

## Transcript

Matters of Engagement podcast

Episode: "Podcasts and Patient Engagement, with SPORcast, PEP Talks and Matters of Engagement"

<https://mattersofengagement.com>

**Jennifer** 00:07

Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. This is Jennifer Johannesen. Now not to worry, Emily Nicholas Angl and I are busy preparing for our next season. But in the meantime, we have a fun episode to share with you! It's the recording of the webinar we did in collaboration with our friends at PEP Talks and SPORcast. It was a live session called "Podcasts and Patient Engagement". Our moderator was Paul Fairie from PEP Talks. And the speakers were Bev Pomeroy of SPORcast, Sandra Zelinsky, also of PEP Talks, and Emily and me, from Matters of Engagement. We each talk about our respective podcast projects, why and how we got started, ideas about sustainability, how we approach our topics and much more.

**Jennifer** 00:57

Now, one word of warning: there are a few substantial drop outs in the recording, maybe half a dozen. And there was just really no way to fix it. So I just cut them out and added a short musical break each time it happens. It sounds like this: [drum beats]. When you hear it, assume you're missing around 15 to 40 seconds of dialogue. Hope you enjoy our conversation. And thanks so much for tuning in. We'll be back soon.

**Paul** 01:28

We'll start off with the first of our three podcasts here. So I'll invite Bev Pomeroy to talk to us about to talk to us about SPORcast.

**Bev** 01:43

Great, thanks, Paul. And for me, it's good morning. It's nine o'clock here on the west coast. I'm here in Vancouver, BC My name is Bev Pomeroy, for those of you who don't know who I am, I'm a pretty activated patient partner here in BC and throughout the country. And really spend my time focusing on patient oriented research. And, you know, I come to my role as a patient partner through a caregiver role of my daughter, Sophia, who was born with a complex condition and spent about 16 years navigating the healthcare system - both through hospitals, but also Community Care until she passed away at the age of 16, four years ago. So it really is how I sort of got my jumpstart into patient oriented research - I really wanted to have an impact - and thought this was the best way to do that with the work that I'm doing. So that's just sort of me. I go by pronouns she/they, and I'm a member of the queer community here in BC. So, you know, really appreciate everybody being here. Our collaboration really kind of stemmed off of Twitter, and a conversation on storytelling, and sort of led the three of us to really come together and do a series. And then this panel conversation, just sort of sharing who we are, and maybe answering some questions and sharing some of the things that we've learned along the way, and kind of getting to know sort of our models a little bit better.

**Bev 03:04**

So I'm with SPORcast and I do have a co-host, Lisa Ridgeway, she's taken a bit of a hiatus. I'm here solo, but not to discount Lisa and I started this podcast together. Weirdly, at ABSPOR's conference two years ago almost, where SickBoy podcast was speaking. And so Lisa and I sat there in the evening listening to them. And we're really sort of encouraged and moved by the fact that these three guys could put together a podcast and have so much success and impact. We thought, "Oh, we can do that." So within five minutes, you know, I was on GoDaddy buying a domain because Lisa said "how about SPORcast?" and within about 5-10 minutes, we were off and running and had started the the initial sort of design of our podcast, and that was almost two years ago.

**Bev 03:51**

So we launched in the summer of 20... what are we 2020? I guess 2019? ... to a lot of success. So we had a lot of feedback on our show. And we sort of just kind of ran with that. And we really didn't... we put thought into it. And Lisa is sort of the whiz at the pre production side of things. But really for us, starting SPORcast was we wanted to really sort of inspire patients and clinicians and researchers and decision makers to really get involved in patient oriented research. So they could create their own impact. It wasn't necessarily about us creating impact. It was really trying to inspire other people to get involved people who maybe were trepidatious or kind of thought about it or really just to encourage others to to, to do that and to find ways to make patient into research relevant and meaningful in the areas that they're interested in or the areas that they're passionate about. And so we sort of launched with that mentality. And in doing research on podcasting here in Canada, you know, it's grown huge and it's grown incrementally in size due to people having smart speakers in their homes, believe it or not - that's what actually has sort of grown the industry of podcasting. There nearly 11 million Canadians here in Canada that are listening to podcasts - it is a huge audience, I think there's a lot of room for a lot of different content. And when I talk about these smart speaker owners, it went from 15% to 43% in one year between 2018 and 2019. And so it really kind of spurred Lisa and I to, you know, jumpstart our podcast, you know, with patient oriented research, and that predominantly is our focus.

**Bev 05:41**

Now, I think one of the things that we're talking about as a group was, you know, kind of sharing where we're going with our podcasts, and at this point in time, I don't have an answer to that question! You know, just because of things that are going on here in BC, but you know, we're going to keep doing our podcasts and keep wanting to inspire people and making a difference and building capacity within patient oriented research. So, obviously, we'll have some more questions, you know, from the audience and from us that you'll learn a little bit more about us. But that's really just our basic model. We're more of a knowledge exchange platform, you know, where we have conversations, and we introduce ideas and concepts and people and hopefully create relationships along the way. So that's sort of my sort of intro story, and happy to answer any questions as we move along. But I don't know if I'm handing off to you now, Jen. Is it Sandra?

**Paul 06:40**

Yeah. Next up will be Jen and Emily's talk about Matters of Engagement.

**Jennifer 06:45**

Sure, thank you. And thanks, Bev, for that outline. So I'll start a little bit about myself, and then describe how we kind of came to do Matters of Engagement, then I'll hand over to Emily to fill in some other blanks. So I guess, I mean, if you've been following my work for a little while, you'd know that (I shouldn't assume that you have been!) but I'll just tell you. So over the years, I have been doing quite a lot of critical writing, talking, presenting - on big themes in healthcare, particularly around patient engagement. I've also done some work around patient and family centered care and looking at some of the assumptions that we make about the value of these activities in healthcare. And, you know, what are some of the motivations and who's benefiting and things like that.

**Jennifer 07:31**

So, thinking about the various media that I've explored, you know, I've done presentations and keynotes and book chapters, articles, it even led me to doing a master's degree in bioethics. And so I've always had this kind of burning desire to find different modes and platforms to think about my own experience in healthcare, as a caregiver to my son. (That's a whole other story, but just assume that I have lots of healthcare experience!) So when it came to thinking about podcasting, it was a very natural extension to carry on some of that work. And in my professional life, I'm a web developer, I'm a content developer, I do a lot of video production for clients. So this idea of doing audio production and podcasting was really interesting to me, personally and professionally. And just thinking that, you know, this could be a way to help give some of the ideas some breathing space. When you produce something and just put it out in the world, it just sits there like a rock [laughs]. And I don't always know what's gonna happen with it, or sometimes I reflect on it and think, "you know, I might have said that differently now", or I evolve as my ideas evolve as I meet new people. So, the podcasting format felt like this really interesting way to grow ideas and to build on concepts.

