

Transcript

Matters of Engagement podcast

Episode: "How did we do? A debrief on the role of Lived Experience Advisors (LEA) in a healthcare research project"

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SPEAKERS

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Jennifer 00:02

You're listening to Matters of Engagement, a podcast examining issues at the intersection of health, health care and society. I'm Jennifer Johannesen.

Emily 00:12

And I'm Emily Nicholas Angl.

Jennifer 00:17

Hey there, Jennifer here. I'm hosting solo for this episode, because we're turning our focus to a research project in which Emily is actually part of the leadership team. You will be hearing from her later, just not in the hosting role.

Jennifer 00:30

So let me first say that this research project (we're about to talk about) is kind of complicated. I am going to give you a brief overview because it's important for context. But honestly? The details of the project are not really what this episode is about. Instead, our intention is to showcase a number of different perspectives about the use of patient partners within a federally funded healthcare research project. You're going to hear from two of the project's researchers, two patient partners - they actually call themselves Lived Experience Advisors, or LEAs - and of course, Emily, who helped to bridge communication between the two groups.

Jennifer 01:06

Now, what's really interesting about this project in particular is that it studies the behavior and communications of physicians and other clinicians when prescribing opioids and antibiotics - super relevant to patients potentially, but the actual subjects of the study are clinicians and not patients. And that's interesting, because the funder - the Canadian Institutes of Health Research, or CIHR - well, they require this project, like most others they fund, to have patient partners. So fair enough. In principle. But how should a project like this, that focuses on clinicians, actually utilize those patient partners?

Jennifer 01:45

Now that the project is wrapping up after several years, we wanted to know a few things. How were the patient partners actually used? And how did everyone feel about it? Was it helpful? Worthwhile? And what did the Lived Experience Advisors think? So that's really what this episode is about.

Jennifer 02:05

Now, let me just say a few words about the study, and then we'll jump right in. So this project is what's called an "innovative clinical trial", which means that it uses methods alternative to more traditional randomized controlled trials. The research had two streams, both related to primary care - one focused on prescribing opioids, and one on prescribing antibiotics. Both of these are areas where there can be serious impacts at the individual patient level, but also in terms of public health more broadly. And particularly with opioids, defining exactly what appropriate prescribing looks like is really tricky. And primary care physicians aren't always aware of, or maybe just aren't following, the most recent evidence-based guidelines. So this project explored if and how some specific interventions could shift prescribing behavior towards established best practices.

Jennifer 02:59

Okay, so that was the project. And I think in that context, it's reasonable to ask: what exactly is the best role for patients? Well, it's hard to say definitively. Funders like CIHR often require patient involvement, but very little direction is provided beyond general frameworks and guiding principles. Often project teams just have to sort things out on their own. So we're curious to find out how this one particular project handled it.

Jennifer 03:27

We're going to hear first from the principal investigator, Dr. Noah Ivers. He's a primary care physician and researcher at Women's College Hospital in Toronto. We'll also hear from Celia Laur. She's an implementation scientist and health services researcher on the project. We're also going to hear from Barbara Sklar and Michael Strange, the recruited Lived Experience Advisors or LEAs. Then finally, you'll hear my interview with Emily, whose official role was Lead LEA. As always, you can check the show notes for links and more details.

Jennifer 04:00

Okay, let's get started. Here's Dr. Noah Ivers:

Noah 04:04

My research generally is about trying to improve quality of care and doing trials of interventions aiming to do that. And so when we're trying to improve quality of care, typically, you know, the target of my interventions that we're testing - the target is it's actually clinicians. I'm trying to change clinician behavior so that patients get the right care more of the time. So then the question arises: how do we include patients in a useful way in how we're developing interventions that actually target clinicians?

Noah 04:44

We thought okay, if we're going to craft things that helps, for instance, family docs talk to patients about antibiotics, we better we better have some patients to talk to you about how we go about doing that. Like. what

it is that we tell family docs to say to patients, or what resources we provide them to give to their patients. I mean, it just stands to reason that we should have a way of patients sort of vetting that, and so on.

Jennifer 05:10

Right. So Noah shared his rationale for why including patients may be helpful, and that's to get their feedback on specific materials and resources. But he does also see value in having patients involved for more general reasons.

Noah 05:23

So there was some technical things that we needed patients to do. And then there's the sort of, I would say, more usual things that we wanted patients to play a role in. Which is... let's make sure we're thinking about outcomes the right way, for instance. And, you know, there's the role that patients have in keeping us sort of grounded and not sort of navel-gazing. By having them in the room, you tend to focus on what matters. And that sort of thing.

Jennifer 05:54

Noah is describing here a common assumption that including patients is both necessary and important. But of course, there's always the context to consider - whether it's particulars of the project, timing of the project phases, or even the personalities of those involved. Celia Laur, one of the researchers, describes some of the logistical considerations.

Celia 06:15

So one of the additional complexities of this was that there's two streams of work - one related to antibiotic prescribing, and one related to opioid prescribing. And we had to figure out the streams within both of those, and then realizing that they ended up coming together. So the plans that were in place for each stream changed. So I didn't feel as much pressure to make sure that we were always really actively engaging the Lived Experience Advisors in some of the early phases of the work, because I knew that they were very technical, very behaviour change heavy, and there wasn't really a clear way to be able to engage them, other than keeping them updated, having some conversations... but that was kind of okay, because there was also the opioid stream that was happening. And we knew the interviews with patients of the physicians was coming. So I knew that there would be a really strong component of patient engagement that made a lot of sense and where people could be involved. And then we had to figure out the new plan.

Jennifer 07:26

Noah continued on to describe how COVID impacted their project,

Noah 07:31

The project was funded for four years, and now we're into like year six because of COVID. And so we had this longitudinal relationship with our patient partners develop. And also, both because of COVID and changes in the healthcare system - and even prior to that changes with our stakeholders and how we had to adapt what our projects look like - there was always a need to adapt what the project plan involved, and therefore trying to keep, to some extent, our patient partners up to speed on what the project plan was, and in which exact ways

they could contribute. There was a lot of adjustment over time and a lot of figuring out as we go, and I hope, a lot of learning. But that's part of what this podcast I think is for - as a chance to really reflect on what have we learned and what ought we do do different.

