Transcript
Matters of Engagement podcast
Episode: “Engaging in Storytelling (Part 1) - The Patient Story Experience – episode produced by SPORcast”
https://mattersofengagement.com

Jennifer 00:01
Hey there! It’s Jennifer, from Matters of Engagement. We have a special miniseries we're releasing this week: Engaging in Storytelling, a 3-part collaborative podcast series with SPORcast, Matters of Engagement and PEP Talks. We each cover a different angle on patient stories and storytelling. And together, all 3 episodes provide a rich picture of some of the challenges, concerns, and also opportunities when it comes to engaging in storytelling. I’ll let Bev Pomeroy take over from here.

Bev 00:28
This one by SPORcast is the first of three and it's called The Patient Story Experience, Cost or Benefit? I, Beverly, have hosted a conversation between an activated patient partner and a trauma-informed practice expert on storytelling, the entry point of patient engagement in healthcare. We hope you enjoy it. If you're listening in order the Matters of Engagement episode is up next, followed by PEP Talks.

Bev 01:15
Hello and welcome to SPORcast, a Canadian podcast discussing patient-oriented research - research done in partnership with patients.

Bev 01:24
I'm Beverly Pomeroy

Lisa 01:25
and I'm Lisa Ridgway, and we are patient partners who sit on a variety of patient councils and advisory groups, all with the vision to encourage research to answer research questions that matter to patients and aim to improve healthcare.

Bev 01:41
Thank you for joining us today. We hope you will be inspired to get involved and create your own impact in order to support healthcare research be more relevant and meaningful. Please enjoy the show.

Bev 01:55
Well, welcome to SPORcast, another episode here of our podcast on the Strategy for Patient-Oriented Research. I'm Bev Pomeroy. I am solo today for today's episode, and I do want to acknowledge that I live and work on the unceded and traditional homelands of the Coast Salish peoples here in Tsawwassen. And I'm here today with remarkable guests Claire Snyman, an incredible, incredibly activated patient partner, and Marika Sandrelli, who's a knowledge exchange leader, and who really stewards trauma and resiliency informed practice. And this episode is one of three in a 3-part series that we're doing with Matters of Engagement, and PEP Talks, all around engaging in storytelling.

Bev 02:37
And just to kind of give a little bit of backfilling for those who aren't on social media, or who haven't seen the conversations: this episode stemmed, for me anyways, from an opportunity in September that I was given to speak and share my story and my daughter's story at a national sort of event. And I kind of put it out there. Someone posted on Twitter that I was going to be participating. And next thing you know, there's this huge dialogue on, you know, patient storytelling, and "oh, I don't do that anymore". And "that's why I wrote my book". And, you know, it really started to make me think of: why am I telling my story? And is there harm in telling my story and [inaudible] of losing my daughter. And so I was like, okay, like, what does this mean? And I actually changed my entire presentation. For the most part, removed my story. And from that Matters of Engagement and PEP Talks, [we] decided we do this 3 part series. So I just want to say, thank you so much, Claire, and Marika for being here today. And I know Claire, like you, seriously, you're like one of the most activated patient partners out there. You know, when we think of storytelling, we do it all the time. And do we ever really... I mean, I'm bringing in the word trauma because Marika's here... do you ever really consider it traumatizing or re-traumatizing to us?

Claire 03:54
I think that's a really good question, Bev. And thank you very much for having me here today. It's a pleasure to be here on this really important conversation and topic today. And, you know, I was thinking about sharing story and what does that really look like? And when I've been sharing my story, gosh, since 2016. I was diagnosed with a non malignant brain tumor in 2010. And I had brain surgery for it in 2012. And so I've been sharing my story for for quite some time. And it's also morphed over that time. sort of from sharing about my brain tumour experience, to putting your health in your own hands, and advocating for oneself in the healthcare system and how it impacts patient experience. And I can say for the majority of the time that I've shared my story, it's been a positive experience - through the environment and the setting in which I've shared my story.