**Jennifer 08:53**

Emily and I had met many years ago, in different spheres. And we had been talking very loosely about collaborating on something. And at one point, the idea of podcast came up and we weren't quite sure how to proceed with it. And that actually quite serendipitously dovetailed with an opportunity with OSSU where they were looking to support a patient led project. I had worked with them on a previous white paper that I had written on behalf of the Patient Partners Working Group for OSSU. So it was a natural fit. When we were exploring ways to work again together, I floated the idea of a podcast with them and they quite liked the idea. So Emily, and I crafted a proposal into them. And we've been running with it ever since. And so you know... the branding of it, the focus of it, that kind of evolved over the course of writing the proposal and getting approval from OSSU. And we'll get into this maybe later in this panel, but we contract with OSSU where they fund, what we're just calling loosely "seasons" - so with every six to eight episodes, we renew our contract with them. And at the moment in terms of the future direction of our podcast, we're just waiting for the next round of SPOR funding to come through. And it looks like we will be proceeding with our next season, which is great. So I'll pause there. And Emily, if you want to hop in with where you're at...?

**Emily 10:24**

I'll just round out what Jen said there because I think she gave a nice backstory - but just to say that, when I came to this project, as Jen said, we sort of knew each other before but when we discussed what we were

interested in doing, I think the idea was: we had been sitting in cafes at times or places (remember when we could sit in cafes?) and discussed some of these really tricky issues around patient engagement and things that we struggled with - I knew I struggled with, as someone who had come fully (as many here I'm sure can sort of relate to) from being a patient to this whole idea of "I'm going to be engaged" to "now I'm a patient partner". And now, I had come to a place where I had a lot of skepticism about what it had become, and I had all these questions. I was having a bit of a "crisis" of conscience, I think, working in patient engagement and not, you know, having these conversations as much as I would have liked. So Jen and I had been having, you know, ongoing conversations. And we thought, like, "Where is the forum for this?" Or "how could we do this in a different way?" And so I think when we started exploring the podcast, I remember saying, "No, they'll never go for it" like, or, "I don't know if it's gonna fly". But like, this would be really cool. Because it would mean sharing with more people and thinking through this with a broader audience.

**Emily** 11:50

And, and so yeah, so just to give that sort of aspect of why I definitely was excited about this idea to explore some of the things that I felt like I wasn't hearing a lot of conversations about necessarily, but in a way that we could sort of broaden the group that we were talking to, or hearing from and discussing with. Yeah. And so I think other than some of the questions that I think we'll get to, we'll sort of round out maybe some of a description of what we do. But just to say I was excited about the opportunity to do podcasting in particular, because it was a medium I hadn't explored before, even though I had worked in a lot of media and healthcare communication, when I worked with Dr. Mike Evans, doing sort of whiteboards and stuff like that. But this felt like a different area to explore. So that was really exciting. So yeah, looking forward to this to the rest of the questions today.

**Paul** 12:51

Last, but hopefully not least, is Sandra and I! So do you want to introduce PEP Talks for us Sandra?

**Sandra** 12:59

Sure. So I'll just introduce myself first. So my name is Sandra Zelinsky, and I'm the lead patient research partner for the Alberta SPOR Support Unit Patient Engagement Platform, and have a scroll, you know, a super long list of lived experience. So like Jen said with her story. But really, it's what motivated me and inspires me to do the work that I do, which is completely out of the box from where I started. So I've taken the Pacer program, eight years ago, and then have been doing this type of work since, specifically really focused in the research field. And so last year, this is a bit of a COVID story for us with PEP Talks. We were in the midst... so the Alberta SPOR Support Unit Patient Engagement Platform and also we have what's called the Albertans for Health Research Network... so we were in the midst of planning a patient engagement retreat. And well, COVID happened. We were trying to get there and get through it but we had to pull the plug a week before I think it was the retreat was supposed to take place. So we already had all of our speakers booked, slide decks submitted, everyone sort of had put all that effort into their presentations, in different sessions, panel discussions or whatnot. We had patient partners that would be joining us from across the country, as well as Alberta and other stakeholders. And so we thought, "Well, what can we do now that we're kind of, you know, going into this virtual space where we can still highlight the work that these people were going to share?". And so, PEP Talks sort of came from that where we thought okay, well, we can start a podcast, we can record virtually, edit virtually, do all the things that

we need to do to be able to share this information, as well as we did some webinars early on as well, as a way to share the work that people have been involved in. So I think that was really sort of the... I don't know the word... catapult? to get us going into the podcast space - was really thinking around that idea of "how can we share the work that people do?" Paul, do you want to add anything that I might have missed?

**Paul** 15:39

I was actually looking through [music break due to audio dropout].... having to cancel the event, which - just to tell you how good the timing was, this was at the beginning, before everything was being cancelled. And then genuinely, I think, an hour after we officially pulled the plug the WHO declared a global pandemic, and we're like, okay, we don't feel so bad! So born out of this vaguely emergency situation we started with, we thought it was a great opportunity to highlight a lot of the work that goes on from all sorts of different perspectives, primarily in Alberta. So both Sandra and I work directly for the Alberta SPOR Patient Engagement Platform, which is one of the teams of the Alberta SPOR Support Unit- one of the four teams right now. So we do try and use the podcast for some of our other various goals. Our team is meant to connect interested patient research partners, and interested academic researchers and clinicians to work together on projects. And I would say that - we can talk about this a bit more during the questions, I guess - but it has been a great way of us highlighting some of that work, even making some of the connections and really just letting people have conversations just about what's going on. And it's being used... some of our podcasts have been used sort of as resources for other people like in coursework, or as just things to listen to, to kind of orient people towards the practice of patient engagement in health research.

**Paul** 17:16

So Sandra and I in our roles, at least in the episodes so far, I've sort of been primarily that sort of host figure, and I think that was sort of born out of I just ended up doing it. I don't know if there was a major plan around me becoming a host, but I have this almost pathological willingness just to try new things. So it just seemed like a new thing, I think, to me, on a personal basis. Anything else that I missed Sandra?

**Sandra** 17:45

I think internally within our team, we just voted that he had the more sexier voice than, than me [laughter]

**Paul** 17:54

It's my burden.

**Sandra** 17:58

Yeah. Yes. I think that's it, though.