Jennifer 08:27

Throughout our conversations, I noticed just how much effort was made to keep communications alive in the face of all these changing conditions and project plans. So much so though, that it sometimes seemed to me, like that was kind of the focus of engagement overall. Just to keep the LEAs in the loop. We talked a bit about why it was kind of challenging at first to figure out where patients might fit.

Celia 08:53

The first phase of work for the opioid project didn't really involve patients. It was document analysis when a very specific way. So the conversations were more about the antibiotic project had a bigger priority at that point. So it was kind of balancing out some of those aspects. And when the antibiotic project didn't have as much anymore and more of the emphasis went on to the time for the opioid project. There was a limited amount of time, a limited amount of budget, and we needed to prioritize people's time. And I also think it really comes to the people that you're working with.

Jennifer 09:34

In previous podcast episodes, we've had lots of conversations with some very experienced patient partners. And they have pointed out to us that perhaps patients could and even should be involved in more technical activities, like document analysis. I mentioned that to Celia. Couldn't the LEAs have been trained in more of these technical tasks?

Celia 09:53

I honestly can't remember if we asked people if they wanted to be in document analysis, but also recognize that it would take... like I got trained on how to do that. If there was somebody that was interested in that, there might have been more conversations. But I also don't think we would have had the budget to be able to do the amount of time that was needed for that.

Jennifer 10:13

Right. So this is pretty common. Lots of ideals and aspirations. But the reality is that, well, researchers have a lot of training. And enrolling people without that training? Well, it might give different perspectives. But it also means you might have team members who aren't ready to jump into certain activities. Just because it's a funding requirement, doesn't mean there's enough resources to integrate patient partners in an ideally fulsome way. Here's Noah, reflecting on this tension.

Noah 10:42

You hit the nail on the head, I think. Like, what we asking patients to do, versus what they have the expertise to do? And I don't want to waste anybody's time either. Some of it has become sort of just... that's what you're supposed to do. But that's not a good reason to do it. You know, I think the idea of having patients give input to things that patients are ultimately, in an ideal world, is going to be provided by their clinician to them in a

consultation, like in helping us design those things... that makes perfect sense. You're building an artifact that patients are meant to interact with, like, you'd better get patients to... that's just user-centered design, right?

Noah 11:23

We had to have patient partners due to the requirements of the application that forced us into a box that wasn't necessarily totally right for all aspects of this particular project. There was a real limit to the amount of changes we were able to make, in terms of like the intervention options, to make a difference in these spaces - antibiotic prescribing, opioid prescribing. In fact, the opioid prescribing... the intervention was already done. We were evaluating something that was already out there in the system. You know, if our patient partners could say something like, "I really wish they had done it this way", I'd be like, yeah, totally agree! But we have no power. And even with the antibiotic approach, because our goal was to, as written in the grant was to, you know, materials to clinicians, basically province wide. And we achieved that. The ability to get down in deep about, perhaps, teaching clinicians to speak to patients in a certain way, or bringing the patient voice as relevant to each each clinician... it was limited. And so when we came back to our Lived Experience Advisors, as we call them, it feels problematic to say, "Yeah, I want your input. But no, I can't do that. And no, we can't do that either." And, you know, it's like... it's inappropriate.

Jennifer 12:53

Yeah, Noah is really thoughtful in his contemplations. There's a healthy dose of uncertainty, even inner conflict. And no wonder. It can feel pretty confusing to know that you have to fulfill an expectation, but you're not really quite sure how to go about it. Let's turn to Barbara now, she's one of the LEAs on the project. And I think it's fair to say she's a little less conflicted! She knows why she's involved and how she wants to be engaged.

Barbara 13:20

Initially, when we first started out back 10 years ago, or whenever, you know, as pioneers, nobody knew anything about using patient advisors. But suddenly, the hospitals all had to have patient advisors. And so it was like I say, it was like the Wild West . And no one really knew how to use a patient advisors. But the initial benefit was that the patient would, or the patient advisor, or family member, whoever was involved in that particular...like I was... let's just say I was on a committee forum. I've been on so many of them, you know, harm, and how to deal with people who have been harmed by the system type thing, ethics, safety issues, whatnot. And the patient advisors are very helpful on that kind of committee because they told their stories about being harmed by the system. And it helped the staff to get a different perspective and to keep themselves grounded in what exactly they were doing and not making it so technical and so protective. You know, it changed the whole atmosphere. And it was very helpful. But when you're doing research... research is not passionate. There's no emotion in research, you have a thesis, you do the work, it's just different. So the advisor doesn't control the project, they just contribute in whatever way the researcher finds is necessary. Once you've set out the rules, and you make sure that you engage your advisor and you tell them what's going on, and follow up and you do all that. There should be no obligation at all towards the patient advisor as far as taking on their opinions or, you know, keeping them engaged. That's not what I find to be productive.

Jennifer 15:18

So just to be clear, Barbara is contrasting patients volunteering on committees with being patient partners involved in research projects. Now, she mentioned research as not being an emotional endeavor. And certainly while there are many aspects to research that are necessarily more detached and scientific, I would say the individual experiences of patient partners varies quite a bit. We've met lots of patient partners, and also researchers, who find research work to be quite emotional. Emotionally rewarding, emotionally draining. People can be quite emotionally invested. Here's Michael. He's the other LEA alongside Barbara.

Michael 15:57

I think part of my interest in the whole thing was... it was really selfish. Because a number of years back I had a couple of injuries, I guess over 20 years now. And it's trying to make sense of it all. And I found that being able to just say, "well, this is what I've experienced. This is what I've discovered, this is what I've heard, this is what I've seen, this is what's happened to me." Not that it's right. Not that it's wrong. But that's my perception of what's happened to me. Maybe that can help somebody else. And that's kind of what it boils down to is just being able to share what I've seen. That was the whole real reason for me trying to get involved in this. And it still is.