Claire 04:53
But I must say they have been a couple of times where sharing my story has been a traumatic experience for me. And it's actually been two times out of the countless times that I have shared my story. And however, those two times really do stand out for me because of the impact that they had to me as a patient partner. And so my patient story involves medical error. In my patient story, when I talk about it, when in 2012, I became very acutely ill with vertigo I had an unresolving migraine that would not go away despite my GP's interventions. So she sent me to the ER, requesting a CT scan, and found my brain tumour. And just to paint a picture for you: so my condition by now, unbeknown to anybody, was that my brain tumor had actually doubled in size, and was blocking the cerebral spinal fluid in my brain. And so I had hydrocephalus and had an intense migraine and vertigo, my memory was starting to go and I was trying my hardest to explain in the ER waht was needed. I gave my request forms for a CT scan to the ER doc and I was dismissed by the ER do. I was given migraine meds and sent home. And so while I'm telling the story, I was questioned twice by listeners, and these individuals were from the health care system. And it was asked, "Why didn't you ask more questions? And why didn't you demand more when you were in the ER". And, to be honest, this really took me by surprise. It stopped me in my tracks. And I actually didn't know how to answer this. Because I questioned myself. I felt like I should have done more. But I knew I actually did as much as I could possibly do in that moment, because I was actually really

seriously ill. It made me feel betrayed by the healthcare system again in that moment. But I knew it wasn't me, but it felt like another layer of trauma and PTSD after my surgery because of a medical error. And this just felt like another layer another trigger on top. So I think there's episodes there when patient partners are telling their story, that it can be a traumatic experience.

Bev 07:10
Wow, that's extraordinary Claire, and we do tell our story a lot. And people do get up and ask us questions. But that's, that's unbelievable that the onus was put on you. And now bringing you into the conversation Marika, I understand there are many ways to understand trauma. And when we're talking about engaging in storytelling, and in particular, Claire's experience, maybe you kind of help us understand, you know, the ways that we can understand trauma in these particular situations.

Marika 07:37
Yeah, thank you, Bev. And thank you, Claire. Good to see both again, you know, how we define trauma has really evolved tremendously over the last few decades, as I think we're finally not just listening to people with lived experience, but we're actually learning and we're open and receptive. So it's becoming... there's quite a few variations of how we explain trauma - which is good because people are unique - oOne of the definitions that we find most relatable comes from Tara Brock. And she explains trauma as when we've encountered an out of control, frightening experience that's disconnected us from our sense of safety, coping, love, and resourcefulness. And I think in your story, Claire, by healthcare providers not believing you, challenging you, minimizing or minimizing what you're saying and questioning you. You know, all of us when we feel that way, not just you but when you're put in a position where you're exposing yourself and putting yourself out there, and there's a lot of power in the room....that sense of feeling out of control, you know, really disconnected in the the sense of safety and people. That is one of the trauma effects. So that definition of being disconnected from your sense of safety, coping, love, resourcefulness - is really helpful for us, whether we're in the role of you know, listening to stories as a researcher, evaluator, a service provider or a family member - whenever we can help people stay connected or reconnected to feeling loved, that they can cope, that they feel safe, that they have access to their resources - we are minimizing the effects of trauma.

Bev 09:45
[crosstalk] So what do you think it is then that when we're sharing our story, I mean, we've already gone through our trauma, right? And then we go and share our story and, you know, what is it about sharing our story that is really traumatizing. What can re traumatize?

Marika 10:04
I'm gonna actually go to Claire first to kind of ask you and then and maybe I can riff off what you say, how's that?

Bev 10:12
Yeah, Claire?

Claire 10:13

I suppose I really go back to the basis of why we actually share our story. Because for me, even though I had those two episodes, where as I said, I left the room and it actually dwelled with me for quite some time afterwards, because it goes to the heart of who you are, as to like, really, what is this all about? I'm sharing my story. But as I said, it's a trauma, it's a trigger. So I think I go back to why do I actually share my story, and what is it all about? And I think it goes back to the issue of human connection. For me a story is all about conveying an idea. It's all about sharing information. And they say that a picture's worth more than 1000 words. And I think the same is very true for story. I think for me, and for many patient partners, we come to the space with a purpose.