**Paul** 18:01

Okay. Great. So again, I'll remind people: I have some questions that I'm going to ask the panelists as well obviously, but if any of you have questions, I'll be monitoring the monitoring the chat. But for now, I will kick off with our introductory questions for, for all the panelists. So the first one, sort of maybe digging into some of the things that we've talked about....

**Bev 18:27**

[music break due to audio dropout] .... engagement, which I think is such a fascinating question, because I never actually had considered that our podcast would advance the "science" of patient engagement. Lisa and I really came to this quite innocently thinking, "Oh, well, you know, we can create a safe space where us as patient partners can have conversations with people of interest or profile projects." For us, it was sort of a modality that was accessible to us as patient partners. It wasn't super, um.... didn't cost a lot of money, timewise [laughter] I mean it's a whole other conversation as you're learning to build a podcast! But really, we never really thought about thought about it as patient engagement, believe it or not. We just thought, "oh, let's share some stories and meet some people that are doing patient oriented research." And very quickly, you know, we realized that what we were doing, our conversations, really was about this knowledge exchange - rather than the science behind it. It wasn't really ever our focus, with the work that we're doing. And often our guests, you know, we try to hit all four stakeholders that are interested in patient oriented research. So, you know, we interview patients, we interview clinicians, we interview academic researchers, and a big part of what we do is actually bring forward the voices and try to get the voices of leadership within patient oriented research, knowing that we can work as hard as we want as patient partners to make change. But if leadership doesn't have buy in, then, you know, it's a bit of a moot point. And so that very quickly became our model that we wanted to sort of ....

**Jennifer 20:21**

[music break due to audio dropout...] ... not really where I see us situated in a way. A lot of the work that, well, I'll say it this way: the space that we try to hold with our podcast is specifically around critique - not to necessarily improve things in a particular way. It's more to observe from a slightly dispassionate distance, maybe try to interpret or witness things that are happening and see how that connects to broader social issues, specific contexts - so that's kind of the exploration that we're trying to do. So when we think about "what is it we're bringing to this landscape of patient engagement", what we're trying to do is truly carve out and hold hold a space for critique [music break due to audio dropout...] ... fulfills the mission that we've set out for ourselves. And, you know, sometimes we minimize or choose not to go in certain directions, because we know that it's well covered by others. These are promotional directions, or these are kind of enthusiastic directions that other people are holding, or maybe they're more trying to elevate certain types of programs or voices or initiatives within patient engagement. And we just think, well, "that's not our space". So we don't do that. So if somebody's listening only to our podcast wouldn't necessarily get a well rounded picture of engagement - you'd just need to listen to all three podcasts to get a well rounded picture of different viewpoints [laughter]. So I'll pause there, Emily, do you want to add anything to what is it we're bringing to this space?

**Sandra 22:02**

Well, I'll give Sandra or someone else a chance to go and then I'll round out at the end if it comes to it just so we give another platform a chance to talk now.

**Sandra 22:14**

Sure, I'll jump in. So first thing I just want to pick up on, you probably heard Bev say "knowledge exchange" a couple times. And between the five of us we actually had a discussion about this and came to this realization without maybe realizing it prior to having these discussions that, in fact, SPORcast has that knowledge exchange kind of feel to it, Matters of Engagement has that knowledge translation where you're kind of really picking

apart and trying to figure out how to, you know, get people thinking about it, that critical inquiry. And then we were thinking about PEP Talks and more around that knowledge mobilization. So I'm going to just go off of that idea around that mobilization of knowledge, because I think that really is a good description of what we do with PEP Talks. I know for me personally, I see a chasm - and especially with the internet - of science, and then information that you can get. So the public trying to access good information and the scientific community kind of holding that information in academic literature, which we really don't have access to. You even see it in this whole COVID space where people question so many things. So I feel like with PEP Talks, it's a platform where we provide a space for people to share their work, and in a way that is conversational, a way that easy to understand. So if somebody has done specific research where they've partnered with patients in research - it's a place where they can share that work. And it's not all in the published literature.

**Sandra** 24:09

So I see it as a way of bringing many perspectives, patient research partners, or duos - so a patient research partner that is partnering with an academic researcher - academic researchers... whoever has done some of this work in this space, whether it's new, or they've been around for quite a while and have done quite a bit of work. I think it's great to get all those different perspectives and ideas and be able to share that with one another. So I think our hope with the podcast is really bringing those voices and experiences, the work that people do, to be able to share that and hopefully.... other people that are listening to our podcast to think differently, perhaps, or learn different approaches to patient engagement or patient oriented research. Or even think, "oh, wow, this is actually really interesting. I think this is something I would like to try out or get involved in". So planting that seed for potentially some individuals as well. Paul or Emily, do you want to jump in?

**Paul** 25:28

I'll just make one small point - it has the additional, for us, as the Alberta SPOR Patient Engagement Platform, so very much this intermediary role, trying to excite interest in patient engagement and facilitate it in the province - it provides provides us with a really practical library of resources. Literally, we can say, hey, you're interested in this for the first time, maybe listen to these one or two specific podcasts that we can point out to kind of socialize it around. So I do feel like a real advantage of it is just sort of normalizing and socializing some of these practices. Because as much as I think a lot of people who use patient engagement approaches in research from all perspectives feel like it's sort of normal, there's still a whole world of health researchers out there who have never even really considered it terribly deeply before. And I think the podcast approach that we take is helpful to this sort of audience as well.

**Emily** 26:30

[music break due to audio dropout...] One thing I'll just add, that I think has come up in our podcast and that I feel strongly about in terms of this idea of these podcasts "enhancing the science", if we can call it that, of patient engagement is just the amount of "doing" that happens in patient engagement. And as someone who works in it, or has worked in patient engagement in terms of trying to facilitate patient partners, and doing the evaluatio... it's a lot of doing with a lot of assumptions, I think, at this point. Because we created this world of patient engagement out of an underlying concept of needing to hear from people with lived experience, or patients, or however we want to term it = but then it became sort of, "Okay, now go!" And so this research project will have to do these things x, y, z. And then somewhere along the way... not somewhere along the way,

excuse me.... I didn't feel like there was a lot of space for what we're talking about here - for those researchers, or for whoever's doing it to stop and think about some of these muddy issues, and some of the things that end up contradicting each other and some of.... there's not a lot of space for that. And so if we are to "enhance" at all the science, I think, you know, in Jen and my case, the way that I would only see that happening is not so much as, "here, we're going to direct you on the science or here's what we can learn about how to do patient engagement" - it's that it would create some pause or critical reflection, and sort of taking a step back from just the doing. And I think that's come up for us a few times, even in interviews with people, and actually, from feedback we've had from others is that that might be something that our podcast has done for them - is to say, "wow, I just always just did that. But I didn't really necessarily stop and think about it". So if we were to be enhancing it in any way, or contributing to it, I would hope that that would be where... and I know that for my own work, in the way I would approach patient engagement, that's what it's done for me is stopping and actually questioning what I'm doing.