Jennifer 16:39

So Michael thinks of engagement primarily from the perspective of someone who wants to contribute and share. And it's also an opportunity for him to make sense of his own experiences. Now, whether his input gets used or actually sways opinion? It doesn't seem to be of pressing concern to Michael.

Michael 16:57

I'm under no illusion that if I say, you know, something's blue and everybody else says it's pink... I don't expect everybody to suddenly come over to the blue side. I'm just an opinion, I'm sort of offering one point of view. And to expect whatever I say is going to bend opinion is going to shape policy.... I hate to say this, but I think it's kind of ridiculous. I think somebody going in with the expectation that "I will change policy"... No. You can give an opinion, you can say well out of, you know... "I feel this way" - a hundred other people might not. It's too much to expect [that] a couple of people are going to make that much of a difference. You sort of say your piece, and you hope that somebody's listened and, you know, take it into consideration.

Jennifer 17:45

There's a fairly clear and narrow scope here in Michael's mind as to how much influence he may or may not have. And Barbara agrees. As Lived Experience Advisors, they believe they're there to lend a hand in whatever way the research calls for. And to expect more, in their opinion, seems unreasonable.

Barbara 18:03

You know, as far as using your patient advisors, it's at a very granular level. Like you know, they'll send me a questionnaire that they're planning to send out to 20 doctors or whatever, like you were doing. And it's like, if you were a patient reading this would, how would you like to word it? Or what would you like to include in it or not include in it or, you know, that kind of thing. It's not so much that we're directly wanting to influence policy, per se. It's kind of like the liaison between the outside world and the research world - trying to sort of make sure that the research world understands where the LEA is coming from, and vice versa. And that creates a better

research project. Because you know, the doctors' letters...they were changed and rewarded so many times to try to make it more inviting for doctors to participate. And so, in that respect, Michael and I helped, I hope, and some of the wording as far as these letters are concerned or that kind of thing. It wasn't like we were sitting there telling our story every day. Or thinking we were going to change a policy tomorrow.

Jennifer 19:32

Okay, so maybe you can imagine that not all patient partners feel this way. One of the challenges we had in making this episode is that Barbara and Michael's views on how patients ought to contribute to a project are not entirely aligned with what we've heard other patient partners say. We have had other guests who have very high expectations about how their input ought to be used. Now for Celia, this is an important consideration to think about: where and how the patient partners themselves want to be involved.

Celia 20:01

When I'm working with anybody new, like a new student or a new person that comes to the team, you're also trying to figure out what their interests are so that you can make sure that you direct projects towards their work. And I think I took some of that kind of approach that I use in other areas - like, what are you interested in? What are the spots that you want to be involved with and seeing what makes sense. Because I think people can also be more engaged and more involved and provide more feedback on the areas that they're interested in and want to be able to delve in a bit more. So kind of balancing some of that out within the project as well, knowing there's specific times and places that it's very clearly for a patient, but then also knowing the people that you're working with, what are they interested in? What are their ways that they want to be contributing. So I think it's some of the same approaches that I've used in other areas.

Jennifer 21:00

So it sounds like there's some good alignment here between the leadership team and the LEAs. Celia and Noah, as researchers, are keen to provide opportunities for the LEAs to contribute in whatever way they want. And the LEAs themselves are happy to primarily respond to direct requests for feedback. But at the same time, Noah reflected on whether the required structure of having patient partners throughout the project was entirely necessary.

Noah 21:28

And so I think in an ideal world, a lot of what we could have achieved we might have achieved simply by consulting ad hoc with relevant groups of patients when needed, as opposed to having this kind of advisory structure on an ongoing basis when really the advice was difficult to operationalize. There was just so many constraints in this particular project.

Jennifer 21:58

Constraints can be helpful, of course, because they help to delineate what's possible and can help to focus everyone's thinking. But Noah's comment is more about whether the requirement to include patients was appropriate in this context. Perhaps a more focus group type of arrangement would have served the project better. But it's also possible they wouldn't have received funding, if that's what they initially proposed. It's a real

dilemma faced by projects that receive CIHR funding. Barbara does a really good job of teasing out these tensions from her perspective.

Barbara 22:29

And when you're doing research, I think it has to be very rules based. Like it can't be all over the place. Every research project should use their patient advisors in the same way. There should be continuity in that regard, because I think it's so important for researchers and patient advisors to be separate. You know, like, we always talk about them as patient partners, but we're not really partners in research. Researchers do the work. The patient... it sounds controversial, I guess... But my view is - my view only - that patient advisors, or Lived Experience Advisors is what I prefer to say... sometimes called patient partners in research... but they're not really partners. They contribute a great deal to the conversation, and they tell their stories, and they keep researchers focused on, you know, who they're researching, etc. But they're really not... we shouldn't be... we have to be at arm's length from the research to keep it legitimate. You know, I was on a research project where it was a systematic review. And, you know, they asked us to go through about 200 of these studies to pick out words, special words from each one. And, you know, that was a big ask, because that, you know yourself, that takes a long time to do those things. And so it was not the appropriate use of a Lived Experience Advisor.

Jennifer 24:14

So Barbara has strong views about how LEAs should be used in a project. She's not especially interested in participation for its own sake. She's also not particularly interested in being seen as an equal partner or co-researcher. But there is a lot of pressure to include patients in increasingly integrated and robust ways. I asked Noah how he thought about this, and how the team had planned for including patients.

Noah 24:41

I think, you know, to be honest, there was a lot of figuring out as we go. And you know, I don't feel that terrible about that to tell you the truth. Because it was emergent and that's the way it was. And, you know, there's learning in that regard. In this particular project, because of the nature of it, both the longitudinal aspect of it - you know, many, many years - and also the aspect where, you know, arguably the key users of the intervention being tested was not patient -, they were sort of the distal sort of, hopefully, beneficiaries... but the key users were actually clinicians. There was this emergent process of figuring out: how do we take advantage in a respectful way of the input and advice that we can get from these people?