Claire 11:09
There's why there's something very powerful that has driven us and impacted us that we want to share our story. And it's what continues to drive our story. We're hoping to connect whether it's others and a similar situation, or we want to inspire people or drive change or collaboration. So there's so many different purposes behind why we actually share our story. So I suppose it's that's why it's really integral. But I suppose as you said, as it's been sort of, why do we continue to do this, even though there is a trauma sometimes that's associated with it? And for some people, that trauma can be too much. And I think it's really important acknowledge that sometimes there is that trauma. And the patient partners are aware that there can be a trauma when sharing their story. And what does that look like?

Bev 12:00
Yeah, over to you Marika

Marika 12:03
I felt really quite connected to you, when you talked about kind of the sense of relationship and connecting, that comes with storytelling. And I think in health care, you know, psychological, social... there's many kinds of trauma. And, you know, whether it's kind of a single incident trauma, where, you know, you've been in an accident and have to go to the emergency room - that can be quite traumatizing - you witness something, to complex trauma of living with a disease or any kind of chronic condition, or, you know, we've got ambient trauma, which, you know, comes from being oppressed, you know, whether it's living in poverty, racism, transphobia, homophobia, all of that is ambient trauma. And, there's also, you know, complex, repetitive trauma that happens, and social trauma which is what you've talked about Claire. Where social trauma is probably one of the most neglected and misunderstood traumas, I think in healthcare.

Marika 13:19
And it really comes from the kind of social pain you can experience when you are misunderstood, or you're not believed, or you have to fight to be who you are, or you feel really excluded or you don't belong, or you're discredited. That elicits a response, that's really when you look at CAT scans of the brain, the same areas of the brain light up, whether you've had physical pain, like a severed thumb, or you've had a severed relationship. The same areas of the brain light up, people are feeling immense pain. And I think the healthcare system really has a hard time grappling with that because it's a highly mechanistic system. And it's used to being a system where, you know, you see a physical injury, like physical trauma, you see an injury, you know exactly how to fix it, you know, it's highly mechanistic. Here's an injury, here's a disease, here's a pill, here's a process, here's a device, it

gets fixed, you can see it, it's very instrumental, it's high task, and immediate results. And that's what people go into the health care system for - that form of healing. The psychological social trauma that people experience, it's really... you can't see it to treat it and there's multiple sources. And really, the healing happens in relationship and in connection and requires vulnerability.

Marika 14:57
And I think that the healthcare system, how it's completely structured, there really is not, you know, fertile ground for this to flourish. And a colleague of mine says that one of the greatest human sufferings is to be deeply misunderstood. One of the greatest healings is to be deeply understood. And I think that's exactly what I'm hearing from you, Claire. And when people are feeling misunderstood, they feel pain. And it also triggers and activates a neurological response in us, where we feel a sense of threat, where we don't feel safe, where we don't trust. And we have to fight to be who we are, and that can be quite debilitating. Not just for the person sharing their story, but it can activate people who are listening, that are carrying their own trauma histories. And if they're in a position of power, and not attending to that, then they can further create trauma for the storyteller.

Bev 16:16
I'm just so fascinated by the whole idea of social trauma. And we're talking about engaging, you know, your storytelling, engaging in storytelling. Because I do, I just don't think I have never really heard that term before social trauma. And I'm fascinated by it when it comes to patient partners sharing our story. And I know I was sharing my story, obviously, you know - I'm one of the invisible, right, I've got social trauma, I lost a child, I don't wear a badge. Nobody knows. And I was speaking at an event. And afterwards, the person who actually was sort of in charge of the entire organization came up and took me aside and was weeping. You know, this this big man, right? Like this big guy that you wouldn't expect and was weeping because he had lost a child. And so in that moment of my sharing my story, as much as I was riveted, and I get blotchy and red whenever I tell my story because it's bringing up all kinds of, you know, memories for me. But this gentleman also experienced exactly what I think you're speaking about, Marika, is the idea around social trauma. And Claire, I'm just so curious, from your perspective, like, what are your thoughts on that?

