

Matters of Engagement podcast

Episode "Hiring People with Lived Experience, with Katherine Dib and Katie Birnie of SKIP"  
SKIP's approach to embedding patients, and considering the term 'lived experience'

*\*Correction: In this episode we misidentify SKIP's funder as CIHR. SKIP is funded by the Networks of Centres of Excellence.*

00:07

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

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Emily: And I'm Emily Nicholas Angl.

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Jennifer: We've been keen to do an episode on 'lived experience'. It's a term that's frequently used, and there seems to be a common assumption about what it means and what it signifies. But at the same time, it's rarely defined or interrogated as it pertains to patients and patient partners. It's a good point of inquiry for us, because it's often the basis for justification as to why patient partnership is so valued. Patients possess this all-important 'lived experience', which most experts don't have. They have skills and training and education, and typically have experience only from the treatment side, not the patient side.

01:00

Emily: So yes, it's a rather obvious statement to say that patients and experts have different experiences and perspectives! And we don't find that problematic. What we do find interesting is that the term 'lived' experience seems to mean something significant, beyond just using it to describe a person with a particular health background - and that it does some kind of extra work when used in particular contexts. It's become shorthand for something, and we're curious about what that is.

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Jennifer: Getting a better handle on how the term 'lived experience' is used is one of our goals for this episode. It's less about defining the term and more about trying to understand what it signals and what it accomplishes, and for whom. But we're going to save that discussion for later in the episode.

01:48

Emily: We thought it would be helpful to first set the stage to hear from an organization that is known for its strong commitment to both engaging and embedding people who have lived experience. The organization is SKIP: Solutions for Kids in Pain. They're a CIHR-funded scientific network that translates and disseminates research about pediatric pain. The high value they place on lived experience permeates everything they do. And we wanted to hear from them - not only why they think lived experience is important, but also to find out how it shows up and, let's say, gets utilized, within their organization.

02:29

Jennifer: After our interview segment with SKIP, we'll shift into our own discussion about use of the term 'lived experience' and consider it in the wider context of patient engagement and partnership. The term is so widely used, and it's used in such a way that it suggests we all know what it means. And we all know why it's important and that we all agree it's necessary. Which to us is a good flag that we should maybe hit the pause button and talk it through! We think there's value in clarifying the term, understanding what work it's doing, and investigating some of our assumptions around it.

03:06

Emily: Let's now hear from our guests. Katherine Dib. She was hired as SKIP's Patient Engagement Coordinator, a role reserved for someone with lived experience of pediatric pain. And Katie Bernie, SKIP's Assistant Scientific Director. We wanted to get both perspectives: what is it like for Katherine to work in a role that has been designated for someone with lived experience, and from Katie's perspective, why it's so important for SKIP to create and fill this role. First, here's Katherine, explaining how she first came to work at SKIP.

03:43

Katherine: Hi, my name is Katherine Dib. I'm the Patient Engagement Coordinator for SKIP. I actually was working on a patient engagement and research project with our now Assistant Scientific Director, Katie Burnie. That's how I got introduced to Christine Chambers, SKIP's Scientific Director who asked me to become a patient partner for the network. So I did a few activities with SKIP...[including] the launch event in Halifax. And then when it came time for a one-day conference event, Erin from our team reached out to me over the phone to see if I'd be interested in just attending as a patient partner. With a little bit of chats back and forth, she decided it would be great to create a role for someone with lived experience to coordinate all of SKIP's Patient and Family Partners. And I have to say I was so excited because right off the bat, she said they would do everything they could do to be accommodating. And up until then I had had a few jobs in university and I had to give them up because of my pain. So for once, I thought it was very interesting that I was being hired for my experience with a pain, instead of in spite of it.

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Jennifer: That was Katherine - and now here's Katie with a bit of background on SKIP.

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Katie: My name is Katie Birnie. I'm a clinical psychologist by training I'm an Assistant Professor in the Department of Anesthesiology at the University of Calgary, and also Assistant Scientific Director for SKIP. And I also do a little bit of clinical practice as a psychologist at Alberta Children's Hospital, primarily with youth who are living with chronic pain conditions of some sort.