Jennifer 25:44

So at the beginning of this project especially, things were pretty hard to pin down and plans kept changing. But the project has been underway for a number of years now. So I asked Celia: what were the actual substantive pieces that LEAs were eventually able to support?

Celia 26:00

So there's three kind of areas that I think up to be able to answer that. So the first is being the very obvious piece that we mentioned - where it's recruitment material, it's focus group questions - that very much patient facing piece. So there was a lot of contributions to those helping to write letters, etc. The next one, which is where I think there was more learning on my perspective, that I won't necessarily... like, it doesn't change the

results, but it changes the way that I speak about the results. So being able to talk about these complex concepts in a way that is understood and is clear. Like, how can I present this information in a way that somebody can then discuss, think about how do I tell that story, and being able to tell that story to people that know enough about the project to be able to understand what it is... but also don't know the details of it. So they can still be able to say whether it makes sense or not. So we did a lot of calls of presenting back preliminary results, seeing how something got interpreted. So there's one example where we presented a bunch of quotes from physicians. And the way that the others read those quotes was very different than the way that I did. Which was really, really interesting to be able to know that that's the way that that quote, could be interpreted. It doesn't necessarily mean that everybody will interpret it that way. But to be able to have a different perspective on reading exactly the same words, and knowing what comes out of it. So that I'm able to keep that in mind when I'm presenting, when I'm writing these pieces to make sure that it's clear, and acknowledges some of the other questions that might be raised by the same point.

Jennifer 28:05

We are going to carry on with Celia. But something occurred to me as I reflected on her comments, and it's that, well, in this project, there were only two Lived Experience Advisors. Now, is that sufficient if what you're looking for are different perspectives? Perhaps. But I wondered how Michael felt. If he felt pressure, even just within himself, to somehow represent patients as a larger group.

Michael 28:31

Well, I would hope that policy changes, policy adjustments, would be done by a much larger group than just a few individuals. And that would require a lot of research to, you know, to make such changes. I don't know how to address that.

Jennifer 28:49

Yeah, it's a valid concern with no simple answers. Or maybe there's just many possible answers. Okay, back to Celia. She contemplates the value of including patients - not just in gathering data and information, but in the discursive encounters where perhaps new ideas and perspectives enter the mix in more intangible ways.

Celia 29:08

...is really just around the conversations, like having all of these questions that got raised all the way along. And just Emily and I chatting about it is one thing - but being able to know all of the different ways that people want to be involved, previous experience, knowing what you're thinking about, has informed the way that I do other work and other work with patient engagement, to be able to always question and always come back to making sure that it makes sense, that it works for that person, for that project. And not just because it says you have to do that in the funding application, but how can you really make that beneficial for the people that the project is supposed to benefit?

Jennifer 29:12

Okay, so we've spent a bit of time talking about the value of patient perspectives and the role of Lived Experience Advisors in this project. But let's pivot slightly and think about things from a slightly different angle. The LEAs put a lot in, but what did they get out of it? For Michael, it's not only personally meaningful to give

back and make sense of his own health related experiences. He's also on a bit of a mission to counter some of the public messaging around opioid use. As you'll hear, Michael has lived experience with opioids, and feels that public perceptions are a bit one sided.

Michael 30:34

I've become in my little way... I don't know what the word is. It's not upset, it's not angry... Disappointed, I suppose. In the news media, about opioids. I'm a great believer in the medical profession, in the pharmaceutical, because they've given me a life back. And when I see the news media get on about opioids and the evil of them and everything else it makes... I just go nuts. So I've actually taken to writing letters, writing notes. I've talked on a couple of radio pieces about the benefits of opioids. You know, take them as prescribed, they're not a bad thing. They're not an evil thing, they can really help some people. And I think the general population needs to know some things like that. And again, I never intended it to be that, but it sort of is a way I seem to be going with things. It's just trying to educate people who don't know that. Here's something that, you know... I'm just a normal person, nothing special. And I got some issues. This is a drug that really works. It's not an evil drug, it's not a bad thing. And I think researchers need to hear that, too. You know, it's the smaller groups that are able to, you know, make the news media, influence more policy, influence people, influence my neighbors who don't know anything about the subject. You know, they hear all this bad publicity about it, and they - we - start to form opinions based on one side of the fence. They need to hear the other side.

Jennifer 31:58

In putting this episode together, we thought this was a really important testimony to include. I mean, sure, it's interesting to hear people's stories. But it's also important to remember that patient partners, or Lived Experience Advisors, well, they have their own opinions and motivations. And they're not always disclosed in such forthcoming and honest ways. And Barbara also has her own motivations for being involved.

Barbara 32:24

I'm a people person, and I just, you know, I really enjoy the meeting all kinds of people and getting their perspectives and talking and sharing and all that other stuff. That's just who I am socially and professionally. And yeah, I get a lot of benefit out of it. I think that I try to give it value to my, you know, invitation that, you know, I respect the invitation, and I try to give value to what I'm being asked to do. But I think I get a lot more out of it than they do in a way. So I've met some really good friends over the years through it, and opportunities also to contribute to some things that are important, like this project. It's important stuff. And even though research sits on the shelf for like 10 years before somebody remembers it, occasionally something happens with the good research, and, you know, so you have to kind of keep optimistic about it, and keep trying and including as many people as you can. And I find the experience really good. I mean, there have been some committees that I've had to say sorry, I'm busy - because it also has to be a good environment.

Jennifer 33:54

So after these discussions, I was left thinking about the fact that here we have two very experienced and mature advisors with particular preferences and expectations about how they want to be engaged. And we also have the researchers who are not only trying to just get the research done under challenging conditions, but they're also feeling their way through and they're not 100% sure about how to appropriately engage the LEAs. As Noah

says, they're figuring things out as they go. Now, this is the kind of mix that could make things go off the rails pretty quickly. But it didn't, and that's due in large part to there being another person who bridged the two teams. And that's Emily Nicholas Angl, usually co-hosting with me. In addition to her work on the podcast, Emily is also an independent consultant and researcher who has worked with many Canadian institutions and organizations on their patient and family engagement initiatives, including hospitals, government agencies and research institutes. She was hired into this project early on to support patient engagement. So we're going to hear from Noah and then Celia, sharing their thoughts on Emily's role.