**Jennifer** 28:55

Yeah, I'll just I'll just add: I really liked in our last episode, Emily, one of the things you said was that this process is really complicating your relationship to it. And I really liked that a lot.

**Emily** 29:06

Yeah that was that was the point.

**Jennifer** 29:10

Yeah, exactly. And it's part of what we hope would happen for others- is that it complicates their relationship to it.

**Paul** 29:18

So we have a great question in the chat that I'd like to build off for our next question for the panel, which is the simple and complicated question of: do we have any way to evaluate impacts - a question from Mary, and just a reminder to everybody else to put your questions in the chat. So how do we know we're succeeding or, or doing a good job with these podcasts?

**Bev** 29:43

I think that's another interesting question around impact. And I think it also is: what does impact mean to you? Right? As someone who has a podcast, all of us probably have different ideas of what impact is, or what we would like to impact along the way. Obviously we have statistics, we know who our listeners are, we know what countries they're from, you know, we know how long they listen to our particular episodes, we know which episodes garner more listeners than others. So, you know, we see themes that are going on in our community of patient oriented research that resonate with people or particular guests that resonate with people and their personality. So we definitely have the hard stats of who's listening, where they're from, and what they're what they're listening to. So, you know, I think that with any digital platform we always have to look at analytics. And that's something we all do, I think, with all of our podcasts, but when I think about impact, I guess for me, it's a lot of different things. So, how do I know that we've had an impact? Well, we get a lot of emails from our listeners, we get a lot of requests, and I think Mary put one in the chat box there too - yes, we get a lot of emails

and requests from teams to profile or highlight the work that they're doing. So that's how we know that we're having impact because people want to come on the podcast, and share their stories and share the work that they're doing. So for us, that means "Okay, we're getting traction". We know even through our social media how many impressions we get. So there's all these different things, but like Mary brought up in the chat, that's how we know we have impact when people are reaching out to us and contacting us and saying, "I loved that podcast, can we talk about that too", or here's another angle to that impact. The other piece too, is that often, many times a week, I'm getting emails and requests for support. To help other organizations set up their podcasts, and support and build the capacity of podcasting itself. Not just this idea - I shouldn't say "just" but you know - beyond patient oriented research and patient engagement, supporting other people to create podcasts for their organizations for their particular audience.

**Bev 32:15**

So again, that's how we measure impact. And the other piece for me around impact, really is some of our content. So we don't shy away from having difficult conversations. And we know there are certain episodes that probably are a little bit prickly for people to listen to and may challenge some thinking and can be a little bit provocative. And, I always go back to my conversation with Charlotte Loppie around trauma and trauma informed practice, which is a big thing for me right now in patient engagement that I think we're missing is trauma and resiliency informed practice for patient oriented research. So as an idea of impact from that episode, we all got interested in TRIP, which is what we call it. And as a result, we have developed a two part workshop for trauma and resiliency informed practice, specifically for researchers and evaluators. So there's a tangible.... there's a product or a service that has been created as a result of a topic and a speaker on our show. We definitely don't shy away from that. So those are just some things that that we think are impact. And just from a personal perspective, again, because we're not necessarily associated with any organization or individual, just from a personal perspective, it definitely has increased our brand awareness, and has absolutely provided opportunities for us to attend events to speak, to really increase our impact and our audience along the way. So that's just... when I look at those questions, that's sort of my answer to that. And I'm curious for Jen and Emily and Sandra and Paul to hear your take.

**Jennifer 33:58**

Okay, no, I was gonna say, Sandra, you don't you go next? Because I think ours is maybe a little bit more anecdotal. You go ahead, and I'll follow you.

**Sandra 34:07**

Paul might have a totally different perspective or a way of looking at it, then then I do. But so with the work that we do at the Platform, a lot of what we're trying to do is to get more people involved in doing this type of work, really. And so, for me, my measurement is probably a lot smaller. I feel like that if we have somehow one person with lived experience or researcher who listens to the podcast, and it shifts their way of thinking or shifts like thinking, "Oh, this is something I would be interested in getting involved in, I have lived experience. I have a lot of knowledge behind what I've been through", I feel even having that little stone in the lake with the ripple that might happen is an impact to me. So I'm not looking at it as if we have a million followers or retweets or something like that. If it helps people in their work, or it helps people get involved in this work, you know, I'm happy, even if one episode helps one person do something a little differently than they did before, or they got

involved in a different way or something along those lines. So, obviously, it'd be nice to have more than just one person listen to one episode! But the point being that, you know, it's those small changes, because those people also go out and then have impact with the work that they're doing and make changes. So, yeah, I'll stop there.

**Paul 35:58**

I wouldn't add too much. I mean obviously, as you said, like we don't... [music break due to audio dropout] ...quickly after, after releasing most of the episodes, so from that perspective, it's already more than a great replacement. But I think for us, additionally, maybe two things: is it a resource that we can share with people when we're helping them with the process and practice of patient engagement? That's always a success to me when we do that. And as well, one of the processes that our team is supposed to sort of engage in is literally engagement! So sometimes literally the act of recording an episode is its own success of allowing us to reach out to people, and this kind of gives us a venue to do that, as well. So it sort of has some interesting, unexpected process implications and benefits for us as a team embedded at a university.

**Jennifer 37:00**

So for us, you know, the question of impact is really complicated because - the way I expressed it earlier about holding a space for critique - it's hard to observe that out in the wild! That somebody is now thinking critically... we don't have a feedback loop that allows us into people's brains to see how an episode has landed. You know, obviously, we have statistics, we know that with every episode we released, there's a little bit more of a base of subscribers, a little bit, you know, listeners... we also know that people discover our feed all the time. And so they might go back and listen to older episodes. So our numbers go up, but they're listening to older episodes. And so it's sort of hard to parse all of that out in terms of listens or downloads, so I don't pay a whole lot of attention to it. Although, it's interesting to note which types of episodes are more popular and which ones seem to get shared more - so that's interesting. I would say that if I could just reframe it slightly, it's maybe thinking about how do "we" think about success. And so impact would be nice to understand - I don't really know, I do have lots of anecdotal stories, you know, people writing to us or connecting with us in some way.

