruit people who use drugs, then someone with lived experiences in those communities is really essential. If I'm trying to figure out though, like, what are the ethical implications of different approaches to recruitment, then there's probably some academic or research expertise that's necessary to help answer that question as well. So there were lots of discussions that involve lots of different combinations of people with different combinations of expertise.

Emily 08:40

Just like we see in patient partnership, Lori came up against some of the practical realities of working with a diversity of people living in a variety of different circumstances.

Lori 08:50

So we had in this project team, like quite a large team of academic investigators. And we had the 4 peer research staff that we hired. And there's lots of overlap between those categories in terms of having lived experience and having research experience, right? But not all of those people were consistently around the decision making table when decisions were being made, because some of us worked in full time positions in universities. And some of us were working one day a week on this project and juggling lots of other things at the same time. So while, we, you know, really valued that expertise and experience, the practical reality was that the way the project was structured - and necessarily structured, because of the budget, and so on - was that some people's expertise was more available to decision making than others. That's one of the failures that I talk about in the project is that that happens - the decision making structure of the project is often in place before you hire the peer researchers, because you have to have that team together before you can even apply for the grant. Like that's just the way the funding mechanism works.

Jennifer 10:04

This is a common critique of many types of funded research that include community members, stakeholders or patients. Typically, there's just no money to compensate people until the project is funded. Yet increasingly, there's pressure from communities and patient partners, as well as the funders themselves, for there to be engagement during or even before the application process.

Lori 10:27

Whether you're calling it participatory or community based research, absolutely, in an ideal world, the communities that the research is about would be involved from the very beginning in formulating the project. That's absolutely correct. So was this project then properly participatory or not...? I'm sure different people would answer that question differently. For me though it does come back to questions about, like, who's experience counts as lived experience? Because there were academic members of our research team who had experience working as peer researchers as well, right? So it's not like those perspectives were completely absent as we were conceptualizing this project. But obviously, someone who is now situated in an academic position... their experience of that is quite different than the person who is currently at that time working usually in precarious contract to contract type of work.

Lori 11:26

That ideal scenario where the community is involved in conceptualizing the project... that's pretty complicated given the current funding structure, unless you're asking people to do free labour, right? Like you, you need to have money in order to properly engage people. I don't know, maybe 10 years ago we had a funding landscape where that was more possible, where actually, some of the major funders had funding envelopes that were meant for that kind of development work. And that does still exist in some capacities. But my experience is that it's very competitive. So your project actually has to be pretty far developed before you are competitive for those funding envelopes that are about building your project.

Emily 12:11

This is definitely an issue in academic research projects that go through the usual health research funding process. It's quite a bit different from community based research where the research question is often formulated well before others are brought in or funding applications are made. We asked Lori if there was some way to bring this idea into academic projects. Rather than involve stakeholders only after receiving funding, why not conduct research on questions that have already been identified? At least you'd know that the community endorsed the question in the first place, because it was theirs to begin with.

Lori 12:46

Well, no, I've definitely done it that way, too. Like I've done projects for sure where what happened was the community came with a specific question. And we worked together to figure out how to get that funded and do that work. But what you said is absolutely true then - typically, for most funders, the community organization isn't eligible to hold the funds. And then what if it's not an organization? What if it's a community activist or you know, a grassroots organization, that doesn't have any kind of infrastructure to hold funds like that? So the funding comes through the academic institution. And then like you said, all the rules and policies and whatnot of the academic institution apply. And so the power lies where the money sits.

Jennifer 13:37

As we were talking to Lori about the PEERS project, we learned that they were actually writing up an independent piece, separate from the findings of the research. It wasn't part of the original plan, but it emerged as something relevant. It's a reflexive piece about what the researchers saw as failures.

Lori 13:54

We were thinking about it as kind of a meta project where you're doing the same thing at the same time as you're studying it. And so we anticipated that our experiences would give insight into our questions about the benefits and harms of peer research alongside the data that we were collecting - we sort of saw it as two different complementary data sources. It hadn't really been planned to have the two different perspectives in an intentional way. When we wrote about the auto ethnographic component, we were really talking about the peer researchers experiences - that we would support them in terms of time and resources and skills to collect their own reflections in whatever way made the most sense for them.