Noah 35:03

So maybe we start by saying like, in my mind, Emily was our... I think the name was Lead Patient Partner. But, in my mind, she was like the intermediary between the research team and the research mission and the patient partners and Lived Experience Advisors and all that they could bring to us. That kind of adaptation over time was something Emily really took on. So we should reflect back the question to her about what we learned over time.

Celia 35:37

For me, having Emily being that connection was a major factor in the work that was done to be able to have somebody that could ask those questions, because I don't feel as a researcher, I could always, especially at the beginning, wouldn't really know what questions to ask or know what, what to make of those, those meetings and having somebody that could be there, lead those discussions, making sure that each person was involved and comfortable. And once we got a bit more into that groove, I think I got a bit more comfortable with being able to acknowledge some of those, those bigger questions at the beginning and getting a bit more of that that structure going. And also knowing that there was somebody there that could debrief that could follow up on ideas and making sure that somebody was okay, especially after, if it was a somebody was talking about an experience that was particularly rough, it may not have always been appropriate from my side to be able to follow up, especially at the beginning. So having that somebody that was able to help navigate that process was a was beneficial for me. And I think it was beneficial for Barbara and Michael as well.

Jennifer 37:04

Both Michael and Barbara indeed found Emily's role beneficial. Michael shared how important it was for him to establish trust.

Michael 37:11

I found it great. I found everybody very supportive. We talked about before, way back in the beginning, you talked about, you know, confidentiality, keeping things contained, and that put me at ease. Yeah, again, I just keep going back to, if anything, what I've experienced... I mean, heck, in life, Barbara too, I mean everything...it may benefit somebody else down the road. And that's the whole... as far as I'm concerned, that's the whole key, you know?

Jennifer 37:40

In this project, Emily is playing a multifaceted role. She's the lead patient partner. She's a bridge between teams. And she's also been instrumental in developing and supporting the engagement strategy for the overall project. Lots of having to navigate relationships and interpersonal dynamics. Okay, but what about their actual subject

matter contributions related to the research? Who decides what is relevant, reasonable and actionable? I asked Noah.

Noah 38:08

I think ideally, it's the PI [Principal Investigator]. I think in reality in this project, it was sort of distributed. By which I mean, you know, Emily played a big role. The research coordinator on the relevant streams of work played a big role. And I tried to give my two cents when I thought it could be helpful. To be honest, I'm not sure there's a right answer. There's multiple ways to go about research methods to answer a given research question. And, you know, depending on your approach to the world, there can be multiple right ways to do it. Maybe that's the case also for patient engagement.

Jennifer 38:51

Right, so a bit of a moving target. And it sounds like context matters quite a bit. Celia also commented on the value of the role of lead patient advisor, particularly when research teams don't have a lot of experience collaborating with patients.

Celia 39:05

I am seeing that kind of role coming out a bit more as one of the ways to be able to also potentially make people a little bit more comfortable in engaging in research when they know they've got a main contact point that knows what's going on, that knows how to be able to do that. And lead people into the work. And as somebody gets more comfortable with that role, that bridge person may not be as necessary or as needed, if both lived experience [advisors] and researchers all have done this work a lot before. Then that bridge person may not be as required. But especially in projects where there's a bit less experience, I think that role is really beneficial.

Jennifer 39:50

Celia went on to wonder how the process might be improved.

Celia 39:54

I'm hoping that there can be more recognition of that development that's getting people connected but also acknowledging that that's not always possible. So what are some of the other approaches that we can make sure that people's perspectives are being included in a way that makes sense for them, for the project, for the work that's being done, without just trying to fill in the box that says, "you must have this."

Jennifer 40:21

Noah also wondered about ways to engage not only patients, but also other stakeholders in more relevant and appropriate ways.

Noah 40:29

It's inappropriate these days to say like, "there are areas where patient input is less relevant." But surely there are areas where patient input is less relevant. And, you know, some aspects of this project probably met the one end of that spectrum, and other aspects, the other end. And I think one of the hard things about managing the patient engagement aspects of the project was figuring out what to do with those different ends of the

spectrum. I guess my hope is that we might think about all the relevant users, as it were, in that process. So in my research that's predominantly clinicians, but not "just." I mentioned that case earlier, where clinical managers played a huge role. Moving forward, I hope we can really engage with like, "why are we doing this?" And help support PIs to do their work in a way that aligns with the answer to that question. We don't want to tick boxes. We ought not to just tick the boxes.

Jennifer 41:45

We'll finish the segment with Michael, who offers some insights into his own journey as a Lived Experience Advisor.

Michael 41:51

I am proud to be part of this group. I really am. I've come away from a couple of sessions a little emotional, always with changed perspectives. And that's a good thing. You know? I have a friend of mine who is big on youth recidivism. And I heard the other day that one lawyer was saying that especially the male brain isn't fully developed until about 25 years old. And I've always been a very law and order guy! You know, "string 'em high" kind of thing. And, you know, listening to all these the people last few years has changed me a bit. And that's a good thing. You know, and I find the same thing with this, all the people here in the group. I go in with one... I'm honest with my opinions, what I've seen, what I think I've seen, you know... but when I hear other opinions, other people talk, I go, "Okay, that's a valid point, I should maybe think about that more carefully." So it makes me grow. It makes me into a better person, I hope. A little bit at a time, a better person.

Jennifer 43:01

So typically, at this point, you would hear Emily and I chat over the themes and insights inspired by the conversations with our guests. But instead, I actually interviewed Emily as a guest. She had a chance to listen to the recorded conversations with the other team members. And then we sat down to talk it over.

Jennifer 43:22

One thing I'm curious about is after you listened to all four of them together, talking, do you have any sort of overall comments about what you heard?