So there's an incredible amount of research, evidence and knowledge about how to manage pain well for kids, from procedures to chronic health conditions to surgeries. But there's a huge gap between what families and parents actually know, and also what health care providers know, and even some of our health policies. So we are a network across the country who do all of our work in partnership and in

partnership with other organizations, and with people with lived experience, to really bridge that gap through any sort of collaborative activity.

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Jennifer: So let's now hear from Katherine about the role of Patient Engagement Coordinator.

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Katherine: They were kind of starting SKIP from the ground up and looking for ways that they could do better, and better engaging people with lived experience. And that included hiring someone with lived experience, rather than only having patient partners, which, again, it's great that they have patient partners, because not everyone even does that portion!

I manage the Patient and Family Partners. So that seems like a small role, but we actually have over 80 patient family partners who signed up with us. So I manage the database, all of their information, I look for opportunities to engage them. And I also facilitate ongoing relationships between the project leads, and the patient family partners. Most of my role is making sure that they feel valued and appreciated, and checking in with them, checking in with the project leads. I don't get into the nitty gritty as much with the project. So I do find there is a balance of making sure that I'm up to date on what's going on in projects, but also not being inundated with emails - it's more so making sure that everything is going well on the patient partner side.

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Jennifer: Katherine's job of Patient Engagement Coordinator requires a good amount of organizational skills. But it also requires strong communication skills, and a degree of diplomacy. We asked about some of the challenges or tensions she encounters.

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Katherine: And I find this can be a problem sometimes... Patients and families will give their opinions we'll ask for their advice... and when it's brought to the organization, it actually doesn't get done. So it kind of feels like they're wasting their voice, which I don't feel like is great for them. I think that it's great for people to feel like we are asking for something from them, and we are actually putting it into practice rather than wasting their time. So, but, also being said, being with an organization that I think is very, very open, but it is national, and we have a lot going on. So there's times when it's not as easy to put something into practice. So I'm sort of that that person in between trying to make sure that we're taking their advice and trying to put into practice the best way we can. But also understanding that it's not always possible, if that makes sense. So it is kind of difficult being that middle person.

There have been times where I've had to sort of intervene, just to make sure that they know what's going on. So I always want to make sure that they're being updated properly. And I do find that with patient partners it's great, because I've never had an experience where at the end, they're like, "Oh my god, that was terrible" - like never! It's more so, like, as we're going on, check-ins here and there, I realize that we can be doing some things better.

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Emily: Katherine is obviously a good fit for the role. And we wondered to what extent the job was created perhaps with her in mind, given that Katherine had already been working this SKIP as a patient partner. Katie describes how the creation of this role is definitely aligned with SKIP's overall plan, but also included a bit of serendipity.

Katie: You know, Katherine, her being in this role... I mean, it was a combination of right person, right place, right time, in a lot of ways, right? She had had experience with patient engagement before, you know, was connected to our team or network in some capacity through the work that she and I had done together. The idea of having someone with lived experience in that role, as opposed to someone without, felt really important, I think because of the approach that SKIP is taking. I think some of the unique capacities that someone with lived experience can play in supporting people or coaching people or identifying the right people to engage in different activities that SKIP might be doing... also the opportunity to educate partners who we might be working with or team members within SKIP about some of that lived experience as well... I think it goes both sides, right? I think Katherine's role supports people with lived experience who are engaging in our work. And I think it also supports us as an organization, our other team members, and our partners who we work with about engaging with people with lived experience as well. So I think there's particular things she brings to the table as someone with lived experience that not everyone can.

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Emily: So, the fit was good. And Katherine brought the right sorts of experiences with her into the role. But like with any job, the specific responsibilities required specific skill sets, for which SKIP provided training, as well as clearly outlined expectations.

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My training came both in the informal and formal sense. So I learned a lot about what it means to be a patient partner on a previous project I did with Katie Birnie, and she did a great job introducing me to the world of patient engagement - some of its challenges, its benefits... and then transitioning into the Coordinator role was easier than you would expect, because you learn a lot of those skills being a patient partner. So skills like team building, presenting, collaborating with diverse stakeholders, relationship building, etc.

So it helps that SKIP also didn't put me in a box. So they helped me learn by leading a meeting. They helped me learn by writing messages to patient and family partners, and then also being there to support me and help me when I had questions. Like you would expect, I guess, for any employees? So making sure that you're there for them, but also giving them the freedom to learn on their own.

