

## Transcript

Matters of Engagement podcast

Episode: "Season 3 Finale: Patient Partner Reflections, brought to you by OSSU"

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## SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Annette McKinnon, Bilqis Williams, Stuart Nicholls

### **Jennifer** 00:06

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

### **Emily** 00:14

And I'm Emily Nicholas Angl.

### **Jennifer** 00:17

Well, here we are - the last episode of Season 3...

### **Emily** 00:21

I know! Can you believe this is our 28th episode so far?

### **Jennifer** 00:27

Yep. And even though it's the last episode of this season, there is plenty more to come! But more on that later. For now, we want to acknowledge the support of the Ontario SPOR SUPPORT Unit, which has provided the funding to get this project off the ground and establish a solid foundation for critical dialogue about patient engagement and partnership.

### **Emily** 00:49

So we're handing this episode over to some members of their Patient Partner Working Group: Annette McKinnon, Bilqis Williams, and honorary member, Stuart Nicholls. We invited them to share their thoughts on patient partnership today, and where they think it's heading.

### **Jennifer** 01:07

We hosted the conversation and asked a few questions. But mostly we stepped back so they could openly share their experiences, thoughts and ideas for the future.

### **Emily** 01:17

It's definitely a good way to end off the season. And Jen, we don't really debrief at the end of this one, so let's sign off here. We'll be back very soon with an update on what's next.

**Jennifer 01:33**

Okay, so without further ado, here's our conversation. See you soon, Emily.

**Emily 01:38**

Bye for now, Jen.

**Jennifer 01:42**

I'm going to go in alphabetical order by first name. So I'm going to mute myself and I'm going to ask Annette, to introduce yourself and tell us a little bit about how you came to patient partnership and research.

**Annette 01:54**

Okay, thanks. Well, I'm Annette MacKinnon from Toronto. And I would identify myself as a patient partner. Once I retired, I wanted to share what I'd learned through 30 years of rheumatoid arthritis. So I started a blog. And I became active on social media. And started reading papers about rheumatoid arthritis research papers that I thought were interesting. And that led to participation in a design challenge of Medicine X, which was a Patients Included conference. And so for the challenge, patients were put into a group with a wide variety of professionals and patients presented an issue that was a problem to them. Actually, we started out with 10 and narrowed it down to three and the group chose one. And so the challenge was to pick the problem and create a prototype and present it by the end of one day. And I ended up presenting my group's results on the main stage at the conference. It took me an awful lot of thinking, before I got past the, "my group was brilliant" to the "my team was brilliant". And realized that in all of the challenges, the patient was part of the team. So that belief that it takes the whole team around the table to produce the best results is at the heart of my involvement.

**Jennifer 03:30**

Thanks, Annette. And Bilqis?

**Bilqis 03:32**

Hi everyone. My name is Bilqis, Bilqis Williams. My background is in medicine. I now practice as a public health practitioner. I bring to the table my experiences as a patient partner, both for myself as a patient undergoing gynecological procedures, also having a child in Canada as a new immigrant, and also being a parent / caregiver for a person for a child. I represent the voice of multiple persons who read and live like me. Thank you.

**Jennifer 04:10**

Thanks, Bilqis. And Stuart?

**Stuart 04:14**

I am Stuart Nicholls. I guess I'm here more in my professional capacity, because I'm employed as the Strategy for Patient-Oriented Research Program Facilitator by the Ottawa Methods Center at the Ottawa Hospital's Research Institute. And so my pathway to here is sort of kind of along those lines, in the sense that I started off studying basic sciences and genetics. Soon realized that a) I was more interested in that sort of implications of genetics and genomics, and also that I was pretty rubbish at blood science. And sort of got more and more interested in that genetic counseling was sort of where I was thinking I was going. And then I did a summer

placement school working with and working with children, one of whom had Rett syndrome, and that became the focus of my undergrad thesis. And started to do as part of that, sort of surveys of public attitudes to genetics. And so that triggered my interest and later on, having worked and studied in sort of healthcare ethics realized that it was sort of not the abstract, ethical, philosophical issues, but sort of: how does that play out in practice? And that was kind of how, how I got into my first job, which was the title was called User Engagement Officer, which was basically patient engagement. That was back in 2003, in the UK, Manchester. And that was kind of my first job doing things like thinking about if we're designing clinical genetic services, what are the outcomes that we should be thinking about? What are the outcomes that are important to patients who come to the clinical genetic service? So that's kind of how I got into that. And then gradually, over the years, just carried on sort of, in that research role of examining, exploring experiences in the healthcare system, and those sorts of things.

