

Transcript  
Matters of Engagement podcast  
Episode: "Patient-oriented to Patient-partnered"  
<https://mattersofengagement.com>

**SPEAKERS**

Vasanthi Srinivasan, Maureen Smith, Jennifer Johannesen, Emily Nicholas Angl

**Vasanthi 00:00**

Yes, everything is oriented towards patients. But are they partnering with you? Are they there at the table with you?

**Maureen 00:06**

I do adhere to that "nothing about us without us" principle. So that would be basically my short answer to: do patients really belong everywhere as partners.

**Jennifer 00:19**

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

**Emily 00:28**

And I'm Emily Nicholas Angl.

**Jennifer 00:33**

We're excited to get rolling with Season Three. We have new topics and guests - and as always, some familiar recurring themes. It feels like it's been a while

**Emily 00:43**

Because it has been!

**Jennifer 00:45**

We're glad to be back at it. Upcoming this season are topics like equity and diversity, participatory research, and moral distress among engagement professionals. We're going to start releasing these in a couple of weeks.

**Emily 00:59**

In the meantime, for this first episode, we thought we'd focus on one of our fundamental questions. What do we actually mean when we say "patient-oriented research"? Jen, you've talked about this a lot, and I definitely see it in my own work. What we mean by patient-oriented doesn't always seem consistent or clear. I'm excited that we get to think this through a bit more.

**Jennifer 01:23**

Yeah, it's a perfect topic for this episode because our main funder for this podcast knows a lot about it! The Ontario SPOR SUPPORT Unit, or OSSU, is one of the provincial units tasked with supporting CIHR's Strategy for Patient-Oriented Research. Now, they've been on board with our podcast project since the beginning. We've been appreciative of the funding, of course... but also the editorial freedom to explore challenging topics.

**Emily 01:50**

As the season progresses, keep an ear out for a new segment we're adding: Patient Partner Reflections, brought to you by OSSU. At the end of each episode, an experienced patient partner will offer their thoughts, their experiences, and perspectives on the topic that was featured.

**Jennifer 02:07**

For this episode, we feature two guests from OSSU: Vasanthi Srinivasan who is the Executive Director and Maureen Smith. She's the Chair of the Patient Partner Working Group and a member of the Board. Vasanthi gives us OSSU's take on the definition of patient-oriented. Then Maureen elaborates on what patient partnership looks like from her perspective, and addresses some of our lingering questions.

**Emily 02:31**

Yeah, and can I just say...? This maybe isn't one of our usual episodes, but I think we both appreciated hearing perspectives that are probably shared by a lot of our listeners. Lots of food for thought. Okay! Well, let's get started.

**Jennifer 02:52**

We've encountered debates about what patient-oriented actually means, and thought it was time to explore it on the podcast. Now, I always understood it to mean that it was research oriented towards patient needs and interests. And to me, that didn't necessarily mean that patients had to be involved. But the term is now often used to describe research that is oriented by patients, which is of course different.

**Emily 03:18**

Yeah, I was curious to and did some digging. And you're right, it is different. And it has changed. The earliest reference I could find was from the US in the early 2000s. And it's really broad. It's basically any research that requires direct interactions with human subjects. In fact, this is still how it's defined by the US National Institutes of Health. Definition seems to have evolved differently in different countries. In Canada especially you can really see how things have changed. I mean, in early CIHR documents, they talked about patient-oriented research as distinct from population-based research, which simply meant research focused on the patient as an individual. That's definitely different from today where CIHR talks about patient-oriented as a way to involve people in informing and designing healthcare solutions. So that's how we describe it here in Canada. But in the US, there's more emphasis on patient-centered outcomes research and comparative clinical effectiveness research. In the UK, they're focused more on public involvement, but not so much on patient-oriented research.

**Jennifer 04:32**

So why is that, do you think, here in Canada? Is the assumption here that you can't really focus on patient needs without having patients on the research team?

**Emily** 04:41

I think there's probably a few factors. But overall, yeah, I think that's the argument that you need patients on research teams to ensure relevance. In this episode, we're going to look at how patient-oriented research has come to mean patient-partnered research.