Lori 14:37

You know, honestly, I don't remember how... exactly what happened or what the conversation was that led to myself (as the principal investigator) and the project coordinators also collaboratively recording our reflections. Except that I know that it did feel like it was really necessary, both because we were asking our research staff to do this thing - so it didn't seem appropriate for us to ask that of them and not of ourselves - but also because there was so much going on in the project that we just needed to make space to talk about and to reflect on. And so our meetings that I had together with the project coordinators, they were... they had as a byproduct that we recorded these things that we kind of were typing as we were talking... but also it was a way for us to just talk and think through what was going on in the project. And just have some some dedicated time together in our calendars to be able to talk together and think through some of the tricky bits it as they were happening.

Jennifer 15:43

So it started out as an activity only for the peer researchers. But Lori and the project coordinators saw the value in recording their reflections themselves as well as they could almost observe their own behaviors and patterns in real time, and come together as a group to process what was happening. We asked about the decision to write it up and to focus on failures. How did that come about?

Lori 16:06

We definitely imagined the peer reflections to be a knowledge translation piece that there would be things that we could learn for that, that we could hopefully share with others who were doing this kind of research. I wasn't really sure what we were going to do with our reflections... as the P.I. and the coordinators.... for a while, like it took a while to kind of sit with it and think about it. And then it just happened to have a call for papers circulate that just really fit, in terms of understanding the complexities of social justice research methodologies - that was actually the impetus to go back and really look at it and and think about what we could say from our experiences.

Jennifer 16:53

Okay, so this is a good moment to mention our decision to only speak with Lori at this point. We went back and forth about this. Shouldn't we also speak with the peer researchers about their experiences as well? Well, maybe. But we decided, not for this episode. As Lori mentioned, there has always been an intention for a knowledge translation piece related to the peer researchers experiences. And that may still be forthcoming.

Emily 17:18

Right. Lori's reflections are her own. And she was very cautious about not representing others' perspectives. So for us, the idea of contrasting or comparing perspectives didn't feel right. And it also didn't feel right for us to be initiating a dialogue that the team wasn't currently having. Or maybe wasn't prepared to have at this time.

Jennifer 17:40

However, we did wonder about the extent to which the peer researchers may have been involved in contributing to this particular paper on failures.

Lori 17:48

Did we debrief? We had lots of conversations along the way... would I consider them to be conversations that debrief this piece? Probably not. I mean, some of the failures that we experienced in this project had to do with the reality that the team mostly was never together in the same room at the same time. You know, we were employing folks to work one day a week. And so they had lots of other things going on in their lives that meant that they weren't necessarily available at the same time that one another were available. Like even having the four staff in a room together, much less the rest of the academic members of the team, was pretty much impossible. So that was, you know, that was one of the failures happening at the micro level that, you know, I could trace back to the way that our grant was funded and structured, that meant we were, you know, precariously employing people essentially.

Emily 18:47

Lori mentioned failures at the micro level. This is part of the wider analysis they embarked on to contextualize and explain what was happening.

Lori 18:56

So when we went back to analyze the reflections, we really intentionally wanted to try to focus in on what we experienced as the failures of our projects. So the situations where we felt like we were not able to realize the values that underlie participatory research, and particularly the values related to power sharing, which are really fundamental to what participatory research is all about. In order to do that, in our analysis, we took a close look at what we have referred to as the macro level factors, meso level factors and micro level factors that contributed to the failures.

Lori 19:36

Micro level failures were focused on things like relationships between people, things like team dynamics and communication. And then at the meso level, we focused on institutions. And so in this work, the institutions that were most relevant were the university where the research was happening, and the funder, the federal funder, funding body. And then at the macro level, we're looking at things like structural forces, so intersecting forms of oppression, neoliberalism. So those things that are happening like on the kind of far outer circle, I guess.

Emily 20:13

Let's pause again here to briefly define what Lori means by neoliberalism, as she mentions the term a few times throughout the discussion. Here's the definition she uses: "Neoliberalism is the ideology that values free market competition above all else, resulting in policies that support privatization and austerity."

Jennifer 20:35

So what this means for public institutions, like universities and public services and governments - is there's a lot of pressure, driven by money and profit, to show relevance, efficiency and to demonstrate impact. And this sounds familiar, right? These are all things we hear quite openly as justification for patient engagement and partnership. They're supposed to make research and health services more relevant. Now, this notion appeals to common sense. But this push for relevance and impact can be traced directly to the valuing of free market competition and privatization.

Emily 21:11

Okay, so Lori went on to explain how the three levels of factors, macro, meso, micro, are connected.