**Jennifer 38:22**

And my favourite types of feedback are.... you know of course, I love hearing that people have been thinking, listening thoughtfully to our episodes, and it's made them rethink... but very occasionally, I get a very punctuated response [laughs] where recently, somebody who I think of as sort of unshakable, listened to one of our episodes and said, "you know, that one really freaked me out!" And I just thought, "Okay, great, we've done something, we've done something cool. So in terms of impact it's a bit of a slow burn. I think critique is not a thing people seek out. People in engagement, I think, who are enthusiastic, people who are looking to improve the space or, you know, connect with others network, do the knowledge.translation in a broader sense, are not necessarily seeking out critique. And so I think when we find when our listeners find us or when we connect with our listeners, it's almost by definition a kind of small group. I think we have a fairly narrow focus. And with Matters of Engagement, in particular, we're going to maintain that focus. And so growing numbers is not really our point. It's more about expanding our thinking. It's about Emily and I getting more nuanced and building our themes as we go.

**Jennifer 39:49**

And so with every episode, we really reflect on how it felt for us and whether we captured what our guests were saying respectfully and fully, whether we translated that properly, how that leads us to other topics. So it's a pretty inward journey for the two of us in terms of production. And I'd be super keen to hear from people at some point, if they have ideas for how to engage in a feedback loop of some kind. I'm so excited about just seeing all these names, even though I can't see your faces. I love knowing that at least some of our listeners might be participating here, because I just don't know any other way. I know for me listening to podcasts, sometimes I listen to something. And I'm just dying to talk to somebody else about it. But because it's so asynchronous, people just listen to an episode and they're in the grocery store and then what do you do? You can't call people, there's no listening community around it. So, yeah, it's a question that sits with me quite a lot.

**Jennifer 40:00**

Actually, it's a great segue to to a comment here from from Paul (not me!) in the chat, that I'll just read it out. I was taken aback by the emotional impact on me as a patient contributor to health research of the Matters of Engagement series, which accumulated as one episode felt the other. Was that emotional space for impact intended?

**Jennifer 41:20**

I'll answer that [mumbles] I mean, kind of Yes. I mean, at the beginning.... well, I'll tell you, we had two seasons so far - the first season..... and I think we said this in one of our episodes, Emily, we did a little fireside chat - but we were able to plan that season all at once. So we had done a series of interviews, and we looked at all the topics, we scoped out what the themes were going to be for the series, but we weren't quite sure what order they would go in and how they would build. We had many conversations about whether we thought the listeners would be ready for certain episodes. O whether we were ready to present certain episodes or to think through some of the concepts. And so we did sequence them in a very particular order, so that it felt like you were kind of slipping into the waters a little more slowly and that we could build to particular themes, where we felt like we'd maybe built enough trust and exposure and interest to tackle certain things that felt very heavy. And then for Season Two, that came together slightly more organically based on opportunity and who we could interview. But there were times when we'd have two or three in the queue, and we would think very thoughtfully about what order we were going to put them in, because we knew that in some ways there was a rationale for the sequence we were going to put them in. So yeah, thanks for that question, Paul. Emily, did you want to add to that?

**Emily 42:54**

I'll add something and then maybe we can sort of open that up to the other group, to the other podcasters too because I think that kind of consideration of emotional impact when this is an area which is interesting, because although we might be talking about health research, and we're working with these health research organizations, there is this sense that the issues we're talking about can be fraught. We talk about impacts and risk. Bev brought up trauma informed practice, and we even have to consider with our guests what we're asking them to discuss and what the impact of that is. I know I have literally laid awake at night thinking "how do we do this in a way that's, you know, thoughtful and critical" - I don't want to shy away from asking questions but also not sort of putting onto anyone else, not criticizing somebody, especially personally or not recognizing how

much emotion - for even I know myself as a patient partner previously or someone who's just the fact that in any way my personal life is connected to my professional life, it's all intertwined in that way. There is this other layer of consideration when you're talking about these topics. And it becomes very.... I become somewhat overwhelmed by it sometimes actually, because it's so complex - how to do it and I don't think there is one way to do it correctly.

**Emily 44:29**

So although I think we definitely approached it wanting to have emotion and consider the emotions and personal aspects of maybe engagement and the broader engagement world - I think that it's also just been something from not so much like "that's what we want to cover in our podcast" but it's also just been something from the approach to our podcast we've had to consider. And I'm glad though that it does sort of ignite emotions in people because that's, um, it's something in terms of our responsibility to know in terms of how we cover things. So having that feedback's useful, and I wondered if the other if PEP Talks and SPORcast also have had that - you know, you start out, you interview people you do, and then the kind of emotional impact or the the more subtle aspects of this work? Definitely, I'd be curious to hear your thoughts?

**Bev 45:28**

Yeah, I can. I kind of live with my emotions on my sleeve - talk to my family about that! It could be a good thing, or a bad thing. I'm a good Irish girl, that's the red cheeks. So when it comes to patient engagement, or our podcast, in some ways, it is a platform and a forum to speak our truth and to speak our experiences with guests on our show, in a respectful, meaningful, hopefully impactful way where people can learn. Or maybe they identify with our conversations. Because our style of podcasting really is a conversation. We want people to think that we're sitting in their living room, having a conversation with them and with our guests. And that's the model that we chose to take, because that's kind of what we want to do, similar to what other people are saying, and Donna's just talked about it in the chat... you want to have someone to have these conversations with. So we really, with our podcast, "use" our podcast because we're genuinely curious about the guests that we have on and the topics that we're talking about. So we lean into our own curiosity when we're choosing themes or guests to come on the show.

**Bev 46:43**

And some resonate more, because maybe we've had a personal experience or impact, with that particular theme or that particular area of patient oriented research. For Lisa, and I, you know, I can't speak for Lisa as a whole...but it really is hard for us to separate us as people, as patient partners, as people engaged in patient oriented research, and our podcast. I kind of think it's just another way that we can communicate our desire to increase patient oriented research to inspire other people to get involved with patient oriented research. But when it comes to the emotional side of things that actually has... it's an interesting question... that has been probably my soapbox item for the last year when it comes to patient engagement. Whether it's through a podcast, whether it's through an event, whether it's through engaging with someone in a research project - I don't think we have considered the emotional impact of patient engagement enough. I don't think we have tools and resources that can inform and build capacity of the organizations and staff, as well as the patients that are being involved in patient engagement.