Emily 43:32

Well, one was sort of how straightforwardly Barbara and Michael seem to approach the engagement work, and how kind of sure they felt in their own purposes and their own wants to engage and feelings about it. And then how many questions we as researchers had. And I'll be transparent: Barbara also raised that with me having read the transcript herself, which was like, "I didn't realize how much people were confused by all this and like, how much thinking was going on behind the scenes." So that certainly was raised for me. And I think the other thing that inevitably was raised is: did I do a good job of this, given my own questioning, my own conflicts about the purposes of engagement...? And yet having real people involved and facilitating it. Where did I sit with how it came out? I resonated with all of it. But I didn't feel connected to either side entirely. So I certainly felt somewhere in the middle. I was also left with how ambivalent I guess I was feeling about things.

Jennifer 43:41

How did it sit with you to hear Michael and Barbara talk about how pivotal your role was? Like how important it was. And then also to hear Noah and Celia talk about - for different reasons, I suppose - how important both your role was and also, they felt that there was good value in having LEAs involved. Did that resonate with you? Or did you feel like, "Yeah well, I mean, maybe they would say that but I don't think so" or did it validate something for you?

Emily 45:13

Absolutely. I think I was sort of grateful for how thoughtful they all were. Certainly though, it didn't fully satisfy my... as much as I thought everybody felt satisfied maybe with how it went and felt good about it... it didn't fully satisfy my own internal conflicts about whether what I felt like the purpose of improving the project from the perspective of understanding or improving things for patients or making it more patient centered, or making it so that patients had been included... some of the loftier goals of engagement. Those all still feel to me like completely inaccessible goals anyways, regardless of what you do with the project. But I think particularly because there's also no sufficient, I suppose, it sometimes feels like in engagement, where there's always more you could have done. And there's always questions about whose voices are there. I still am left with the idea that we had two individuals - and we talked about this - shaping a project, which may have impacts for other patients. And although we did do other, as we called it in our paper a "mosaic approach" where we talked to other councils and I looked at literature around language used in material, particularly aimed at people who had dealt with opioid use disorder, which had been developed by people with lived experience... I tried to use all these other approaches. But I think that feeling of insufficiency always lives within me.

Jennifer 46:57

Having known you for a while now, like I know that your brain goes a mile a minute, right? So in a project like this, where there's a bit of like that nebulousness, and there's a lot of moving parts, you're trying to, like contain something that's not containable. Your own self doubts and all of that. There's a kind of missing piece around just really appreciating your own abilities in that space. I think the fact that they all found it successful speaks volumes to how you were able to manage. And maybe it's also like, actually managed, in terms of your skills and your understanding... but maybe it's also because of your transparency and your accessibility and the way that you can convey your own uncertainty that maybe makes people feel safe. So there's a bunch of things, I think, that contribute to why they would all feel like it's successful.

Emily 47:57

Yeah, absolutely. Some of our, well everyone's best quality or qualities come with multiple sides, which you don't get to be accessible and thoughtful and... if I'm described that way... and not somewhat overly, perhaps conscientious and anxious...

Jennifer 48:15

Does this come up in other realms of your own, either working life or personal life all the time? Or is it only if there isn't a lot of structure? And you're sort of left to kind of figure it out? Is that where this gets heightened?

Emily 48:30

All the time.

Jennifer 48:31

All the time? So even if there was a manual that said, "This is how you do it. This is like a, b, c, d..." you would still be questioning your own...?

Emily 48:42

Okay that's fair. I mean, like, let's say I had to just fill in a database with numbers... I like math and calculus, I tutor calculus. And when I tutor that I'm not thinking, "Wait, but should I have approached it [differently]..." but I will have the meta aspect of thinking about the way I taught or all of the options for how I approach a person and what comfort level they felt. And I've always probably been overly concerned with how other people feel. As well, I think, by nature of this role - something that makes it distinct, and that is an interesting aspect of engagement generally - it's a lot of people who do that engagement work come because they are experienced. I have experience with health research. And my background is med-sci. But I really got into this because I had been an engaged patient and I had lived experience and I had all this stuff. And so I had this other - to use the word meta, again - meta level of expertise, perhaps which was, I had been in a lot of engagement. So I had the lived experience stuff, but then I'd also done and been involved with a lot of engagement.

Emily 49:51

So just through that lived experience had a certain set of skills, or at least knowledge. And so when I come to do this kind of work, it's personalized in a way, perhaps that, like I said, when I tutor calculus or when it's just about my knowledge base, it's not about who I am, what I've experienced, but by definition... well, maybe not by definition... but one of the beneficial factors of me being in this role is that I am clear with people that I've had that lived experience, that I get what it feels like, or we can share things about our personal experiences. And I'm not not talking about my own health. I'm quite open about the issues I've had with my health and things like that along the way. And that is part of why I'm there. And so whenever that's the case, I think navigating that ends up being a lot of levels of thought. And for your own protection too, and that being a lot of levels of thought.

Emily 50:49

Because you're, in a sense, using yourself to help other people feel better using your experience, and also trying to recognize how that benefits you or what the therapeutic effects of that are, and why you want to do it, and also putting certain boundaries up, so that you're not taking it too far. But you're also and so I think, you know, just this type of work has that built in. I'm sure some people maybe don't think that way. But at the same time, it sort of feels like it's a delicate dance. When I used to do, let's say "user centered design" work, that felt much less fraught, in the sense that it was clear that people were being interviewed or talked to in a focus group. Like, this is why they were there. The idea was to shape that one piece of material and nobody had any feelings about developing relationships and having feelings of partnership.

Emily 51:42

So I sort of flipped there. But a few things I think are built into a few vaguenesses and complexities are built into this work. So it's me personally, but I also do think to an extent, to navigate this work - and I think this is what we tried to get in to the paper that we wrote so hopefully complement this - is that was one of the discoveries we had along this. This was the first time I heard articulated some of those things or spoken aloud with the group about what those things that felt conflicting, or sometimes just wrong or uncomfortable. And we discussed them and everyone had quite different thoughts often on it, whether somebody should be compensated, or what it meant to represent a group or whatever that was - it was so beneficial to us as a team to actually learn what everyone else felt. And I know what ameliorated for me this issue of feeling like, oh, it's being unsaid. It's like, I'm lying. Like, there's like a ruse going on. And they don't know that I'm just kind of like... I guess we'll just do it anyway!