Lori 21:18

[...] So we used our reflections to help us understand how all those different kinds of factors were coming together to lead to the failures that we saw happening in our project. So when we did that, we could see much more clearly how the higher level forces, so macro level, and sometimes meso level forces were ultimately leading to the failures that we saw happening at other levels. We could see, for example, how what we might have experienced as failures in team dynamics and communication were profoundly shaped by the way that neoliberalism constrains what's possible in an academic institution. For example, in the precarity of research

assistant work, and the specific policies around how people get paid. Even the physical spaces where people work... are all structured by neoliberalism, and how neoliberalism defines what an academic institution looks like and functions like.

Lori 22:18

In doing that, then we came up with this idea of proximal actors. So we're defining proximal actors to be the individuals or sometimes organizations who appear to be responsible for a particular action and its consequences, but are actually acting on behalf of or sometimes within the constraints that are defined by an actor at a higher level. So for example, if we look at payment policies, when they weren't grounded in the realities of the lives of our research assistants - which they often were not - it could look, I'm sure, to our research assistants, we - as the principal investigator, and project coordinators - were not supportive or not aware of the complexities and conditions that they were dealing with. And then it looks to us - as the principal investigator and project coordinators - the university is being unsupportive by not by having these policies in place. But if you trace it back even further, you can see that those policies - they're arising out of neoliberalism, right? Working in concert with these different forms of structural oppression, related to class and race and other factors to structure whose labour is actually valued, and how it's valued. Through that lens, then, we were able to see that, you know, regardless of how committed an individual researcher or research team might be to the values of participatory research - when it's happening in an academic institution, at least, in some respects, it's kind of doomed to fail, right? Because you're constrained by these macro level forces that don't actually permit you to do the things that you would need to do to really properly share power.

Jennifer 24:04

While there's value in doing this kind of analytic work, to better explain what's happening, it's also reasonable to think that these particular outcomes could have been anticipated. We asked Lori: isn't it kind of inevitable that you'd come up against institutional constraints?

Lori 24:20

Yeah, I would say that some things did feel inevitable. You know, the lens that I'm taking into my research already is that structural oppression is everywhere and affects everything. So it's not like I thought that that wasn't going to show up in this project. But I guess what did come up or what... wasn't surprising exactly but was really helpful is that when you're in the middle of the messiness of a project, you can't necessarily in that moment see, with good perspective, what is causing the mess. This process of analyzing our reflections was really helpful for me as a way to step back from the mess and have a better viewpoint on what was really structuring what was happening in our project, and to really be able to trace it back to its roots. So not that it was surprising, but it made things visible, I think, that weren't visible necessarily in the moment.

Emily 25:20

So when it comes to bureaucracy and big institutions, there can be endless constraints and what feels like unnecessary restrictions and barriers. But at the same time, creative ways can be found to get around some of the rules and maybe fly under the radar. We wondered if the team had figured out any workarounds?

Lori 25:40

Yeah, it's a good question. I feel like there was no space. And I felt like the project coordinators worked so hard to look for wiggle room. And even that the, you know, the the university's staff, like the administrative staff really also, you know, felt like these policies weren't working and wished that they were different, but it wasn't within their control. And it wasn't within our control. And it just felt like, yeah, it felt like there was no wiggle room, no matter how hard we looked, and no matter how well meaning the people who were answering the phone on the other end were about it. It really felt like these things were non negotiable. And I think, to your point about we'd all been through this before.... It's true. And yet at the same time, I think there was something about the fact that this was a study of participatory research that probably quite understandably, so let our staff to expect that things would be different this time, right? That even if they had had not great experiences doing research with large institutions in the past, that it would be better this time, because we were setting out to do this study with a very critical lens on participatory research in the first place. And I hope that in some respects it was better. And I totally acknowledge that in other respects it was not.

Jennifer 27:12

I think most large institutions would assume that paid employees or workers would have things like government ID, bank accounts, credit cards, a permanent address - things that allow for traceability to enable reimbursement or payment or other types of employment related requirements. But when working with a diversity of people with a wide range of personal experiences and situations, this assumption can create barriers to hiring and retaining the exact people who may be best suited for a particular role. It's a frustrating wall to come up against.