**Jennifer** 06:11

If we can just go back around the circle again, one thing that I didn't quite catch, I'm not sure if you each said it. Annette, how long have you been a patient partner?

**Annette** 06:19

For about eight years.

**Jennifer** 06:20

and Bilqis?

**Bilqis** 06:22

Four years now.

**Jennifer** 06:24

And Stuart, you've obviously been in the field a very long time. How long have you been in the patient partnership role yourself, outside, perhaps of your employment?

**Stuart** 06:35

So I haven't really been out in that role outside of my employment. It's all been as part of my first job. So let's say the first position was for three years, then I went away and studied. So most recent position I've been in will be two years in September.

**Jennifer** 06:49

Okay, right. Are you a member of the PPWG?

**Stuart** 06:53

I basically sit in as an observer, I'm not actively engaged in a lot of discussion.

**Jennifer** 06:59

Okay, so an honorary member, maybe!

**Emily 07:03**

So both Bilqis and Annette: just wondering how you both came to the PPWG as well, that was something that I wanted to, to ask.

**Annette 07:11**

I was really interested in the idea of SPOR from the very beginning, from when they had the first workshop, and I managed to get a copy of the proceedings. And so I felt as though I was searching for a way to get involved with the Strategy for Patient-oriented Research. And I ended up phoning them and saying, "I've heard that you have a patient working group, and I'm interested in being a member". So after a year or two, they called me up. And the reason I'm still a member after four years, almost five years, is that COVID intervened. So I'm holding a place for a new person who.... we're planning on doing some recruiting this year.

**Emily 07:57**

and Bilqis?

**Bilqis 07:58**

So I served on a panel called ICES. That's the Institute for Clinical and Evaluative Sciences, it operates out of the Sunnybrook Institute for Health Sciences. And so after my term was finished there, they nominated me to join the SPOR Unit. And that's how I became a member of the SPOR Unit.

**Jennifer 08:22**

So Bilqis, why don't we carry on. Since you're next on the list here with the rewards and challenges you've experienced along the way - we could start with challenges, perhaps, and then move to rewards?

**Bilqis 08:33**

So Jennifer, sorry, I'll turn that around. And I'll start with the rewards - because I want people to remember the benefits of doing this, as opposed to all of the negative information that's going around in the world, especially now. So I want people to know that you can change the world from wherever you're seated. So every time you hear about leadership and taking charge, and how you can be a leader in your own right, and being a patient partner is an example of one of those. This is one way in which you can change the world and be the change you want to see. And, you know, accelerate that change by just doing... by just leaving, contributing your voice, representing the other people who don't have the same opportunities as you do. And so I'll start with one of the most exciting successes or rewards that I've garnered from just being a patient partner over the years, and this happened, even before I joined SPOR SUPPORT Unit. Was when I worked with the Institute for Clinical and Evaluative Sciences, ICES, was my actual phrases and words were used in public discourse, when the government finally made decisions about gender and gender language and representation. So say, for example, now, when you do surveys, they would ask you... they don't just ask, are you Black, white or Caucasian? They would say, are you African-American? So are you African-Nigerian, -Congolese, -Ghanaian? Are you African-Egyptian? You know, so all the different strata that you see now, I think that I personally contributed, and they're now public knowledge, then, you know, in public conversations. Also, I would say representation, just the increased representation, in research amongst patient partners as well.

**Bilqis 10:35**

You know, it used to be a certain class of people who would be patient partners, people who were in the know that there was such a thing as a patient partnership in research. But now the diversity has increased, the representation, I believe, has increased. There's of course, there's always more work to be done, and which segues nicely into the challenges, right? There's always more work to be done. I'd love to see more representation. I'd love to see more of what we speak about, more of our efforts, especially in the SPOR SUPPORT Unit, you know, being in public discourse. Actually translating to policies that people use in day to day life, that would be really important. And that's a challenge that we still seek to overcome. Also, I would say, it's just the experiences that people have here in Canada, and I think this differences are starker when you're immigrants or migrants, because not everyone who's come from an African countries immigrating, you know, just to live here forever. Some people are migrating for work, especially with, you know, the fluidity of work now, you can work from anywhere. And that's when we realized that, wow, okay, nothing's equal here. The equity, the equity has gone to garbage when you're when you live somewhere else.