Emily 52:51

We talked about it, and everyone knew that I was trying to muddle through, and that they were kind of muddling through with me. And the process of discussing it was part and parcel of what made our engagement work feel more meaningful. And so we developed these kind of almost feel like it was like a journal club or thought sessions where we would check in about everything update and maybe do a task. But then we set aside time about, you know, what does it mean to evaluate this? Or should we be doing formal evaluation? What are we evaluating? Because it's just us here making these decisions, you know, what does this actually represent? Are we lay people, are we patients, and who is missing and all of those things. And even just conversations that were brought up by the patient partners, or the, excuse me, the Lived Experience Advisors, about how they felt about generally the project so far, and that would lead to sort of some discussions about... So that space, I would say, was certainly not wasted and something I advocate for more now in a lot of the work I do.

Jennifer 54:02

Is this unusual for you? The degree of dialogue that you had within this project?

Emily 54:10

For sure. I mean, generally, you're just not afforded the time. Because, as we've talked about before, often it's very task oriented, this work. And because people are kind of - it's not volunteering their time, certainly - this is not what they do. So if you involve them, talking about a meaningful engagement, what's the impact of what you did? Having agendas, you're working with researchers who usually have very tight timelines too - so to just book discussions... I'm sure people do book discussion meetings on topics, but I think in my experience so far, it's usually been on the subject matter. So like: Let's have someone come in and tell us about drug policy or let's talk about, I don't know, behaviour change theory or something like that, so that we have better understanding of the material.

Jennifer 54:58

Does it feel like um... well, I'll give an observation maybe. And it's that a lot of the talking that you've just described, seems fairly self-referential. Like, it's its own little feedback loop around engagement. It was actually like... I don't know that this will be in the podcast... but it wasn't entirely clear to me that even Noah and Celia felt... I felt like they were both kind of grateful that there was something to say about it, which was, you know,

"the dialogue" and "Emily" and it was all like, "everyone did their best" and "we're learning as we go". And it's like that's sufficient. It's just a lot of talking about talking about it. And I don't... I still don't quite get it...

Emily 55:49

I should clarify! I'm not saying like, "every week we should sit down and have these discussions." But we incorporated them, included in meetings, or when it was sort of relevant to something we were doing. And I don't think that always those kinds of conversations... and some of just the logical inconsistencies had been more put out in the open. So it was less of like, "let's just ruminate on it". And more of just like: huh, actually interesting from a pragmatic point of view like that, actually, yeah, logically doesn't make sense. Or maybe we should think about that. So I think that was helpful. I also think there were two tangible outputs from what we did from the work. And I think, like you said, everyone was grateful for that. We definitely met all our deliverables. And the only thing that we couldn't do, which was the patient interviews was like, logistically impossible. Not for lack of trying. Yeah, and we shaped some things. And you know, everyone felt satisfied with that.

Emily 55:54

But I completely take your point and agree and would have to add it to my, like, fourteenth level of meta thinking, which was: I being very self-centered about this whole thing. Like making it about the way I'm thinking about it, or my own concerns. Or I had a lot of times where I'm like, "Emily just get on with it, this is a lot of you just reflecting." So there's somewhere in between.

Jennifer 57:08

Yeah. And one thing that stands out in what you're saying - and I think I hear it, otherwise too, so it's not just you - but the sense of the building of trust, the community aspect, trying to create a kind of a bubble of sorts, where people feel like they can share and not feel judged and all that stuff. It seems slightly incongruous to have that perspective on something that, for Barbara and Michael in this project, they both talked a lot about the practical aspects that... you know, they weren't sitting around telling their stories, they were there to help and to support what the researchers wanted and to vet things and look things over. So where do you see this all this dialogue fitting in? It's dialogue and also just the effort that you would put in to build some sort of sense of common purpose? Is that even necessary? Like, how is this different than some other just task within the team? Why would trust be an important thing to build amongst the Lived Experience Advisors, as opposed to the whole team or between researchers or... you just don't hear talk about that a lot.

Emily 58:24

I do feel like it was about the whole team. So it was about how we all interacted. I didn't mean to imply that it was trust only between the... it was how we all work together, and I'd say that developed over time.

Jennifer 58:35

And is that because it's a kind of interdisciplinary thing? Like you've got lay people, you'd have to sort of create a container for everybody, is that part of it...?

Emily 58:42

Yeah, like, I think everybody had to feel comfortable having the kind of conversations we were having and working on something together. And there were tense moments where people totally disagreed. And unless you have some sort of rapport, I think, or having to have chats with those people before... it can be difficult. Like if you just invite a researcher in or a team member in just for that one conversation, and then the way they speak... and like it was helpful to have everyone kind of be understanding. But also, I do think the key part to be fair though, is the way that the Lived Experience Advisors feel. And I just think that's like somewhat just an ethical or moral onus. Which is, here are people who are coming and talking about something very personal. And that was the other part to me. Like, it's not benign, if you don't do this well. And we've talked about this on the podcast. And so that was always weighing on me, which is like: it'd be one thing if like, we just have to get the tasks done and everyone feels fine about it. But I didn't want to sit with like: Yeah but... they might feel okay, but I know that they just came to that meeting and told a very, very personal story about something that happened to them or their own health issues. And I know from my own experience, they're gonna leave and have to sit with that and the other people there didn't share anything.