11:52

Katie: It is a job, right? So in terms of identifying, you know, there is a formal job description, there are all of kind of the formal pieces that would be in place for an employment - a part-time employment position- in this capacity, both on the side of the person in the role, as well as on the organizational side. You know, having those clear expectations around what the roles and responsibilities are: doing a job interview, you know, checking references, ensuring that the person who you're hiring is suitable, you know, to do this job, and I think you said it nicely when we spoke... I mean, Katherine's very

competent! You know, she's, she's well spoken, you know, she's an intelligent person, she has the experience, you know, and the capacity to do this position. And so, certainly, that's a piece of the conversation. The goal wasn't just to go out and hire someone with lived experience – it was to hire someone with lived experience who can do this job, right. So I think those things go hand in hand, from an organizational standpoint.

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Jennifer: Katherine herself also recognizes the organizational value of having someone like her in this particular role.

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Katherine: I think, again, that's where the personal experience, the lived experience helps you handle and encourage people differently. We're not just looking at what can you bring to us. It's very much like, I want to make sure that you guys are okay with everything. I want to make sure that you're comfortable talking about this, etc.

13:24

Emily: We've heard both Katherine and Katie talk a lot about the value of having someone with lived experience and the role. In this particular case, though, Katherine actually has two kinds of lived experience. That is a young person living with chronic pain, and also as someone with experience as a patient partner. As a liaison between patient partners and the research teams, Katherine draws quite a bit on her own engagement experience to help facilitate communications and ease potential conflicts or tensions. So we wondered if Katherine's patient-related lived experience also comes into play as part of the official capacity of her role.

14:01

Jennifer: Both Katherine and Katie shared the same story about an opportunity, Katherine had to provide guidance to another patient partner. Here's Katie's account.

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Katie: You know, I'm thinking of an example recently, where with one of our affiliates, we connected her with a youth who's creating some blog posts, you know, about her experience with living with chronic pain. And the youth was trying to make some decisions about did she want those, those series of blog posts to be anonymous versus, you know, have her name on it. And I think having someone like Katherine to have those conversations with her is really important, as opposed to having those conversations with the physician or health care provider partner that is working with that youth or supporting that youth or to to promote and create the platform for those blog posts. I think they had conversations to think through pros and cons of that. And I think that's really important because any potential power differentials there, are just are not they in the same way, right? That having that conversation with a health care provider who, you know, is providing compensation for you to create these blog posts or whatever. It's different. You know, having someone like Katherine to have that conversation with I think was really valuable.

Emily: So listening back, I think this was perhaps a crossover moment where elements of Katherine's personal experience and patient partner experience were both helpful in providing guidance to this young person. Obviously, to be a patient partner is to be someone with lived experience as a patient. And in this case, the boundaries which delineate these experiences are less clear...

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Jennifer: ...which makes our project a bit more challenging! But let's carry on. Despite the serendipity of how Katherine ultimately was hired and has helped to shape the role she's in now, it of course, wasn't completely ad hoc or informal. Embedding people with lived experience in paid roles within SKIP goes beyond any tactical benefits. It's part of its organizational identity.

16:06

Katherine: So it's actually part of the job description, that you have to have lived experience either as a parent or as a patient. But that being said, a lot of my role is very much supporting patient partners, supporting family partners, and also supporting people on the team. There isn't a whole lot in the role specifically about presenting or doing a webinar on my personal lived experience.... It just helps inform what my role is and what we're doing.

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Katie: Of course, being 'Patients Included' as an organization, and really valuing the expertise and perspective of lived experience has been part of SKIP's Foundation, right, I think from its initial conceptualization and its design and, and people with lived experience, were part of, you know, that initial application, and conversations around what SKIP could look like. This idea of having someone with lived experience support in a more structured capacity, like a role...or a part-time job if we're being really practical about it... has been part of kind of the initial discussion, I think around SKIP as well. Then it became about bringing that to life, and who that person should be and, and what that should look like in a more formal sense.

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Jennifer: Part of our inquiry about lived experience is thinking about the extent to which it's made visible, when someone is hired into a role with the requirement that they have lived experience. Sure, there will be moments of interpersonal connection, which facilitate moving something forward. But what are the actual expectations in terms of identifying themselves as someone with lived experience, and also explicitly telling their personal stories in the work context?

First, we asked Katherine about her own feelings on sharing her personal story, and asked her to elaborate a bit on what advice she gave to the young patient partner about sharing her story.