Claire 17:17
I mean, the one thing that I wanted to say, and Bev, thank you for sharing that story. Because, for me, Marika, what you were saying about the social trauma, and then the, the healing part, what you said about that was really interesting. You gave a beautiful quote there. And something that just came up for me there, I think, is that one of the reasons just going back to like, why do we share our story. I know for me when I've been sharing my story is, when it is in an environment that is positive and embracing, it is tremendously healing. And I actually think, Bev, what you're saying about this gentleman who you connected with, from on stage to an audience, for him, you connect to it. And in that moment, I can actually feel myself with tears... in that moment, you actually connected with him on a level that for him, was acknowledgement of his grief, of his trauma that he had been through, and was on a level that was healing for him, of acknowledgement of his pain and suffering. And I think when we share a story, and we're able to as a patient partner, it is part of our healing process, if it is in an environment that allows us to do so. And I think when we are doing that in communities and environments that allow us to do so, it's not just us that are able to heal, there's often individuals in environment that we are

talking and sharing that it allows them to as well. And I think that's a unique thing about storytelling and narrative is that we're human. And that's how we connect, is through storytelling. So when we look for those opportunities, it's the double side of the coin, right? It's both sides of the coin. How do we take it and ensure that we are able to use story for both sides - for the healing of trauma that's existing, but making sure we don't induce further trauma as well.

Marika 19:17
I love what you're saying. I think that, you know, we say that education because what we learn when we listen to stories and education can be healing and exactly what you're saying. You know, if we create environments where people stay connected, or maybe they get a stronger connection to their sense of safety, coping, love, resourcefulness, we go back to Tara Brock's definition - if that happens, it can be incredibly healing, not just for the storyteller, but for the listeners. Because I think that that kind of bonding, relatability you know, on a neurological level when that happens, that kind of caring connectedness that story's are our vehicle for, you know, neurologically, you know, what's happening is instead of a stress hormone, when we're feeling unsafe, which is, you know, cortisol adrenaline going through our veins, you know, all of a sudden, that's replaced when we feel cared for, connected. When we feel relatable, when we feel an incredible sense of empathy and relatedness. Cortisol and adrenaline, it's replaced with oxytocin and dopamine, you know, who doesn't want a hit of that, right? It's the love drug, you know! We all want that, we crave it. People go to great lengths to get it, including, you know, taking illicit drugs and fentanyl because they're in so much social pain. So I think what you're saying is just really important for all of us to really understand and hear, that I don't think we truly optimize the power of connecting and minimizing the effects of social pain through storytelling. I think it is an act of healing, and that we have a responsibility to create healing environments for that to happen.

Bev 21:12
Well, I guess my next question to both us how do we do that? Because I think we all know when we're in an environment where we feel safe to share our story. And I think we also are very aware in those situations where... oh, yeah, this might not be the best place for this, or I'm not comfortable. And so I guess that's my question. Especially in a healthcare setting, which we all work in - so how do we work towards creating a safe space, you know, to tell these engaging, meaningful, you know, influential, informative stories that we all have based on our living experience? Either one of you would like to give a go at that?

Marika 21:49
I'm gonna turn it to you, Claire, because I'm curious as to how have you been able to, you know, identify a safe space? And how have you adapted?

Claire 22:00
I think that's a really good question. Because I think there's two parts of it. I mean, from my side as a patient partner, I share my story in many different environments, it could be, could be a brain tumor conference, it could be a medical conference, it could be a library, it could be a friend of a friend who has a health crisis. So it there's so many different pockets. And I'm very open to sharing my story, anything from my brain tumor to other chronic health conditions that I have written the book on it, I'm pretty open.

Claire 22:30
But there's certain aspects of my story that I'm not so willing to go into detail on. And that's, for example, for my family because this was their journey to and still very much is. And that's their story to tell if they would like to do so. But I think as a patient partner, it's important to think about when you are telling your story or thinking about telling your story to define for yourself, what is my safe space? And where is my safe space? And what are my boundaries? And where are my no-go zones? And what does my answer look like if it's a no-go zone? Because believe me, those questions will come up. And it's a sense of, what does that look like if a question comes up that is not a safe space for you, to protect yourself? And what does that look like? What does the answer look like to that.