Lori 27:48

[...] you know, like, that's a huge institution, how could this not have happened hundreds of times before, but that's what it felt like... it felt like everything we encountered seemed like the first time. When you're funded through a federal funder, there are really strict reporting requirements and potentially auditing requirements. And if you are found to have used funds in ways that are not consistent with the funding regulations of a federal funder, then you will no longer be able to hold federal research funds. So you know, as an academic researcher, that's pretty serious business! There are certain accountabilities as the principal investigator you hold, that would be very risky to not follow pretty strictly. I think we probably all find ways that we feel are safe enough to work in the gray areas that you're talking about. But with federal funding, I think those gray areas are not very gray. Like, it's pretty black and white.

Emily 28:57

Thinking back to some of our conversations about patient engagement and partnership, a common theme is honesty and transparency. So if there are known barriers or limitations or challenges, it's advised to be upfront about them and communicate them so people can decide if they want to be involved under those conditions. So in this conversation, we said, well, if this is how things are, maybe just be honest with people... so they know what to expect.

Lori 29:25

Yeah, I don't know, I don't feel like a lot of it is solved in that. I think it's definitely better to be transparent than not to be transparent. I think it's very unhelpful to set things up, you know, set up expectations for anyone that participatory research is going to be able to have, you know, really true proper power sharing - the money's all sitting in an academic institution. So not to say that transparency is in any way bad, but it doesn't actually solve any of the problems, right? Does it really help for me to transparently say, "I can only give you a six month contract because that's what the institution will allow even though I have funding for two years." No, it doesn't actually help anything. My research assistants are still going to feel like they need to be looking for other work just in case something happens and their contract doesn't get renewed. Do you know what I mean? So it's like we can we can be transparent about these things. But it doesn't actually, I don't think, solve any of the problems that they create for people.

Jennifer 30:26

These are big, intractable problems that Lori is describing - bit of trying to fit a square peg into a round hole. And it would definitely be easier to just shrug and say, "Well, we're doing our best." But this reflexive process that Lori and the rest of the team have embarked on means that they can't - or won't - let themselves off the hook. Being honest doesn't fix anything. It just maybe avoids further compounding problems. Which brings up a more fundamental question. I mean, why do this all in the first place, if you know deep down that conditions aren't likely to be different? We asked. And it's a question that Lori sets with, every time.

Lori 31:09

After every participatory project that I do, I go through this period of disillusionment, where I'm just disappointed that things did not go the way I wanted them to go. And, I kind of question whether this is the way I should be going about trying to answer the questions that I'm trying to answer. And then I seem to forget, or I feel like it's not ethical to do certain kinds of research without being engaged with communities who are affected by the research. And so when I write the next grant, I write it as a participatory study anyway. And I guess just hope that I will have learned things that will make it a bit better. But I'm not sure, honestly. And I feel like, I'm less sure this time around after finishing this project. I think because in this project, we were actually studying it. We were actually studying the messiness of it - not just, you know, some other thing using these methods. And so it's definitely left me with lots of questions about whether it's necessarily better. If this is the space that we have to conduct research in, is it necessarily more ethical to bring communities into it, then to try to find other ways to do the work? I'm not sure. I haven't answered that question for myself yet.

Lori 32:41

Anybody who's involved in these conversations pretty universally feels that it's not okay to be producing knowledge about communities without the input of communities. But at the same time, we're acknowledging that if we're situated in large institutions like a university, there are ways that we are constrained in being able to do a good job of that. So what I want to be involved in is conversations about what are the alternatives? Like what are the ways in which we do responsible and respectful and ethical work that has meaningful impact for communities that doesn't reproduce these power relationships?

Jennifer 33:26

Hi, Emily.

Emily 33:27

Hey, Jen.

Jennifer 33:29

We covered a lot in the conversation. So let's just pull out the things we want to highlight. So first of all, I was really struck by the discussion about the concentric circles of different forces - with micro in the middle surrounded by meso, which is surrounded by macro. And along with this idea was the notion that each of the inner circles were proximal actors for an outer one. Now, these are complex ideas - but even just on the surface, I think they shed some light on why things can feel so frustrating, even when it seems everyone is just trying to do the right thing. Basically, I think what's happening is that the people who experience the most frustration are perhaps the least empowered to make change. And with this framing that Lorie described? I'm not even sure it's ever clear who is empowered to make change.

Jennifer 34:23

Now, this wasn't something Lori said, but I'm guessing that's part of why these conditions persist. It's almost impossible to identify who or what is responsible for creating inequities in the first place. I mean, what does one do to hold neoliberalism accountable? I'd love to dive into this more, but we should probably wait until the research team has completed writing this all up and the work is actually published. So hopefully we can return to this in another episode. I'll move on to the second thing that stands out for me, which is the way academic funding works. It just doesn't support early involvement by community members or stakeholders.