**Bilqis 11:58**

Because when you live in a homogeneous society, you realize that there are many things that you took for granted like access to health, you know, how you're treated when you do access public services. And that really highlights, you know, all of those inequities and lack of representation, and the absolute disregard for diversity and diversity needs, when you're rendering a service. And I think that that's one of the advantages of having different population of people in the same society, because it helps you to realize what you didn't know was a problem, and what may eventually become [...] become like Pandora's box. So what most would [be] considered a problem can actually be the panacea for all of the problems that we have now.

**Annette 12:54**

Can I go back to the research experiences from the first question? The first research project I was in was a lucky accident. Somebody, a researcher, asked for help. And I didn't even realize that the team I was on was doing formal research. It was great because the whole team had their skills, and they were all valued and, and everything was, was great. The second one was a lot less clear. It was for a research application. And they gave me a one-page summary of the background before the meeting. When I went to the meeting, they moved the location while I was on route. And then they introduced me to the team, but they didn't introduce the team. So I didn't know who was in the room but they all had stacks of paper six inches thick. And I tried to write the patient engagement portion of the grant application. But I didn't feel supported to do it. Plus, I was very unqualified at that point. After those experiences, a team of patients including you Emily, funded by the Ontario SPOR SUPPORT Unit, created tools to help researchers know more about what patient's expectations were when they got involved in research, and what patients needed to know when they got involved in research, including the timeline. And that's just recently been translated to French and it was in the OSSU bulletin for March. So they're still there, although they're a little bit dated being six years old.

**Annette 14:43**

So after that experience, seven years later, now I'm a part of the patient engagement and research scale research, the PEERS scale, that evaluates patient engagement. And I'm a co lead with another OSSU patient

partner in the SPOR SUPPORT Unit, on an Evidence Alliance scoping review that is titled "Approaches to end racism in patient and public partnership in research", where Samira Chandani and I had input to the work plan, including the keywords and the budget, and we're now reviewing abstracts and getting ready for data extraction. So we feel like full partners, and we're really involved in all of the technical parts of the research, as well as being named as patient partners, but having a small role.

**Jennifer 15:39**

I'm wondering if you see that shift in how patient partnership has gone for you as an individual - from the beginning until now, like in terms of it being a perhaps, you know, better impact, more involvement - do you see that as because the field is improving? And the capacity is improving? Or do you see that as a factor of you being more skilled and more confident in the contributions... like, where do you attribute some of that shift?

**Annette 16:06**

I attribute most of the shift to this Strategy for Patient Oriented Research that CIHR started. I think that if it hadn't been that researchers had to include patients, that it would only be the rare individuals who were involved. I look back at the first time I ever heard of a patient being involved in research, and that was with the OMERACT, which was for outcome measures in rheumatoid arthritis. That was 10 years before I was involved in any type of research at all. I didn't get started thinking that I could be involved in research. I just stuck with that belief that the patients are part of the team, and that you need the whole team. It's a tremendous improvement. In the Patient Advisors Network, which has a large percentage of people who are patients involved in research - we've got 240 members across the country. So I'm not unique. I think there are many people in the same position. And it's been great to see the field increase, I just wish we would see more of an effect in a higher percentage of people believing in science. And perhaps this is a way to help.

**Emily 17:32**

You mentioned that you weren't qualified at the time to be contributing to the grant proposal. And I wondered if you could speak a little bit more to what you meant by "qualified" and if qualification.... and how much qualification comes from these tools that we talked about in terms of like, structured preparation and teachings versus your experience over time...

**Annette 17:57**

I think it takes a whole lot of work to get a qualification to feel qualified. The problem in that early research application was that they didn't realize how much I didn't know. And I didn't have anybody to talk to about that. So when faced with writing the patient portion of the of the grant application, I talked about how what they were doing in research would affect me, and how important it could be to patients in general. But when it comes to the actual structure of grant writing, I think that's a skill you have to develop and learn with experience.