**Bev 47:52**

And with the podcast, it is something that we're very mindful of and, you know, this coming year with the different episodes that we're having, that sort of self compassion piece is definitely gonna gonna sort of be within our podcast itself and to encourage safe space. And again, I'm part of a queer community that, you know, we have not been treated well in healthcare. So you know, we are a little bit trepidatious. So I'm just really mindful of the emotional impact that we can evoke within our different podcasts that we have. But I don't think it's something that we have considered enough. And I think it's something that we need to start ensuring and modeling in the work that we're doing in patient engagement, particularly in patient oriented research. So I'll get off my soapbox item right now, but it definitely is something that I think about a lot.

**Sandra 48:46**

I'll just say, real quick thing. I think this is a great discussion, really important conversations to have. And the point around having a space to actually talk or feedback and talk with one another about it - we actually discussed this as part of the planning of this session, where we thought "oh, maybe we'll make it kind of like the podcast Journal Club". So we bring our storytelling series to this group, and we have more of that journal club style conversation. So anyway, it just brought that up because I think it is really important. There's so many topics to dig into. And I think many of us have patient research partners have really probably walked that line on, you know, on the fence where you're like, "am I in or am I out because I'm not really sure how things are going here. I'm really struggling with certain aspects of this work. Is it meaningful, you know, am I really making an impact?" There's so many questions that come up with doing this work and so I think these are really important conversations to have that we can't just ignore. The podcasts are a great space to have one on one discussions or, you know, two on one or whatever two on two discussions with people. But yeah, it could definitely be brought out to that larger community as well, I think. And I'm sort of building off some of the comments in the chat box of that feeling. And I know too, I've listened to SPORcast and Matters of Engagement, and I'm out for a walk, I'm like, "Oh, I have respond, I want to talk to somebody about this!" And well, they're not listening to the podcast, at the same time, whoever I'm going to try to call or reach out to so yeah, it's I think they're really important discussions to have. And I'll just leave it at that.

**Jennifer 50:49**

I just wanted to add one more thing too, about our process. I'm not sure how evident it is in the final product when we release our episodes - but truly, Emily and I agonize over some of these questions about... we're calling into question some very deeply held beliefs that people have, and they've put a lot of their time and energy, money, they've invested themselves into a system and a process that Emily and I are kind of chattering away about, "Oh, is this thing worth it?" And, you know, I think we sometimes handle it more sensitively than others. But you know there are times when I look at what we're about to release, and I think, "are we just leaving people with nothing but criticism and despair? What do we do with this? And where do we wrap up this episode?" because we've done something potentially upsetting - you know, like the one person who said that episode really freaked me out! And I can appreciate that these are difficult and I think about moments I've had listening to podcasts or attending seminars where I think "I can't do this thing anymore", whatever that one thing is. So I think it's important that we all, in whatever we produce for public consumption, has a measure of sensitivity to that. And then if we err on the side of sometimes softening the message a bit too much, then that's fine. I think that's better than alienating people or causing damage, which is not really what we want to do at all.

**Paul 52:35**

Maybe one final thought that I'm having about this. So I feel like our episodes maybe don't veer into as much of an emotional journey, perhaps as some of the other podcasts. And I mean, I do spend a lot of time when we're preparing for them, trying to think about how to phrase questions just to make people feel comfortable sharing them. But it's also I think, the focus of the content is more about the process and practice of patient engagement, which maybe doesn't inspire quite as much strong emotion in people. I'm just asking "what project did you do? And what should you undertake?" So it might be that. But I feel a lot of that preparation is actually, we do spend quite a bit of time thinking about how to ask questions in a way that will make people feel comfortable asking. Because essentially the process for recording is part of the context here as well, which is that half the time, it's people I have now met for the first time seven minutes before we've started recording. So creating even a basic level of comfort is important just to have the conversation go anywhere particularly useful.

**Bev 53:45**

I just want to add to that, Paul, and just say that creating a mutually safe space is just as important online as it is offline. It may look and feel a little bit different, but they're just as important.

**Paul 54:01**

Oh, no, for sure. It's just as important. And maybe just me feel like it's a little bit harder even... [pause] So maybe this next question combines a few things from the comments and some of the things that we've talked about before. So we do have all these different positions of what our podcasts are supposed to do and how they're positioned sort of organizationally. Maybe we want to chat briefly about what are the future plans for our podcasts? How do we plan on sustaining ourselves into the future? And what what does this year and next year look like for us?

**Jennifer 54:50**

I could go. So our model is.... pure capitalism [laughs]. I'm joking. But we are well- funded, and it allows us to have time to create our episodes. So OSSU funds us for the moment. And as I said, we renew it contract by contract and for the foreseeable future, barring... anyway who knows, but our next season is... (everyone can see me crossing my fingers) is going to go through. One thing I want to say about the sustainability part is we've kind of set up a model for ourselves where it is essentially required that we be sponsored in some way because of the amount of work we put into it. So I was doing a back of the napkin calculation - and Emily, I think you and I, between us, we spend easily somewhere between 30 and 45 hours per episode - to plan, interview, do the research, and then the scripting and also all the technical configuration of an episode. So it's an immense amount of work. A lot of it - if we figured out our hourly rate, it would be really low! - but in terms of what would a commercial podcast cost to produce, it's certainly good value for what we're providing.

**Jennifer 56:13**

So where we could work on sustainability and efficiency is maybe in streamlining our process a little bit, trying to figure out how to maybe find less expensive resources to do some of the tasks that we need done. We each have our strong suits and our our skills that we bring to the table and there are a few things that we maybe don't need to be doing ourselves where we could have somebody else do some of the scheduling. So there's

pieces around when we talk about production sustainability that we could work on a little bit. I also think that maybe varying up some of our formats might be helpful. We've actually had some occasional feedback where people might like to hear more long form interviews, as opposed to always these edited essays that we produce. So [mumbles] well, it's less production in the long run, to host an interview and produce it. So I could imagine maybe varying up some formats over time, in terms of trying to be more efficient with how we produce our episodes. Yeah, I think that's it.

**Sandra 57:30**

I'll jump in next Bev, just to mix it up and then we'll put you last this time, or Emily, or Paul, if you want to jump in too. So our approach has been quite different, hey Paul? Because it was a COVID story, we really just jumped into the deep end, and almost in the flurry of COVID really started. So I did a lot of the background work and logistics of planning and booking and connecting with people. And then Paul would do the interviewing. And so we're at a space right now where right now we're playing catch up. And we have to do a bunch of editing and then releasing episodes and planning that schedule out.