Emily 35:04

Yeah, and it's the same with SPOR and generally CIHR funding as well. CIHR is a strong proponent of patient partnership. And they often require the engagement of patients in the research process. But patient partners have been pointing out that early involvement just isn't possible without expecting free labour. CIHR guidelines kind of acknowledge this problem, but don't really offer any real solutions. And most recommendations rely on financial policy changes at the university or academic hospital where the research is based. I've experienced these barriers on a number of projects, and definitely resonate with a lot of what Lori described. Like we've talked about so often before, it feels like the mandates and the enthusiasm are there, but the structures to support it or not.

Jennifer 35:55

So what was one of the key things that stood out for you?

Emily 35:58

Well, I'm interested in this part about identity and community representation. We've touched on this in several other conversations - that people can get hired or recruited because of their lived experience, or maybe because they're members of a specific community - but then what happens when they're now engaged and contributing?

What are they bringing to the discussion? And how is it valued? I mean, obviously, people bring their full selves into each experience. But is that how others see it?

Jennifer 36:28

Yeah, I think people can get labeled as representing a community when in fact they never signed up on that basis. And it gets especially fraught when there are maybe unstated diversity goals or maybe people feel they're being tokenized. Now in the PEERS project there was a high degree of transparency about the recruitment process and what the goals were - but that's not always the case.

Emily 36:50

And there's also this issue of who 'counts' as a community member. Lori described there being a lot of overlap between these categories of people with lived experience and then the academic investigators on the team who were involved from the beginning. Is there a point when someone becomes so embedded in the institutional structure that they're no longer be seen by the team as community members? This issue certainly comes up when we consider who can be called a patient partner, and whether people can wear those 'multiple hats' we often talk about.

Jennifer 37:22

Okay, so I did also want to go back to one of the ideas we lead with at the beginning, about how terms get interchanged and how we kind of forget what's what. I know this is unusual. But let's bring in something Lori said that didn't actually make it into the earlier part of this episode. And it has to do with differentiating types of research and whether or not peer researchers constitute a community.

Lori 37:44

[...] I think that's probably part of why we went with the language of participatory research rather than community based research in this project. I think you can define community in lots of different ways, but I don't think peer researchers necessarily consider themselves to be a community. But the project was participatory, from the perspective that we had folks engaged in doing this work who have had that experience. And then layered on that is the reality that the folks who tend to be engaged in peer research are engaged because they have particular lived experiences that are sometimes connected with what we might might more typically consider a community.

Jennifer 38:27

I wanted to bring this quote in here because I really like the careful consideration about definitions, especially around notions of community. In patient engagement and partnership, I think we use the term community to just mean... well... "everybody else". And I guess that varies depending on who's actually in the room, but it is a very institutional view on things. Whether certain groups of stakeholders self identify as a community is not often considered, they may be only "a community" in the eyes of the institution.

Emily 39:00

Well, this all really highlights just how much of a disconnect there can be when community based or participatory methods are brought into an institutional context. Whether that context is a university, like the

PEERS project, or a hospital, like is often the case for patient engagement projects. There's almost an inherent misalignment of priorities and goals, and a lot of energy is spent trying to work around barriers. Lori used the term "doomed to fail" at one point and well, maybe she's not wrong. It also brings to mind something I'd read recently about basic principles in this kind of research. And the first one is do no harm. This is hard to reconcile with the kinds of experiences we hear about.

Jennifer 39:43

Yeah, I think it's worth returning at some point to all of this. As Lori expressed, it's a widely held belief that it's not okay to produce knowledge about communities without involving them. And I think there are a lot of assumptions packed into that belief, which kind of sets up an uneasy tension between communities and academic research institutions. I'd be curious to find out what it is like on the community side, how is community based or participatory research experienced from their point of view? And I think this PEERS project starts to chip away at some of those questions. And I know there's other literature on this. So yeah, let's definitely come back to it.

Emily 40:21

Okay, I think that's a good place to wrap up for now. Thanks to Lori Ross for participating in this episode. We'll include a link to the PEERS project in the show notes, and we'll provide an update when the team starts publishing their findings. If you have any questions or comments, please get in touch through our website at mattersofengagement.com. Oh, and by the way, we now have a listener phone line! You can call and leave a recorded message which we may use in a future episode. You can check out our website for details.

Jennifer 41:04

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