**Annette 18:47**

I think everybody comes to it in their own way. And some people have formal training and some informal. Before being involved in those research projects. I had been in online patient groups for many years, since I first got a computer. And a lot of what we exchanged, the information we exchanged with one another was research

papers. We would find things that were relevant, we'd send out the links to one another. And we'd highlight what we thought was important. And that experience of reading so much research helped me develop a more critical eye. So I began to look at pieces, at research, and think, "why did they go back to 1950? Because that's not relevant". You know? Or "why are they talking about this as an outcome, when I know that most people in patient groups wouldn't care about it?"

**Emily** 19:46

Thank you. Okay, Stuart, did you want to respond then to the original question around how far we've come, or not?

**Stuart** 19:59

Yeah, I mean, it's interesting to reflect on my first position back in 2003, and sort of what we were doing that and that was kind of all new INVOLVE in the UK, we still hadn't been going that long. And then where we are now. I have to say, when I was back in the UK, there was a big, again, centralized push, so that the the institution where I was working, which was called the North [???] that was one of the five government funded to major funding mechanisms in the UK and the NHS, five sort of Centers of Excellence, if you will, around genetics and genomics, and part of the piece that was written into that was about patient and public involvement. So that was a stream that the all of those different centers had. And I think that was certainly the first time I had sort of really experienced that as a sort of top down mechanism, although we worked with sort of umbrella organization.

**Stuart** 20:57

So at the time, it was called the Genetic Interest Group. I think it's now part of the Genetic Alliance, which is also the name of the US umbrella organization. And, you know, they did a lot of advocacy work, and so they were sort of quite adept at working with specific research teams or working with that. So in some ways, we were doing a lot of learning about engagement involvement from them at the time. You know, we would meet and learn from them. But there was also sociologists who will do more about at the time, it was called the Public Understanding of Science. And this idea, this sort of deficit model of knowledge, you know: if the public only knew more about science than they would agree with us and agree that science is good. So we did a lot there and it was a, but it was still the work we did anyway, I know there were other groups who were doing so what you might, again.... we were just discovering Arnstein's ladder of participation, and all that sort of good stuff.

**Stuart** 21:57

But a lot of the work we did was sort of consultation, kind of traditional focus groups, but then with other bits built on, really working to find novel ways to explore topics. So we had an Artist in Residence, we had other things. But we didn't really have that... well I didn't see the same funding, kind of project based funding that we have from SPOR. So I think that's a big difference I'm seeing and I think that's one of the things I've got, you know, the next set of questions about what we're doing well, and where to go is I think that the infrastructure is a big piece of what we need. And if we think about patient engagement and research, and we think about sustainability of that is, you know, how do we move from, you know, mechanisms, which is still fairly short term funded support structures, to something where it's either embedded, or we find another ways to continue to

support this, if you feel that patient oriented research is something we value and want to invest in, in terms of health research.

**Stuart 23:03**

So I think we've come a long way in terms of Canada is learning from things that have happened previously in other countries and looking to those. But I think the challenge is things like, you know, I, my position is funded through SPOR is directed to support that, you know, I'm biased, because that's my job. But I think it's a great initiative. But again, what happens after this period of funding? I don't know how many institutions, for example, have taken up a role like mine centrally within that institution to support this. So is it something that we hope gets translated and taken up by institutions, and therefore SPOR is no longer needed and it becomes just part of health research and what we do? Or is it something where maybe the fact that SPOR is this specific entity in this idea of patient oriented research, having this visibility is something maintains it in the consciousness? And if we didn't do that, does it... do we not have the same thing? So I don't know where we're going to go with that. And I don't know what the answer is. But I think those are questions that I think we're going to have to start thinking about in terms of what's the future for patient oriented research and how we manage it?

**Jennifer 24:19**

To what extent are you aware of opportunities for patient partners via the SPOR SUPPORT units or through some other mechanism... who's contributing to that conversation specifically, about the future of patient partnership and sustainability and the infrastructure? And do you personally feel like you have a voice in how that is going to be shaped in the next say, five to 10 years in terms of where patient partnership is going?