**Sandra 58:17**

So obviously, we're supported by the Alberta SPOR Support Unit Patient Engagement Platform to do this PEP Talks podcast. And so between Paul and I, we've sort of folded in one other team member to help with some of the editing, which can take quite a bit of time as well, and then just spread out our roles a little bit more. You might hear my less sexy voice on some of the podcasts [laughs], just recording some of the intros just to try to maximize our time and spread it out evenly in between the three of us that will be taking us on as we move forward. So the near future plans are really to get out some episodes we've already recorded. And then look at after that looking at who are we booking, and what kind of guests are we going to be looking at having and how often are we going to be releasing those podcasts. Maybe Paul, you might want to add a little bit more to that but from being fully transparent that's kind of where we sit.

**Paul 59:31**

I mean, totally true. We were halfway into it before we even planned about what we're gonna do. I think that is sort of partially the truth. But I would say our model for sustainability in the podcast has its pros and cons. Pro, because Sandra and I are literally like we're [music break due to audio dropout...] ...part of all of our other things. So sometimes the resources available - ie time - to do the work sometimes ebb and flow for us. So it's sort of good sides and bad sides to the approach.

**Bev 1:00:10**

I guess that leaves it to me or Emily?

**Sandra 1:00:14**

Bev, why don't you go - I might just have a comment right at the end.

**Bev 1:00:20**

So SPORcast is completely independent. Our sustainability model is coffee and ferry rides between Lisa and I, from Vancouver to Victoria. Obviously, with COVID, we've flipped everything over to Zoom. So we don't have a

formal relationship with any organization or group here in BC. It definitely is something when we created us SPORcast that we had anticipated and obviously want to have collaborations but with the timing and different things, it wasn't something that we were able to do. However, we do get asked a lot, or I do anyways to consult and help other people set up their podcasts. And it's a fee for service. And then some sometimes we do series for organizations, and again, those are fee for service for those series to be on our platform. So it's almost like an advertorial for certain organizations or topics, similarly to a lot of business magazines. So that's sort of our sustainability model.

**Bev 1:01:25**

Moving forward, I'm not quite sure. Lisa has taken a hiatus. So it's kind of fallen all on me - gratefully - that we can still do this. So I'm looking at ways to do this in a way that's meaningful. And I'm just looking at Colleen and Lucy's comments in the chat box, talking to Jen and Emily about critically discussing key issues. You know, and we need talk more about that. And then Lucy talking about elements of labour behind engagement projects and funding behind projects. And I think they're two of the same, right? So if we're looking at podcasts or patient initiated work, which I think our podcast falls into that lane, what is the sustainability model? What is the financial model? What does a contract look like with patient partners that are being engaged with particular organizations or academic institutions? I think these are all questions that we don't necessarily have the answers. And I don't think there's any one model. That's the end all be all to how we move forward with patient engagement or patient initiated projects like this. I think there's a lot of discussion that still needs to occur. And of course, the big thing when you're partnering with organizations, and I don't know what Jen, Emily, and Sandra sort of perspective is on this, is the editorial. So that is something that we've considered moving forward, is we want editorial control over our content. And that often is a barrier for us to create a sustainability model in regards to a contract, or support or sponsorship with organizations. So that's another thing - do we remain independent and have editorial control? And do it off the side of our desk? Or do we enter into a relationship with an organization and lose some of that editorial control, if not all of it. So those are just some things that that we think about in regards to our podcast, but we're still moving forward. And we'll continue doing SPORcast as long as it's meaningful and fun. And people... [music break due to audio dropout...]

**Emily 1:03:28**

...You know, actually, let's move on to the next component, just because there's only so much time left. And I want to make sure that if we have another question or anything?

**Jennifer 1:03:36**

Well, I just want to follow on one quick thing Bev said... just to give you hope that it may be possible to find an organization that is willing to give you full editorial control. I mean, "full"... if I said 100% it might not be it might not be fully accurate because Emily and I both are aware of where our support comes from. And so we consider that as we develop our episodes. But it has not stifled us in terms of how we editorialize or how we talk about engagement. And we've been, frankly, pleasantly surprised that there's been this much autonomy in our project. And it's what we contracted, but whether that was going to play out in reality, we weren't entirely sure. But it's definitely something I came right out of the gate with in terms of ownership of the content, even when sponsorship ends, for example. So the Matters of Engagement podcast is ours to continue as we see fit along with all of the content with the first however many seasons sponsored by OSSU. So that's how we've set it up.

So I'd encourage you and anybody else thinking about that balance to, you know... there will be compromise at points, but I wouldn't say it's mutually exclusive that you have support and sponsorship from an organization and editorial control.

**Sandra** 1:04:59

One quick thing, just with several of the comments more recently in the chat box around compensation and the power dynamics involved in engagement, I think that could be really great collaborative (planting a seed!) collaborative series where, you know, we explore separately, different aspects of whatever that specific topic. So it's if it's around compensation or around something along that line, that can be another type of collaborative series. Because I think that the positive - and this is just my perspective around the storytelling series - is that we went off and did our own episode, but yet we really came out with very different information, perspectives, conversations that came from those episodes. And it's a way to kind of dig in deeper, without just doing one episode as a solo podcast, like say SPORcast during an episode on a specific topic - we can really kind of dig in, and get more information when we collaborate. So I'm just saying I love the collaborative part, and sharing a three part episode series, because you just get more out of it. I felt so, anyway...

**Emily** 1:06:25

And maybe that's where we can have a sponsor who's looking to investigate a certain topic, like, I have thought about this in terms of models, you know, that there could be... there's a lot of researchers, organizations, people who are looking to explore some of these issues, as we see they're resonating with a lot of people here. And I think, being able to say "Yeah, what if we did look at building some content around that", it would still have editorial control to explore it but what it would do is, if there are areas that people are looking forward to take a deeper dive into, or to do an exploration with people with different perspectives, or just a different medium. You know, I do think this is an interesting way to kind of approach - maybe research is the wrong word - but like investigation and reflection - to do something like this, if organizations out there were looking to get creative with how they investigate and explore these things, and involve people in exploring them and making them accessible to explore. I do think that's part of what you know, we can offer. So "now a word from our sponsor". But I do think that is, you know, these kind of one off projects or pieces can be another way to look at it instead of just in a series

**Bev** 1:08:00

Podcast listeners predominantly listen to the podcast, not just for content, but because they follow the host. So the majority, from a research perspective, and the podcast data that's out there in Canada, is that podcast listeners will follow a host more than they'll actually follow a topic, believe it or not. So what you're talking about completely resonates. And there's an add value, you know, to hosts and to podcasts that we don't typically talk about in a healthcare setting, because we're a social healthcare system. But if we look at social enterprise or social innovation models, it would be safe to say, Emily, that that model would be very successful for anybody who wants to engage with us, collaboratively or not.