18:12

Katherine: So I share my story a lot. And I think it all depends on the audience. So I definitely wish that I had been less public in sharing my experience. So when it is at a conference... or obviously my job right now... I do share my experience because I feel 100% comfortable sharing it with our team members. But I wish that in the past, as a patient partner, I had been a little bit more cautious of promoting my personal journey more widely, if that makes sense.

So it's things where I wouldn't necessarily share with people that I do have chronic pain. So I'm very open and sharing my experience with people in this field - and if, you know, people find out that I have chronic pain, that's totally okay. But when I started dating my now fiance, I remember his dad googled me, and I felt so bare knowing that he could have potentially seen a lot of my personal experience, my journey, which I wouldn't have necessarily shared with him in person.

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Jennifer: This is definitely relatable! We've both done this, I think - shared something that we realized was something we didn't think we'd have to account for again. So for me, I don't think I've had exactly this kind of anxiety that Katherine is talking about. It's more about having some of my own stories quoted back to me with this expectation that I either still feel the same way about it, or, frankly, that I even remember the story all that well.

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Emily: Yeah, I definitely resonate. I've become much more cautious about how and where I share my experience as a patient. Like Katherine, it was only in retrospect that I realized, or even thought about, the repercussions of sharing really personal details about myself.

And this is definitely a good example of how Katherine's time spent as a patient partner informed her role. I imagine someone who hadn't been a patient partner might not have thought to offer this kind of useful advice. More broadly, I think it underscores the importance of carefully considering why and how we ask people to share their lived experience, and what preparation and supports are necessary if they do so. Since lived experience is an essential part of her job description, we asked Katherine whether she felt an expectation to talk about it.

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Katherine: With my role, I actually don't feel pressure at all to share my personal experience ever if I don't want to. I just choose to because I think that it's very helpful for everyone on our team, to hear my journey and to hear different personal stories. I think it leaves a better impact on what we're doing. So I actually find in my role, I'm not expected very much to share my personal experiences. But I choose to just because it is an environment where I'm very, very comfortable doing so.

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Emily: Katherine has found a comfort zone about telling her own story. And based on our conversations, we can, I think, easily assume that SKIP is pretty respectful of that. And would likely support any employee that didn't want to tell their story at all.

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Jennifer: Yeah, that sounds right to me.

So let's think this through a bit, though. So there's a role created where lived experience is one of the prerequisites. But there's no actual requirement for the person to talk about their personal experience. But let's say the person, indeed, chooses not to talk about it, or doesn't even want to identify

themselves as someone with lived experience. My question is: is that lived experience requirements still useful in some way if nobody knows? Or to put it another way: is lived experience primarily helpful if it's spoken out loud, or on display in some way, or utilized productively? I know it's a complicated question and we'll return to this later. But an aspect of it did surface in our conversation.

At one point with Katie, we talked about whether this kind of job is on a spectrum of patient partner opportunities. Like: you're a patient and you have lived experience, obviously, and you become a patient partner. So that's now your role or your label. So in that identity as patient partner, you can be a little bit engaged by, say, volunteering at events or telling your story to a small audience... and you can be a LOT engaged by being hired as a fully embedded patient partner, assigned to perform certain tasks. So if this is the case, identifying yourself as a patient partner with lived experience, is actually part and parcel of the job. And we talked about this a bit with Katie, and it was a little inconclusive. But Katie does refer back to that here acknowledging that there is an aspect of wanting to draw on the person's lived experience. And that maybe the job itself is indeed, on the spectrum of engagement.

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Katie: But certainly her lived experience shows up in terms of how we direct some of our SKIP activities, or where we prioritize or other things like that as well. So as you were talkin... like there's a spectrum, and I was like, "yeah, we still live within the spectrum!" you know, within her job. Like, her job is not like, "we decide and you work to engage others" - like, obviously, we want her expertise as someone with lived experience to help us make some of those decisions, and certainly encourage her to share kind of her perspective and ideas as well.

Emily: So on this note, we asked Katherine if she felt any particular burden by being one of just a few in the organization with lived experience. We know she doesn't feel pressure to tell her story. But there's always a risk of tokenism, which we asked her about.