**Bilqis 24:46**

I'm confident that... I'm sorry, Stuart, I can see your hand up, sorry! Yeah, so I'm going to give the floor to Stuart because I believe that he's the one who can tell us much of what you'd like to hear, you know, technically, but also, when you did say about, you know, having a voice is there a sustainability plan..... And this is where I always talk about self advocacy, and, you know, leading from where you are. I for example, I've created like a track for myself, where in my community or amongst persons of colour that I know or persons with disabilities, I always, you know, send out these opportunities and say, there's this opportunity for being a patient partner. These are the advantages. I will make sure to list the advantages of being a patient partner. You know, and very many times people are concerned about remuneration and honorarium which is relevant, but I always make them see the bigger picture. And so even during the course of my work, as patient partner, as I serve as a patient partner, before the opportunities come for, for call for patient partners, I often share this wonderful experiences like that one time, where my phrases were used in surveys are now internalized into surveys around the country. I'm like, Okay, you can lead from where you are.

**Bilqis 26:08**

This is definitely this is something that I did a few months back and it's now mainstream. It would be politically incorrect to do anything asides from this, and I literally just did this from my bedroom. You know, you could do this too. And so that piques people's interest and you can follow through with that. And so you're not just calling

them off a blank slate, it's basically something you've been feeding them. So you can create that sustainability plan pipeline by yourself. And SPOR is, you know, the leader in sharing with us opportunities, pushing us into corridors where our voices need to be heard, even when did not know that they need patient partners on that team. And I want to personally thanks Stuart for all of the opportunities, as well as Maureen and Annette who are leaders in PPWG for sharing these opportunities with us and pushing us into those corridors where our voices matter.

**Stuart 27:05**

I can certainly tell in more in more detail, like local level, of what we're doing locally. So I mean, one of the things we're actually trying to do, I think this is something we need to do more of is we're actually trying to publish a paper which is under review at the minute, where we're trying to sort of get into the literature - the different infrastructure that we've put in place locally to support this. I think ICES published a paper recently about their infrastructure and how what they feel, and I think there's a CAMH also published something fairly recently about the word. So I think that's, that's another good thing is that people are now talking about how they're building programs, support structures, things like that, to support patient engagement and patient market research.

**Stuart 27:52**

And one of the things we've done locally is, we've worked with the hospital. So the Ottawa Hospital Research Institute, and the Ottawa Hospital, are technically separate entities. But we work closely together. So the patient and family advisory committees. So the Ottawa Hospital has multiple committees that are supported by a Patient and Family Engagement Program. And that's all on the hospital clinical side. But so there is there's a patient from an engagement lead on that side who manages the committees but also has a pool of advisors - if you have indicated interest to be involved in some capacity within the hospital, whether it's helping develop the part of the website or quality improvement initiative, all these different things within the hospital. So what we've done is we've worked with them, when we sort of... thinking, researchers have a question or wants us to work with patient partners or, or get some feedback, we've we've worked with the hospital side to sort of facilitate that, and we work together collaboratively to bring the two together. And, and that is central, you know, that patient family advisory committee or the program, I should say, is supported and paid for [...] through the hospitals. And so that's, you know, that's a sustained program.

**Stuart 29:20**

But it's still one person who manages a lot of that with some volunteer support. So that's, I guess that's one way where we're, we're starting to see, well, what can we do on the research side? Can we leverage some of some of the support there? Can we build in a role like mine, within the Methods Center, for example, at the Ottawa Hospital. And we're also trying to sort of develop things like IT infrastructure. We have database, we have some, a system in place that tries to monitor and, you know, regularly, do a sort of reminder to myself or to my equivalent in the other hospital, to reach out to teams to see how they're doing. They'll touch base or set an end date where there's an automated evaluation survey that goes out to try and capture and see whether things are going well, if there are things that could have been improved. We've implemented things like data monitoring approaches. So our research ethics board now as part of the application process, actually has questions about whether patients are engaged in the research and if so in what capacity. So we know where that patient

engagement is happening, which departments we can sort of track whether there's more studies coming through that have engaged patients as partners.

**Stuart 30:39**

So again, that helps us sort of try and either anticipate or monitor the level. So if we do need extra support or infrastructure placement, that's we can look at those those indicators. At the same time, things like looking at things like that might be on MyChart, can we build something there where there could be a place for people to indicate if they're interested in research and partnering in research. So there's a few things where we're trying to look at what we can do with the existing hospital infrastructure that's going to be permanent is in place and we can still leverage from the research side. But also collect data and try and make use of the data to try and inform our decision making. Now, some of it's still going to be dependent on research. And maybe we have those conversations, but we're all having those conversations. And I know that there's great institutional interest in this. So maybe that's something. But from the bigger picture, province wide or nationwide, I'm not quite sure what's happening. And, you know, a lot of the infrastructure is still was special CIHR funding and so forth. So that's kind of my take on work things.