**Paul** 1:08:51

So we are going to our last 10 minutes. So I was wondering, two options - if there were any final questions from the audience, and then we can move to any final thoughts from the panelists? So I'll beseech you if you have any

questions to offer them now? Yes. Oh, so I see a question from Amy. Amy, do you want to do want to ask your question directly or,

**Attendee 1:09:21**

Okay! Am I allowed to ask my question, am I on? I need to dig through where I wrote it. Where did I write it? Oh, it was just basically to ask that given what you now know, through running these podcasts and inviting a wide variety of speakers onto your podcast, knowing what you know now about patient engagement. What would you say to yourself, say five or 10 years ago, when you first got involved?

**Sandra 1:09:49**

I can start. And this is how I'm kind of ... this is partly a podcast but also through my own lived experience of doing this work and my work with the Patient Engagement Platform, because some of the work I do is in research teams bring together, you know, it's come together as a team. So bringing together patient research partners, academic research, and working together, whether it's forming advisory councils are not. And so I still work very closely with patient partners that are very new. [music break due to audio dropout...] ... very new, having no idea really what I was getting into - just feeling so out of the box, and really not even understanding the value of my lived experience. And so I think it's really that reassurance of that idea that nobody else has an understanding of lived experience unless you've been through it.

**Sandra 1:10:49**

So yes, researchers, clinicians have a very important perspective and have a technical expertise which we value. But if you haven't lived with - fill in the blank - it's a completely different perspective that you bring to the table, in my opinion. So that helps to round out and bring those perspectives to the table, so that you don't leave that behind. And in the end, hopefully, research and the results of research are more meaningful and relevant to the end users. And then also, just by way of doing it that way, hopefully, to the researchers as well, that they feel that their research is more meaningful in the end. So yeah, and I don't know if that's directly related to the podcast, so to speak, where we're really providing a platform for people to share their work. So really helping to educate, bring awareness, share different approaches in patient engagement, or patient oriented research. But really when it comes to, especially patient research partners, it's that value piece. Your lived experience, your journey, is really important. I've been around patient partners that even want to compare - well, that person has gone through so much more than what I've gone through. And this isn't a competition - your lived experience is just as valuable as anyone else's. And that's why we bring, you know, many voices to the table. So that would be my thing is to have... so the advice would be to be patient, there's a huge learning curve, you'll get there, you'll get to know the project, that takes time. And, you know, as you move through it, it will make more sense.

**Jennifer 1:12:49**

I'll answer next. And it's maybe on a slightly different register than something practical. And it's that as we've carried on with this podcast, it's become clear just how much appetite there is for critical discussion in this space at this point. And, I don't know if it would have been there 20 years ago when I was more of an engaged patient at the time, but some of those uneasy feelings that I had 20 years ago, I'm seeing now that people are very keen to talk about it and surface it and question things. And so, I think as a younger, active, engaged patient, giving voice to some of those concerns I had at the time maybe would have served me well. And I would also say that I

still see now, even amongst the more critical discussions, there's still a layer of what I still call ideology - there are assumptions about what is good, what is right, it's like a collection of ideals that all make coherent sense that don't necessarily get probed or questioned. And so when we speak to a wide variety of people, even when there's an earnest interest in trying to get to the meaty stuff, there's still lots of layers of language and terminology and vocabulary that don't quite sit quite right with me. So anyway, I would say that if you have concerns, speak them, bring them forward and get people to really say what they mean, because there's a lot of lingo and language and shorthand in the space - as there are in every space - and so, that's what I would say.

**Bev 1:14:38**

I think for me, I've been a patient partner before we were called patient partners for 20 plus years, in particular in a pediatric space for many years. And I think for me, Amy, things have changed when I first started doing what I was doing in regards to pediatric support and patient partnering. You know, I was an ally and then as I evolved in my journey and my experience of being a patient partner, I then became an advocate, sort of helping other people, advocating for my daughter, advocating for change in health care, delivery services and community health care. But 20 years later, you know, I now consider myself a steward, where I'm now creating an environment for patient engagement, an environment for learning about patient engagement, an environment for patient oriented research where we can be successful, but it's about stewarding this environment for - and I see the podcast as that stewardship. And the podcast is creating an environment for stewarding that capacity building and stewarding those ideas and stewarding these new thought process and stewarding controversy, and stewarding, you know, what our assumptions are - all those different things. So, that's kind of where I'm at. And maybe had I gone back 20 years and said, "You know, you'd have a lot more gray hair and you'd be frustrated" but at the same time, understanding appreciating the evolution of being a patient partner, and our own journey to impact, and just know that we all have our own journey to impact and it looks different for everybody. And I would not have anticipated I would be here where I am today if you'd asked me 20 years ago, in no way shape, or, you know, anyway...

**Emily 1:16:28**

I'll try to do a quick one, because we only have a couple minutes. But I do want to say that, having started in the world of engagement as a "keener", I'll say, with wearing with all the toots and whistles, and "yeah, we're at the conference!" and we're gonna ask... and then really come through a process which was quite - to go back to something - emotional, to start to think about, like, wait, maybe this isn't actually all about just making it better for the world, and roses and kittens and things. And starting to look more critically at underlying structures, which I suppose is just maturing. But I would say to myself at the beginning: talk to more people who disagree with you. It seems so simple. But I do think that because it was the idea of engagement and having people's perspective who have lived through disease or health issues was so logical to me to include in health care, that then I didn't question the fact that there are implications outside of just that logic, for therefore putting people with lived experience collaboratively in with institutions and just doing it. There was a few steps in between. And I don't think I questioned that this underlying logic, which I felt made sense, and then the application of the way that things were being done, there was a missing piece in there for me, where I didn't question how we were doing it, I think. I just took the underlying concept and ran with it. And so I think I would like to go back and surround myself a little bit more with people who maybe were questioning it along the way. So that now in retrospect, I do feel like I end up questioning some of the decisions I made because I wasn't questioning it earlier

or early enough. But that's part of why this is such a pleasurable and enriching experience to do this podcast - is now I feel like I'm starting to have conversations that I never had early on.

**Jennifer** 1:18:46

This episode features Bev Pomeroy, Sandra Zelinsky, Paul Fairie, Emily Nicholas Angl, and me, Jennifer Johannesen. We'll be back soon with another season of Matters of Engagement.