**Jennifer** 05:01

First is Vasanthi Srinivasan. She's the Executive Director of the Ontario SPOR SUPPORT Unit, or OSSU, and a former Assistant Deputy Minister at Ontario Ministry of Health and Long-term Care. She's one of the architects of CIHR's Strategy for Patient-Oriented Research and is a co-founder of OSSU. So she has an inside perspective on why the push for patient-partnered research.

**Emily** 05:26

Let's get started.

**Vasanthi** 05:28

Hello, my name is Vasanthi Srinivasan. I'm the Executive Director of the Ontario SPOR SUPPORT Unit, which is the central platform for the Patient-Oriented Research Strategy of the Canadian Institute for Health Research, and the province of Ontario. They were calling it patient-oriented. But I always called it patient-partnered. Because that's literally what the definition is [in SPOR}. They want patients to be partners with researchers, convey their perspective on issues, so that the research project can go along in a much more enriched way. A much more relevant way. Because at the end of the day, most research in health policy and services is done on behalf of patients. It's being done for patients, for patient care. Why not do it with them? Why not ask them, what it is about the issue that they're most fussed about, and organize the research in such a way that it speaks to that?

**Emily** 06:43

Vasanthi was involved at the very start of all this, working to figure out how best to move forward. Here in Ontario, there were already large institutions or Centres of Excellence, focused on things like health data and research methodology. Some of them already had ways of integrating patient experience. So as the newly formed OSSU, they brought together a coalition of these institutions,

**Vasanthi** 07:07

We had to bring this coalition about, get them to understand what we mean by patient-oriented research, or patient-partnered as I said, where they needed to bring in patients... now not for technical expertise, because we know that's not the patient's strong suit...but to integrate them in the research project. From beginning right to the end. Recruitment, retention, and results. Not to just recruit them in the beginning, find out what might be bothering them, and let them go. And bring them towards the end. And say, "Guess what? You wanted this, so we produced this." No. To actually keep them involved. And to the extent that we could bring about this cultural change.

**Emily 08:00**

Vasanthi had the idea of partnership in mind, right from the beginning. She looked around at other regions and countries who were doing some form of patient involvement or partnership, to see what she could learn, and ultimately decided on a more informal approach.

**Vasanthi 08:15**

So I thought, let's do this in a more of an organic fashion. And that's how we launched into our patient partnerships. So it's been very organic, and it has grown everywhere, not just in the Centre. But in all of the research units that we have. They've all got patient advisory committees, include patients in their work. And things are coming along. I mean, not to say we've reached perfection. But we are beginning to feel comfortable in this way of doing research and producing the kind of relevant work that will have meaning for policy.

**Jennifer 09:02**

Yeah, I wondered about Vasanthi describing things as organic... I mean, there has been a concerted government effort to push forward a specific agenda. But maybe she's referring to the ways that partnership programs get implemented. They seem to be unique to each Centre or organization, maybe even each research project. And it wasn't dictated from the top that it must be a certain way. I can see the benefits to doing it like this. But I think there's also a lot of risk and maybe explains why some partnership efforts are seen as successful. And others not so much. Things aren't standardized.

**Emily 09:39**

Yeah, there's been a kind of "figuring it out as we go" mentality. It's out of necessity, to an extent. Patient partnership relies on things like relationship building and trust. It's really context dependent and can't be too prescriptive. It's generally agreed that there just can't be a one size fits all approach. But you're right. It also leaves room for confusion and muddled efforts. I don't think any of this was surprising though. It's maybe even part of what Vasanthi expected. Early growing pains. We asked about those growing pains. And if there's been resistance.

**Vasanthi 10:18**

You look at it from two perspectives: the researcher perspective - researcher, university trained, a highly, highly engaged academic going about their business saying, "Why do I need this? Why do I need another tag on? I know, because I am doing this on behalf of my patients. These questions have been articulated in some environment in which I'm dealing with patients. And I'm an orthoped. So I'm dealing with hip, knee and whatever. So I'm responding to that. What do I need this patient business?"