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Katherine: SKIP is pretty knowledgeable about that, that like one person's lived experience is not everyone's... but I do find I will generalize more than I mean to, so I'll sort of speak on people's behalf that I'm communicating with and stuff like that. So I try to make sure that I don't do that as much. But no... I find SKIP is pretty good at realizing that tokenism is a 'thing' and that just one person's experience is not everyone's experience. So yeah, I don't find that it's a huge issue as much.

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Jennifer: Our overall task here is to think about how lived experience is valued or utilized in this kind of role, and the extent to which it's made a requirement. I have to admit it's still unclear to me. And I think it's because a lot of the value of lived experience is kind of ambient and hard to trace to a specific task or deliverable. And as we mentioned before, it's really not easy to tease apart, what is simply patient experience. And what is patient partner experience, because one includes the other.

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Emily: But like many in this space, Katherine herself does seem to have an innate sense of the value of lived experience, and expresses it in this way:

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Katherine: In my role, I think that it's very important to have someone with lived experience that is actually taking all of the advice and the guidance and the direction and putting into practice for everyday small, minor decisions. So I think that those small minor decisions add up, and it actually does impact the organization. And I also think that, like you said, when you're talking about working with administration within the organization, those are not always roles that I think we should be bothering patient partners with, or family partners. But we also want to make sure that when we're making decisions without them, that it is informed by what they've told us, if that makes sense. And I think that the best way to do that is have someone with lived experience taking their advice and guidance and working with it.

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Emily: Katherine did have a good example of where her personal experience as someone who lives with pain was very helpful not just to SKIP, but also to people in similar situations.

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Katherine: The fact that we pivoted during COVID, everything was shut down... I kept saying, "we need to do something, we need to do something, we need to do something now!" And I think there was a little bit of hesitation about putting something out just generally and quickly. I think that organizations are cautious about doing that. But we managed to turn around a webinar very quickly, and also the content of that webinar: it wasn't just what I was saying, but the fact that I was in those meetings, directed the content and directed who we picked. So we ended up having someone with lived experience, we had a physician, we had a psychologist, and we had a physiotherapist talking about pain management strategies during COVID. So that could have gone in a totally different direction had we not had someone with lived experience on the team trying to create this webinar and also create an opportunity to get evidence out there fast, when everything did shut down during COVID. So I think that's a good example.

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Jennifer: Yeah, I agree, this is a good example. I can see how this was a positive outcome, where a person with lived experience is in a position to influence an activity that both support SKIP in its work, and also provide something of value to the public.

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Emily: So far, we've only been talking about one role, one job, one person. Both Katie and Katherine commented on the importance of hearing from a range of people in terms of both patient partnership and also embedding people with lived experience in specific paid roles. We'll hear from both Katie and Katherine about some of the other ways that SKIP includes people with lived experience.

Katie: And our goal is to engage lots of diverse perspectives of people with lived experience. So if we were always asking Katherine to share her lived experience in each of these spaces, as part of her Patient Engagement Coordinator role, it wouldn't meet all of those kind of kind of values around it, but also goals around how we want to engage as a network as well.

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Katherine: I think every level of engagement with people with lived experience better the work that's being done. So SKIP has two groups that we consult with, and also that they govern us, who include patient partners on these committees. So the Board has patient partners on the Board, and the Patient and Caregiver Advisory Committee, and we have the Co-chairs who have lived experience as well as all the members. So they let us know what they want to see. And I think in my role, having someone with lived experience, put it into practice is also very crucial. So even small, everyday decisions can make a difference in what we're doing.

So for example, the Board specified last year that they wanted to see more patient engagement work being done. And when I was brought on, I tried to find areas where we can engage more patient partners in everything we did. And this year we reported to the Board and they didn't have that same critique.

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Jennifer: So, SKIP has a number of opportunities for patient partners to become involved in the organization in addition to their patient engagement program. Katie also talks about SKIP's goal of including diverse perspectives, right from the top on down.

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Katie: SKIP having a Co-director kind of approach is part of that. Having a Scientific Director and a Knowledge User Director - although Doug isn't someone with lived experience, I think trying to balance that kind of scientific direction with kind of the... I was going to use a very, like, non-public friendly term! ... but like Knowledge User, you know, piece is a part of that, right? To make sure that we're not just kind of taking it from a research standpoint. I think as you identified, having someone like Katherine's role, our Patient Engagement Coordinator Role is a piece of that. I mean, being a Patients Included organization, and really embedding that throughout, in our approach, as an organization certainly adheres to some of that as well.