Claire 23:30
And I think from a patient partner perspective, as well, is knowing that sometimes telling a story can be emotionally draining, and triggering, and traumatic and allowing yourself to have a safe space, after you have told your story. Some days, you may be in a good space, but some days, you may not be and you tell the story, because you're driven by why and driven by a purpose, to collaborate, to inspire to do whatever it is that you are there to do. But some days afterwards or during, you just feel like a ton of bricks are falling on top of you. And what do you need, in order for you to, afterwards, to decompress. And to feel like you're back in your safe space. And I think that's really key from a patient partner perspective. And it's okay if you don't want to share your patient story. That's totally okay. Because one day, you feel like you're going to, and you're fine. And one day, you may not feel like it's okay. And that's totally fine. So I think it's a sense of knowing yourself, and knowing when, where, and where your boundaries are for telling a patient story, from your perspective.

Bev 24:46
And how do we do that as an organization, Marika, when you're in mental health and substance use and the stories that you're hearing and you want it to impact change and impact patient care and delivery and the environment they're in? Like, how do we do that within our organizations that are healthcare agencies.

Marika 25:02
Yeah, just building on what Claire said - absolutely, I love what you're saying. I think there's there's about four or five things that I've come to learn from listening to you, Claire and other patient partners. And I think the first thing is, is that as someone organizing or hosting stories or creating the environment for story sharing, the first and foremost thing is I don't think the onus has to be completely on the patient partner, to kind of do all the assessing and screening. I think a couple of things here - so I think we have to move away from this idea that.... You know... we have to understand the effects of trauma and trauma awareness. So I always hear people "well so and so declined to share their story or so and so doesn't want to" - I just think language is really important for me, and I think I use language such as "opt out". They're opting out. It's not that all of a sudden, you know, we start blaming the individual that they don't have the strength, or they don't have what it takes to share a story or anything like that. You know, it puts the blame and everything on the person that's putting themselves out there. So something is, is really looking at our language on how we're inviting people, using things like opt out, learning from the patient partner, like, what do they need? What is a safe environment for them - not assume that you know what it is. Everyone's different. Like, what creates a safe, trustworthy environment for you to share your story? What do we need to know? What do we need to avoid? We learn from the patient partner

well in advance that we're responsible for co-creating that environment. And in fact, if we're hosting we are responsible for that. So again, really learning from the partner what's safe, what would create trustworthiness. I think the other thing is to bring as much certainty and predictability as possible, to the person sharing the story ahead of time. You know, what the space looks like? Who's there? You know, what would be some of the questions?

Marika 27:24
If you're moderating, what are you going to do if someone asks a question? that's the no-go zone? Is it on the patient partner to deal with that, or is the host going to support the patient partner in that. And everything about time, room set up, everything. Bring as much certainty as possible so that the patient partner can decide whether they want to continue or opt out, or if they can change something I think is really important. The other thing is, I think it's about the organizers, really... there's a responsibility on the listener. So it's not just preparing the person sharing the story, but preparing the listeners. And I think that's really important. You know, again, doing a grounding exercise, a mindful breathing exercise, so that people in the audience that are hearing - if they're getting triggered, and they have power, you know, they can project that onto the storyteller and create an incredible, violent, harmful, hurtful experience.

Marika 28:29
So I think you have to work with the listeners on, you know, getting a sense of grounding, a sense of understanding, you know, power understanding. Again, I'm a strong believer in self-compassion practices. So I really believe the more that we can bring in self-compassion practices for both the storyteller and the listeners, the more we can show up in a good way. Especially for the storyteller, I think. I don't know, Claire, if this has ever happened, I know it happens to me quite a bit. Maybe I join you in this is, sometimes we go back and we we kind of just dissect what we said. And we said, "I wish I would have said this", or "I wish I would have done this" or, you know, that inner critic comes out right after - or even during sharing your story.

Marika 29:17
And we get really hard on ourselves. Like, we don't think we're good enough or we don't think we've done a great enough job. And that inner critic can get really loud. A self compassion practice really helps us recognize that inner critic and befriend it. And then say, okay, you know, subconsciously we're saying we're really being hard on ourselves right now. And, you know, what do I need right now. There's probably a lot of people in this audience that's listening that are sharing the same experience. Maybe not the same specifics, but they're going through this as well. I'm not alone in this so. And the audience, the people who are listening need to also have that self compassion. Where they get that critical voice coming out where, "I don't know if I believe this, why didn't she do this? Why didn't she do that?" You need to check yourself in to and say, "What is that all about". What need do you have that you're projecting on that storyteller. So priming the audience, preparing the audience, supporting the storyteller, understanding what feels safe for them, using language such as opting in or opting out - are all things that I've come to learn are really essential.