**Vasanthi 10:56**

And the patients would wonder, "How do I ever infiltrate this academic ivory tower? And does what I say make any sense? Do they want to hear me? What can I contribute?" So we had a lot of hesitation in the beginning. Believe you me, the academics and patients both even today, are still learning how to work with one another, how to see the value in what each other brings to the table. It's not something you can write a memo on and say, "This is the value patients bring". It has to be understood through working together. Many of the grant

requirements now ask you for how you're engaging patients, way beyond SPOR, OSSU and stuff. So it's becoming much more the way we do business.

**Jennifer 12:00**

Vasanthi is acknowledging that the value doesn't always reveal itself until people are actually working together, which is fair enough. But many researchers feel compelled to do it because of funding and publishing expectations, whether they see the value or not. And if there aren't requirements, exactly, there is definitely competitive pressure. I can see why there continues to be a lot of hesitation.

**Emily 12:24**

I have seen it shift a bit over time. The initial hesitation was more about wholesale skepticism. Now there's more buy-in and it's also just expected. "The way we do business." People are anxious about getting it right. And this might be where evaluation comes in. Because having a way to evaluate how well you're doing can feel reassuring, a way to measure if you're on the right track.

**Jennifer 12:51**

Yeah, definitely. Vasanthi talked about OSSU's efforts to evaluate how the overall strategy is playing out in the field. And she touched on some of the ways that OSSU evaluates their own impact.

**Vasanthi 13:03**

There's a quantitative way to evaluate. And there's a qualitative way. Much of what we've been doing contributes to the qualitative evaluations. We had, as part of SPOR and OSSU, we had to do a formative evaluation three years into it. Meaning, does this whole concept make sense? Are you able to deploy these requirements into the field? So we did a formative evaluation and it was very successful saying, yes, there is an appetite, people are buying it, you know, and taking it and working through it. And then we did a summative evaluation, which had a lot of quantitative pieces. Because it is research after all - to look for impact and stuff. But also, in the summative, we were able to put in some more hard facts to say: Yeah, all of these research projects we're talking about that have this phenomenal impact in whatever area has had patients driving it, not just the researchers. So we've done that. So we will continue to do both the qualitative and quantitative. Qualitative might look like the soft side of things, but hardly so. It is to measure how this is getting ingrained in the research culture.

**Jennifer 14:31**

Hmm. This is one of the things we talk about, isn't it? We tend to measure engagement and partnership on how integrated it is, and not necessarily on how much impact it has further downstream on things like health and health outcomes, quality of research, things like that. There was mention here of looking at impactful projects and noting that patients were involved, but that's not quite the same thing. Now to be fair, OSSU's mandate is to support and increase patient partnership, so their metrics will necessarily be focused on that.

**Vasanthi 15:06**

So in evaluating, for example, how patient have influenced a particular piece, it's actually quite easy for the evaluator to do that. I realize that. Because they ask very pointed questions, you know, like, what did they

contribute? What did they say? And what made this thing go this way? Or the other way? And where were your challenges? But where did they create the opportunities? So in an honest dialogue, they're able to come up with ways that this research has been influenced by patients. And also the road we have to travel to get to the destination.

**Emily** 15:57

Evaluation will be interesting to watch, to see how it evolves and tries to keep up with emerging or changing concerns. The big question is still, how do we assess longer term impacts rather than just processes? How can we connect the dots between engagement and things like policy change and improved quality of care? It's certainly not straightforward. Anyway, we asked Vasanthi: what keeps her up at night? What does she worry about when it comes to promoting a culture of patient partnership.

**Vasanthi** 16:29

Well it's very, very tedious. It's very challenging, I understand all that. Because the researcher going off on his or her own and doing it would have much less challenges to overcome. This is bringing together a group, appreciating the group dynamic, making sure that their agenda is fulfilled, etc. It's a lot more work. So I feel sometimes, Oh, they'll give up on it because it's just too much. But then on the other hand, I look at the enthusiasm that patients bring and feel that that might be what will sustain this. They will make it sustained. So I have confidence in them. But it's very tough. So it's the tediousness of it that sometimes worries me.