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Jennifer: And we should also mention that Katherine isn't the only paid employee with lived experience.

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Katie: Part of it is having people on the team that have lived experience, then the other part of it is having people in specific roles on the front lines, I think. So we actually have a Communications person now who has lived experience. So she's actually my age. And I think Communications is also a very cool area. So she does all the social media. She controls the messaging that we send out there to patients and families. So I think that's also a very cool role to have someone with lived experience and a very important place to have them.

31:28

Jennifer: Our conversation with Katie included questions about evaluation: Is there some way of understanding the impact of hiring people with lived experience? Well, SKIP has a formal evaluation

framework which includes looking at engagement and aspects of partnership. But as Katie pointed out, evaluation occurs across all activities in which people with lived experience are embedded. So I came away thinking that, in SKIP's view, engaging people in a number of capacities, paid and unpaid, is more of a philosophical underpinning. It's part of their constitution. And, as such, can't really be isolated and picked apart and evaluated in an incisive way. Evaluation in this case is probably more focused on looking at areas of opportunity or improvement, and Katie also talked about identifying impact stories.

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Katie: SKIP had a Lobby Day on Parliament Hill, in April of 2019. So very early on. And we were a group that had some of our Board members, some people with lived experience, youth and parents, some researchers, health care providers as part of it. And without question, the most impactful people as part of that day were the people with lived experience, in particular, at the time, a 13-year-old youth who lives with sickle cell disease and pain associated with that.

And what we learned from that day more recently, is someone who met Adam that day, who works in health policy and that kind of stuff, recently putting together - now, this is second hand so if I have some of the facts wrong, please forgive me! - was putting together an information brief around a COVID vaccine that would go into the Prime Minister's Office, and the Prime Minister would see. And she identified, you know, shared with us, kind of more informally, through a roundabout way, that as she was looking at it, she was reminded about Adam and what he said from that day in 2019, and all of the scientific evidence we have around pain management, especially around things like immunizations, vaccines, needle procedures... and wrote in about pain in the policy brief before it made it to the Prime Minister's Office! That's huge impact! I'll be honest, I'm very humble in my role as a researcher and a psychologist. There's no way I would have been able to have that kind of impact.

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Katie: Because it really was about hearing from the person with lived experience who could speak about the impact on their life that was memorable, right? So from a knowledge mobilization standpoint, getting that research evidence, like into what might come out, you know, and in recommendations or, or things like that around uptake of a vaccine. Right now, that's huge. We have tons of great evidence about how to manage new procedures, often very little of which is actually taken up.

I don't know what more we can ask for I know, as people who are working to advocate for improved child health and pain management for kids. It's less formal from a research standpoint, in terms of evaluating impact. But I think, again, like as a researcher and a healthcare provider, I think it'd be really arrogant for me to think I can have that kind of impact by just quoting some facts. That's not what it's about. It brings things to life. I hope, you know, there's real synergy, right, that Adam is the memorable piece, but it's also backed up by, you know, science and research that said, what he's speaking to, that's his experience, but he's not alone in that.

35:02

Emily: I'm sure this story is probably just one of many. And it's easy to see how they could add up to something significant for an organization like SKIP. And this also relates back to the beginning... if you remember how Katherine was hired, SKIP did have an overall intention to include more people with

lived experience. And then Katherine emerged - the right person, at the right place, at the right time. These sorts of moments can't really be planned or even anticipated. Same goes for the kind of impact a young person like Adam had on Parliament Hill. Engagement is driven by relationships, and for those relationships to thrive and to potentially have impact, all you can really do is create the environment and set the conditions. And for SKIP, that means committing to engagement in as many ways as possible, including hiring people with lived experience.

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Katie: When you talk about the Patient Engagement Coordinator role that we have within SKIP, and how do people listen to that in the room... I mean, I think part of it also comes from the culture of the organization, you know, both in terms of the organization, its values, its mandate, publicly and internally. It's to value the expertise of lived experience. So, you know, when Katherine has something to say, that's important to listen to, you know, as opposed to, you know, an organization that maybe has hired someone with lived experience but isn't embodying that and also how leadership are talking about it, or other team members are talking about it.