Claire 30:31
I think I'd like to just totally acknowledge the one point that you brought up about really setting the stage at the event, because I think often a lot of times people are coming in from all different areas like coming in, and

they're hasty and all that. I think setting the stage and setting the event and the tone for the storytelling or whatever it might be - conference - where the patient story is about to be told - I think that's really integral. And setting a tone of compassion, self compassion for listeners, as well as the individual telling the story, and what the objective is, you know - this is not about criticism, it's not about the... etc and so forth... I think really drives understanding of what the role of a patient story is, and why a patient is here telling a story.

Claire 31:21
Because it often is a vulnerable place for a patient to be telling a story. And as you said, if there's a power differential in the room, and there's questions asked afterwards, and I think it's important to, you know, when asking questions, in a respectful tone, and manner afterwards, etc, because sometimes that can be challenging as well. But I think that's spot on - setting that tone right at the beginning. So people just decompress from the five different places they've been coming in - and the emails and the text messages - and just take a step down. I think that really can help set the tone. And then also, I think, after the event, as well, having a feedback mechanism between the patient partner, and between the organizer, just to have an understanding of what went well, what worked, what didn't work, what could we improve on going forward, friendly learnings, I think is a really important strategy.

Marika 32:20
[crosstalk] is really if the organizer is getting feedback about the event is really communicate that with a patient partner. I know a lot of times, you know, people are invited to share their stor and there is evaluation data that's never communicated to the person that's put themselves out there. And they're dangling out there. And I just think that's such an abuse of power and abuse of withholding knowledge. So that's another thing I want to bring into the conversation.

Bev 32:52
Yeah, and the other thing, too, like, it's funny, because this first series of our three part series is really about, you know, the patient story experience, and how patient story really is the entry point. When I first started thinking about this, this topic, I thought, well, entry point, entry point to that organization, and then being introduced to, you know, this person's experience. But as we were talking about entry point, there are multiple entry points of patient storytelling, from what both of you are sharing and the entry point also being that exit point, you know, going off into your everyday life after your patient story experience. So, that's so amazing, because there are these different entry points that we enter, you know, within organizations. They're up on the stage, or then at question time, or maybe it's an ongoing commercial that we see, you know, within an organization that we see ourselves in time in these different areas and when we're setting the stage for that. Now, are there... I know, Claire, you do a lot of speaking on this as do I and advocacy and same, Marika, you're doing this too - are there resources that you know of that can help support, you know, organizations or patient partners that can do this and reduce harm? Or is it just basically what we're doing right now- starting to have this conversation and then building it out from here.

Marika 34:16
Yeah, I can start. There are some resources out there, I just don't think that we've done justice to this area right now. So I do think it needs to be further developed and I think our conversation here, hopefully is a springboard

that invite all of you to start, you know, connecting with patient partners, and patient partners connecting with host organizations to really sit down and build your trauma awareness and create - take the TRIP Principles - the trauma informed practice principles - around, you know, safety and trust, trauma awareness, creating safety and trustworthiness. Collaborating choice, you know, connection. All of those, you know, skills building and empowerment - all of those key principles is like taking those and how are you going to translate those in storytelling and story sharing and come up with - I don't know if it's a checklist or guiding principles or, you know, even a process that is meaningful for you in storytelling. And not only can that reduce any harm associated with storytelling, where trauma is activated or a traumatic experience is created, I think the process of developing those principles, and those checklists or those steps is a powerful way to create solidarity and to connection that you were talking about Claire - that kind of relational healing that can happen. Even the process of creating those tools, I think is a great opportunity for you in creating that solidarity. But there's tip guides that you can look at - I know in BC, the Ministry of Health, there's a trauma informed practice guide - First Nations Health Authority just released some guiding documents. So, you know, there are a number I think, if you google "trauma informed care" or "trauma informed practice", you're going to see a number of resources now, and many more coming each day