**Jennifer 31:53**

Thank you, Stuart. Why don't we shift over to Annette, and you can see where you land in some of these questions about the field of patient partnership....?

**Annette 32:04**

I've always looked for opportunities. And I've always wanted to share any opportunities I find. So through the patient partners' private website, if I have requests from researchers, if I know of opportunities where they're looking for more people, I'll share them, share the knowledge that I find. And I'll share the conferences that I'm being invited to in in the hopes that other people might find them interesting. One thing that I've seen that shows progress is the Empower award special issue - that's Longwoods - that's going to come out in April, where they're highlighting 15 patient oriented research projects, and where all of these projects got additional funding for knowledge transfer, through the SPOR SUPPORT Unit. That should be interesting.

**Bilqis 33:08**

I have nothing else to say to that except that, you know, there's still more to be done. As everyone has rightly said, more opportunities need to be more representative of the actual population. It shouldn't just be a few people in a certain pay range, in a certain age group, that should be doing this work. Because we want to create a sustainable system, right? And we need to walk the talk.

**Emily 33:37**

That's great. That's, that's helpful. And actually, my questions sort of stems from something that Bilqis you said at the beginning, which was you talked about in terms of sustainability how much you share as an engaged patient partner, and, and as someone who's knowledgeable because of your work with the PPWG... and I wondered how much you felt that that sort of sustainability plan, the sort of organic ways that people share, and Annette you spoke to this as well, can be supported by infrastructure or can be embedded into

infrastructure. And if you also see a role for sort of non-institutional practices of advocacy, of giving feedback, of pushing for a system change, being a part of the future of engagement.

**Bilqis 34:26**

So since social media is the great thing, right, I haven't seen any challenges from the government that says, you know, "the first person to join the patient partner unit for this research is going to get - you know, I don't know - some some sort of incentive", nothing. There's so much that you could do with public communication, and the the ability to reach people with no cost at all, just as with this podcast, and the amount of viewers and followers and listeners that you have. Look at that power can be harnessed for something greater. So why aren't high school kids being recruited to patient partner working groups, you know? These are, sometimes, these are people that feel the brunt of being being a patient or being a patient partner at the most. They have mothers who are critically ill, they have sisters or siblings who live with a chronic condition. They themselves live with a disability. What else.... they need to access many of these public services multiple times in a year, either because they're going to high school or they need some sort of report for something? Or they're involved in sports. Well, where's the voice? I have yet to meet a high school person, you know, as a patient partner, working group. How about other people who identify as an other? How many non gendered persons have you met in the course of being a patient partner?

**Bilqis 36:05**

Radio jingles - there's a popular radio show that I listen to in the morning when I'm on my way to work. And you know, there's often giveaways, "if you call in now you're gonna get you know, \$5,000" or a free show, or it's free ticket or whatever. How about... this is something that, you know the government is working on, or this is a research by some such and such persons and they are looking to recruit patient partners for this work. And this is what you'll be doing as a patient partner, if you do sign up on our show, right this minute we'll give you a free ticket to this person show. You know, those are things that can be done. It's not that hard. It's not rocket science. Even rocket science is now simple, you know, so we should get to it. It's not as hard as we think it is. We just need to put our hearts into serving people and really believe in the experiences of other people.

**Emily 36:59**

Given it's not that hard... just curious... why you think maybe the government doesn't do it, or that that hasn't happened?

**Bilqis 37:09**

In my opinion, it is because, you know, doing this kind of thing... it doesn't generate revenue, right? Sometimes it even costs the government to recruit patient partners, you know, because you had to give them some sort of incentive or the time. And many times I believe that there's disregard for patient partners voices, because they're not seen as professionals. But we fail to see that patients are also persons living their day to day lives. There are engineers amongst us, you know, the doctors, and masters, PhD. Annette can speak more to this because she did some recruiting of recent and they were like so many PhD candidates. We were astounded. So in spite on the fact that people are patients, right, that doesn't mean that their mental capacities are regressing. Just because you live with a chronic illness does not mean that you cannot achieve in other parts of your life. You're a mother, you're a parent, you know, you're an adult, you're a child's adults, because the different ways

in which people have families these days. How else can I think? You know, people are living their lives in spite of being patient! Everyone has something to offer. Everyone is a professional in their own right. And they have experiences far beyond being a patient that they can bring to the table to, you know, improve the services that we render, and the research that we do, and the impending impact that we can give with all of the magnanimous work that we can do, as researchers, as scientists, as governments.