I think there's probably context there too that actually matters. Because I can envision a scenario where someone with lived experience is trying to share their experience and expertise and nobody's listening. I think you have to create space for that person to be there at the table in the first place. But that's not enough - I think you also need to be creating an environment where, and a culture where, that is that perspective is valued and acted on.

36:55

Jennifer: Katherine definitely feels she's had a positive impact for both patient partners and researchers. And I think she connects a lot of this impact to her having lived experience. She sees the potential for this approach to have a similar impact on other organizations, and imagines a future where employing people with lived experience is not only commonplace, but required.

37:18

Katherine: I have this dream of making it very much standard to hire people with lived experience in the roles within an organization. Like when you think about trying to get pain management evidence out there, into the community... that obviously is an organization where it's insanely valuable to have someone with lived experience on the team. And I think there's a lot of other organizations like that as well, where if you had someone with lived experience working for them, it would totally shape the organization. And I think that a lot of organizations could do it - either they haven't thought of it or they don't know how. So I think it would be a really great opportunity for a larger body to come up with how to meaningfully employ people with lived experience.

I remember when patient engagement was very new, and there were all these concerns about having patient partners, and maybe some of the challenges and how that would shape research... possibly for the worse. And I think that maybe sometimes organizations think about that, and worry that it could shape their organization or it could be too challenging for them, so they just don't try. So I think it would be really, really great if there was a meaningful way to hire people with lived experience in an

organization. And I really would like to see it be very much expected, like it was eventually for patient engagement.

So I think it would be interesting one day if we saw this within funding for organizations saying, "Listen, you have to have sort of lived experience not only on your boards or your committees, but actually being hired in certain roles." I think that would be really, really great one day.

39:22

Jennifer: Hey Emily.

39:24

Emily: Hi Jen.

39:26

Jennifer: That was a great conversation with SKIP. It was helpful to hear in their own words and from a couple of different perspectives, what the value of lived experience is to the organization. Emily, you have way more experience than I do in terms of seeing how this all plays out day to day - but it definitely rings true for me that lived experience is seen as having an important, if somewhat intangible, impact. And you know, this again helps me see why evaluation of patient engagement can be so difficult! Anyway, what do you connect with after hearing Katherine and Katie?

40:02

Emily: In some of the work I do, I also carry this extra job description of having lived experience. Exactly how that lived experience comes into play in my role feels a bit hard to pin down. I know it does inform my work, but it's hard to pull out specific examples of how. I would say that most of the experience I draw on relates to my time and someone *being* engaged, whether in research or quality improvement, or wherever. The insight I offer has a lot to do with what felt right and what didn't when someone tried to involve me. What made me feel valued or supported along the way? Since, as Katherine described, so much of the work coordinating patient partnership is making sure people feel good about their role, this kind of experience is vastly useful. The way that my actual patient experience comes into play is more in the kind of 'aura' that it brings.

40:58

Yep, something really does change interpersonally when you find out that you and another person have a shared experience. I feel it as both a parent to a child with disabilities, and also a parent who has lost a child. When I meet another person with the same experience, there's an assumption that we relate even if that personal experience is never referred to or acknowledged, and frankly even if there's actually little in common, except the *fact* of what happened. There's a recognition in each other, even if it's just in that moment.

41:33

Emily: It can feel so comforting and reassuring. And trust is more quickly established because of the perceived shared vulnerability. Katie talked about the power imbalance being removed, or lessened,

when a patient partner talks to someone who's seen as a peer. Well, I mean, the power hierarchy is still there. It's just maybe less visible or interpreted differently.

41:57

Jennifer: Yeah, it has the effect of preemptively smoothing over possible tensions. There's something here about communicating 'authenticity' - there's an instant, "they get me", just in the knowledge of the shared experience. A sense that the other person is the 'real deal', which I think helps to legitimize whatever the engagement activity is. Now, that's not meant to take away from the interpersonal connection. It's just that I think there are many factors at play at the same time.

42:27

Well, I have certainly felt that sense of, "they get it" when hearing from someone I know has gone through something similar. That feeling of understanding is really foundational to the concept of peer-to-peer health care, and also peer support. But another thing that our conversation was SKIP reinforced is just how helpful it is, from the organization's perspective, to have people with lived experience on the 'inside'. Some of the value is in a kind of knowledge translation role, where the person is able to bring their own perspective and also funnel and interpret perspectives from the wider community - not as 'data' exactly... but maybe as a point of validation. It does somehow seem perceived as more valid when the person who channels the input from the patient partners is themselves a patient, as it were.