Emily 59:55

And I did feel that part of my task was to be like: No, I'm going to try to think about this a bit outside of that little box of churn-out and impact, because part of the reason I think it makes it sustainable is to consider those kinds of things, I guess. And I think I talked about it last time a bit, which was there was a sense that I had not fulfilled my purpose because the Lived Experience Advisors didn't feel that level of care about it. They actually felt like: We shouldn't be at every meeting... no, I think there's certain things we should be involved in and other things we shouldn't be. And they're the experts, we're not. Like even Michael says, you know, I wouldn't think that just because I said something, it should be incorporated. They had a very distinct type of advisor perspective, which isn't my experience with all of the patient advisors I've worked with. And I somehow felt like that was a failing on my part. Like I hadn't totally explained why we were aiming for partnership and why people were supposed to all feel equal and kind of feel the need to be compensated because... and it wasn't supposed to just be like: I want to give back. It's supposed to be because you have an expertise here. And as much as I was questioning those things myself - whether those were true - it did feel like it was something in my role that I was supposed to instill.

Jennifer 1:01:19

How do you think you formulated that expectation for yourself? Because it probably didn't come from Noah, right?

Emily 1:01:25

No, I think because of the way that mandates for patient engagement are described. In terms of how patients are supposed to be involved at every level, and they're supposed to be partners. And it's not supposed to be that you always defer to the researchers, or they are more experts. Or, you know, as Barbara sometimes said, you know, we shouldn't even be paid, because we're supposed to be arm's length, we're supposed to not be kind of part of the team in that way. And that is not generally how true partnership or having patients on the team is described - the caveat there being you are supposed to take your lead from the patients themselves or

the people themselves. But at the same time, it's still supposed to be that, I think, that somebody there is at that level. That even if you have people at that different... you have differing levels. But somebody is a partner.

Jennifer 1:02:19

...what if that person was you? [crosstalk]

Emily 1:02:20

...and the argument could have been me. [crosstalk]

Jennifer 1:02:22

Right.

Emily 1:02:23

And I think that's how it was framed in the grant proposal in a sense. Or I was the Lead Lived Experience Advisor. But then again, like my role was not really to do much of that. And, you know, to be honest, part of that was because I felt uncomfortable being a Lived Experience Advisor or patient partner. And I think that was because of my own questioning of whether we should have things like... whether being a patient partner, and particularly me... and it's going to sound self-righteous but like...me, in my own position, knowing who I knew to get on that project, and how I was brought on, that I would be a patient partner on a project for people with opioid use disorder and antibiotic stuff - where I have taken opioids, I've had a total hip replacement. I have a lot of experience with antibiotics because of that actually, and because I also have a kid. But, you know, I certainly have a certain level of knowledge of the research and the team and the people and was asked because, you know, I was already connected to Noah and my role was not going to be sitting there and sharing my experience to form the patient perspective. So it did feel wrong to be called that. Although I think some would disagree that that's what I was.

Jennifer 1:03:45

Yeah. Would you do it again? If Noah said, Hey, I know we're... [fades]

Emily 1:03:51

No, no, no, not even a question. I would take on a slightly different role. I just wouldn't facilitate it. But I'd be happy to talk about his plans for engagement or look strategically at something but I wouldn't facilitate it.

Jennifer 1:04:05

If another researcher said: Okay, I get it, it's not going to be you. But how can I be a better PI for the next one that comes along? How can I better set this up so that we do a better job of either supporting the facilitator or supporting the LEAs. Do you have any initial thoughts on what you would say to a researcher who's trying to learn from this?

Emily 1:04:32

I do think it's so contextual, which is a bit of an out for the question. But I mean, one thing that's really tricky is I think the infrastructure and general limitations of funding and payment options and creativity that you can do within how you might want to do something are just so limited by the bureaucracy or the system that you work in. So it's not a lot of necessarily what I would say to Noah but sometimes it's like: can you change the finance department so they pay this way? Or so that you got more involvement, like you could pay people while they're doing the grant proposal. Because I do think having had more thoughtful time to connect with other organizations about engagement work they were already doing along the same lines or what they knew and who, which communities were kind of working on something similar, interested in something similar. So we didn't necessarily have patient partners but we had like partner organizations or people with similar interests who had interested people. As opposed to going and finding individuals who would be on the project. But that takes a lot of foresight and a lot of pre planning. And so that's difficult. I understand from a PI point of view. And I think the other reality is, is just to bring the bar down a little in terms of projects that are instigated and conceptualized by, you know, pretty hardcore or formal researchers - to be patient-centered and to be partnered. And, you know, I think Noah says it well, explained it well, when he talks about [how] this is a physician facing project about something like implementation science and he talks about the complexity of behaviour change theories, and all of these things. And I do think some things lend themselves to really clearly having a partnered person who's been advocating for something or who has a shared interest. And then, you know, feeling like: well, we need patients on this project because it's a SPOR project.

Emily 1:06:24

So I think I would have been a bit more thoughtful going in and I won't pretend that I didn't have any involvement in the grant stuff, either. You know, the partners were involved already - patient partners - but I did try to think through where we would involve patients. And I think where I thought we would involve patients also got completely changed, because just the nature of the project totally changed. So I had a lot more thoughts, we had a lot more thoughts about just doing focus groups or having interviews, and that's where I feel like there is a lot of benefit, or there is a lot of ability to learn from a much broader group of people. And so I felt good about that. But then that wasn't able to happen. So part of it was that we had to rely heavily on these patient partners in a way that I don't think any of us had intended, as the sole way of getting input.

Jennifer 1:07:08

I think that was part of Noah's reflection too, towards the end when he said something about it might have made more sense, even in this project, to [crosstalk] to have different sets of stakeholders involved at different times. And to just convene people as needed. Like if you need feedback on something, give feedback on something.

Emily 1:07:30

Yeah. But that wouldn't have got you the grant either.

Jennifer 1:07:35

Well, that's a good note to end on. Seems like most of our episodes end in a sort of catch 22! Our hope is that you may have heard some thoughts or perspectives to help inform your next research project. Or maybe what you've heard has shed some light on previous collaborations. Either way, it's always worth considering how different people on the same project team reflect on their experiences. There can be a lot to learn.

Jennifer 1:08:01

Thanks so much to everyone who appeared on this episode: Noah, Celia, Barbara, Michael and Emily. The interviewees also want to recognize the important contributions of the many others that made this research project possible. In particular, Michelle Simeone, who was integral to the engagement work.

Jennifer 1:08:19

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