Claire 36:36
[unclear] I suppose from conference organizers, if you're looking at it from a speaking and sharing of patient perspectives is, specifically if they are looking at being a Patients Included conference, ensuring that they are Patients Included on the committee that is actually going to be running, setting up the conference, and making sure that there are patients on board actually looking at how can we best support patient partners that are going to be sharing their story? And how are we actually setting up a safe environment for that to be happening. On the other side of that as well, how do we support the audience in best understanding and supporting patient partners - and also being listeners in listening to stories. And it's often not just patient partners who are sharing stories, it's other individuals who are sharing stories and being [inaudible] and sometimes situations of vulnerability. So it's a two way street, really. But how do we set up that optimal safe environment and non trauma inducing environment for people to actually share stories? And then on the other side of health authorities as well, when looking at TRIP guidelines, and so forth, how do we make sure that patients, families, caregivers are actually involved, if they are looking at a TRIP training for staff members? How can they be involved in looking at what does that look like? What does trauma look like in their involvement in the healthcare system and making sure that there is the patient family and caregiver voice involved in that implementation at the Health Care Authority level? I think that's really important. So that you can actually understand what that actually looks like, feels like, for the patient family and caregiver lens.

Marika 38:25
And I can just add one more thing, because this happens - it just happened yesterday - and I wonder if this has happened to you? You know, somebody contacted me and said, "Oh, I think we need, you know, patient voices and people with lived experience. We're having this meeting." They asked yesterday for a meeting today. And they said, "Marika do you know someone with lived experience that can come to this meeting? And I'm kind of like... it's almost like, what? You go out to a store and you buy off the rack? You know, it's one of those things where I kind of... and there's no agenda there, I don't even know who's there. I asked all these questions, even to even consider it. And they said, "Well, we don't. W'll have the agenda tomorrow morning." And I'm like, well,

I'm not I'm not even gonna attempt to talk to someone unless we have that degree of certainty and predictability and, you know, it's 24 hours and you know, people feel that they've done enough just by, you know, creating this space or opportunity. But that's not enough. It has to come with a real understanding of the ambient trauma, the power, the the vulnerability that people putting themselves out there and, you know, you just can't throw people into a culture and environment that is not only sometimes foreign, but an environment that has hurt them in the past, or they felt betrayed, or they felt misunderstood, or they felt harmed by. So I don't know if that's happened to you? I saw some smiles but...

Bev 39:57
I was gonna say! I think Claire and I are sitting here nodding and like shaking her head because that's what the whole conversation [inaudible] spending our time together and that's exactly what happened on Twitter. It was a last minute ask and it just snowballed into this conversation that we're having now with this series. But I want to thank both of you so much for being on SPORcast, and Claire for being so open about your experience and really discussing, I know, which is hard a lot of times for us - but we all want to do it with a sense of purpose. And Marika, just your stewardship in trauma informed practice, to me is just such a beautiful thing. And I'm super grateful to have you both on our show today. So any last words before we kick it off?

Claire 40:38
I think just from my side is, as I said, story is just so very, very powerful to move and shape what we do - and looking for supportive environments to do so I think is really integral especially in healthcare. So if we can do that we can create amazing things out of it. So I think looking for ways to do that is really integral.

Marika 41:00
Yeah, I'm going to really riff off your word amazing. I think it is truly amazing what happens when we connect with such care and love through storytelling and because of that opportunity, I think we have a responsibility. That opportunity can create more pain and suffering, or it can create such amazing caring connectedness and we have the power and the tools now to make it a positive experience. So thank you.

Bev 41:37
Thank you both so much.

Claire 41:38
Thanks, Marika.

Lisa 41:41
Thank you for joining SPORCAST today. we hope you will be inspired to get involved and create your own impact through patient engagement in patient oriented research, and help Healthcare Research be more relevant and meaningful.

Bev 41:56

If you'd like to get in touch with us and learn more, you can follow us on Twitter and Instagram at spor_cast - that's S-P-O-R underscore C-A-S-T #SPORcast. We can also be reached via email at SPORcast1@gmail.com or visit our website www.SPORcast.ca.