And then, if the person with lived experience is in a role like Katherine, or, I know from some of the roles I've been in coordinating other patient partners, there's definitely that interpersonal connection piece. And this is critical to building trust and relationships - two things we talked about as being essential in good patient engagement. And actually, it's essential in pretty much any sort of job that involves managing people. It makes sense to hire someone that will instill trust and who will be a good conduit for sharing information.

43:46

Jennifer: Yeah, all of that. And I think there are a lot of intangible benefits as well. When we talked earlier about the mere presence of someone with lived experience, signaling their trustworthiness and their authenticity and shared vulnerability... I think these things all accrue upwards. The organization, and its leadership, are all seen in this same light as well. Organizations that have a Patients Included approach, I think, are seen as, or want to be seen as, more trustworthy and authentic. You use the word aura, which I think is apt. It produces a halo.

44:25

Emily: There's a unique symbolic benefit here. Maybe in some ways, even more powerful than the tangible benefits we discussed. I mean... I suppose most organizations don't really disclose the personal backgrounds of their employees unless it's important to their identity or public persona. I actually ask this question sometimes in my consulting work... I pose this thought experiment to researchers: "If you couldn't tell anyone about your patient engagement and partnership activities, where would you still do it?" Now, I don't do this to imply that there's something inherently wrong with promoting engagement work, but it's important to be clear and to distinguish where the benefits would come from the telling, and where they feel like there would be impact specifically on the research.

45:12

Jennifer: And one thing we learned is that the term 'lived experience' is actually a well-explored concept academically and can be understood with different inflections when considered through the lens of different disciplines. We found references from philosophy, sociology, linguistics, anthropology, feminist studies, all with well-developed ideas about what lived experience means and what it represents.

45:36

Emily: But it seems that here with patient engagement and partnership, and probably throughout health care, the term just kind of floats around without any of that context or reference to how it's being used. It kind of sounds like it's just descriptive or neutral. But it isn't.

45:54

Jennifer: No, that's right. It's doing way more work than that. I mean, if we meant to say 'patient', we'd say 'patient'. If we meant to say 'person with cancer', we'd say 'person with cancer'. But when we say 'person with lived experience'? I mean, sure, it means the person has lived through something specific - but it also signals something. It signals authenticity, trustworthiness, and ultimately, legitimacy. And that legitimacy ripples up and down between the interpersonal, organizational, and even governmental levels.

46:28

Emily: Maybe there's a broader phenomenon happening, where we place a high value overall on something we might call 'patient-ness'. It's one of those things that's hard to describe, but I know it when I see it! It shows up when we hire people with lived experience. It shows up when we use specific patient stories to put a face to the numbers. It shows up when we talk about the patient voice. I'm not saying it's not real, or that there's no substance. There are definitely productive ways that adding that patient-ness improves aspects of healthcare. Well, especially in terms of generating empathy or affective responses.

47:06

Jennifer: Yeah, and I think there's a flipside too. This 'patient-ness' - this special something - it also treats patients or people with lived experience as kind of an exotic species. Even if they're no longer research subjects exactly, they're still a kind of separate class, under a microscope. They're the 'lived experience people' - they bring value just by being physically in the room. I know that patient partners themselves self-identify as having lived experience and maybe there are times when it's important to make that distinction.

But there's an aspect that could be seen as exploitive, especially if patients are utilized to manufacture authenticity on behalf of the organization. Which is what happens when efforts to add 'patient-ness' becomes a checkbox. I think for an organization like SKIP, where their actual mandate is to make research accessible to specific groups of knowledge users - what they're doing makes sense - but their work doesn't happen in a vacuum. I think as engagement and partnership become ever more embedded and mandated, it's important to at least acknowledge all of the ways that organizations

extract value from patients and their engagement activities, including when they hire people with lived experience.

48:28

Emily: We're very grateful to Katherine Dib and Katie Birnie of SKIP - Solutions for Kids In Pain - for sharing their work with us. You can find out more about SKIP at [kidsinpain.ca](http://kidsinpain.ca). And as always, if you have any comments or questions, you can contact us through our website at [mattersofengagement.com](http://mattersofengagement.com).

48:49

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