**Jennifer 38:51**

Bilqis, that was such a good impassioned call to action! I think given the time though, we should finish with Annette and Stuart, if you have additional or follow on thoughts to conclude with, or you want to circle back to anything?

**Stuart 39:04**

Just going back to some of the things about sustainability. I think one of the good things is that there are, again, I'm paid in my jobs as I kind of think it's it's good as well as sort of hopeful feeling that I'm making the contribution. But I haven't spoken to other individuals who are doing similar roles as myself. I think it's either not their entire job - Patient Engagement is not their entire job, it's part of their job. So, you know, they have competing demands, I don't know how many people do it as a full time job. And so I think that's something in terms of just what's where there are support structures, what extent are they committed entirely to patient engagement? Or is patient engagement part of a bigger, a bigger picture? I think there's, there's some, if we're thinking about sustainability, and sort of the infrastructure and how we move forward, I think that's going to be part of that conversation - and then the other thing that we've talked about patient engagement and patient oriented research, but what's what's the roles for patient engagement or community involvement in other aspects of the research agenda? So you know, research ethics and oversight? What's the role there? You know, we're doing some work with colleagues in the US where we're actually surveying institutional review boards. So research ethics boards in the US about how do they identify and recruit their unaffiliated or non scientist members of the boards? Who are they? You know, certainly a good proportion are it's an ex, retired nurse or it's, it's someone who also works in the department, they serve as a non scientists because they a member of the admin staff for that research project.

**Stuart 40:52**

So also, like when we think about the funding, so when we review, you know, CIHR as part of last few projects, [...] competitions has had a priority area for patient oriented research. What's the training given to people who are reviewing grants and making decisions around, is this a good fit with patient oriented research? To what extent, you know, Annette mentioned the Empower awards, patients partners were involved in reviewing those grants. But I don't know, again, how broadly that that happens in terms of the sort of bigger schemes, the funding mechanisms for research. So I think those are also things we this may move the discussion forward thinking longer term, thinking about those other areas of research, research enterprise and how patient partnership can work there, I think that those are gonna be big questions and discussions. And then finally, sort of the interaction between the different SPOR entities now. You know we have a national training entity with the SPOR SUPPORT units, you have small networks, how, what's the bigger picture? And how are those going to work in the future together as as funding sort of slows down or when we think about renewal. So that's, that's kind of my final thoughts on that.

**Annette** 42:07

I think they might be counting on the fact that we've got, we've had SPOR in place for seven years now. And that it's likely to be in place for at least 10 years, we will have changed, we will have, we will have helped to train a whole generation of researchers. And it will be the norm for them to include patients to look for the different ideas, the different insights that patients can add, to make the research richer and more useful, and more likely to have an effect on outcomes. I think the hardest part for patients and getting patients and caregivers, in getting involved in research is finding that first step, that first rung on the ladder. So I'm hoping that some of the the work of the National Training Entity and and other groups will will help get more people into it.

**Annette** 43:07

I've had conversations myself with friends. And we see ourselves as, at this point, the older group, somebody is going to have to replace us. And we're hoping it's going to be really vital, interested, energetic people who are who are younger, and they can carry the torch. I think one of the problems we might have is that there's no actual repository for patient knowledge. Unless we count, hopefully, the Patient Advisors Network. But but there are so many people doing so many different things at every level of research in health care, in the provincial and the federal systems. You couldn't.... I think it would be interesting to find out how many areas patients are involved in. I think the closest we've got to that is Julia Abelson's 500 person survey that she did, on the on people in people who are engaged in research and in advocacy in health care, and in working for change. And we have yet to see the results of that survey. But the interest was huge. I mean, where do you find 500 patient partner, easily, who are going to answer a questionnaire where the average amount of time that people took was 40 to 50 minutes?

**Bilqis** 44:44

I just wanted to say because someone being a patient does not make one incapable of contributing to their own care. You know, patient voices are important and we should listen to it.

**Jennifer** 45:10

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