**Emily** 17:28

OSSU must hear this quite a bit, about the tediousness. I certainly do. Maybe it's not so much it's tedious. But that researchers just don't quite know how to do it or maybe don't even know why they're doing it. And this kind of uncertainty can feel tedious, or at least really slow things down. There's a lot of pressure from funders to meet certain requirements, which gets into the checkbox problem we often talk about. But then there's pressure to go beyond the checkbox and do it in a meaningful way.

**Jennifer** 18:02

Mm hmm [affirmative]. And it's a lot on patient partners that their enthusiasm is supposed to be enough to sustain the momentum. They have plenty of other issues they're trying to address. For example, I'll just call it the diversity problem. There's a lot of self-awareness among patient partners about how homogenous the patient partnership population is. But I'm not sure anyone's figured out a programmatic way to address it. Vasanthi actually brought it up and shared her thoughts on where things are at.

**Vasanthi** 18:33

I keep hearing I think valid criticism that you have not achieved any level of diversity within your group of patients. It almost seems like it's the same kind of people that are drawn to this, that the researcher is drawn to, because it's a two-way relationship. And they keep going from one project to the other. And you don't seem to include other voices. Some of that criticism is justified. We have made some inroads, but I can say we have a totally diverse population that we can talk to. But we have to start somewhere. And we have to show by example, that these things can be done. And these things need to be done. So I'm hoping that as the next

generation of women come up... and I'm confident because even with our Patient Partner Working Group we've made some inroads into diversity in age, and ethnicity, and all of those factors, that we can move forward.

**Emily 19:51**

I thought it was an astute observation. Not only are certain kinds of people drawn to partnership, but researchers might be drawn to certain kinds of patients. It would be interesting to look into that. Do researchers seek out, or are they attracted to patients who come from similar backgrounds? People who readily agree with their ideas? It wouldn't be surprising if it were the case. Researchers often recruit from people they're already connected with.

**Jennifer 20:18**

Yes, and vice versa. Patient partners might be drawn to researchers who are more relatable to them personally. Um, just a quick aside: we both noticed that Vasanthi said "the next generation of women" entering patient partnership. Now listening back, we're assuming she's referring to the specific group of new patient partners that have joined OSSU's Patient Partner Working Group, who all happen to be women.

**Emily 20:43**

I think that's right. Although it's a bit telling that this came up while we were talking about diversity. Vasanthi mentioned progress in terms of age and ethnicity. But I'm gathering there's not as much in terms of gender identity.

**Jennifer 20:59**

Yeah, and I think she'd be the first to acknowledge those gaps. Overall, there is recognition that achieving some kind of perfect diversity is purely aspirational. There's never going to be a moment when things are finished.

**Vasanthi 21:13**

It is an almost.... I won't say impossible task, because it has to be made possible. And it is being made possible.... but it's a very difficult road. And not because anybody is putting obstacles, but it's just that it is difficult to do because research by definition, health research, is done by health researchers. They train years to get get fluency in their methodologies and approaches. So and then we're introducing somebody into this mix, who hasn't had the same background and an approach to issues. So it's bringing together differences and reconciling them and and working with them in order to produce a refined product.

**Emily 22:07**

You know, I was glad to hear from Vasanthi how challenging things can be. The truth is that OSSU is trying to orchestrate a culture change in places where change may not be entirely welcome. And there are valid reasons for that. It may be a long road ahead.

**Vasanthi 22:26**

Yes, everything is oriented towards patients, but are they partnering with you? Are they there at the table with you? And I'm doing everything I can, in the little role that I play in this, to ensure that that kind of cultural

change and that kind of need is addressed. And people are coming together. With all its warts, we're trying our best.

**Jennifer 22:55**

After speaking with Vasanthi we wanted to hear from an experienced patient partner who could speak to the experience of partnership. So we followed up with Maureen Smith. She's the Chair of the Patient Partner Working Group, and a member of the Board of OSSU.

**Emily 23:10**

We're going to play parts of our conversation with her in order to maintain the context of our discussion. But you'll see in some places we do shorten or replace our own comments.

**Jennifer 23:19**

Yeah, we usually get to talk plenty! Here's our conversation with Maureen, she actually first listened to our segment with Vasanthi, and we carried on from there.

**Maureen 23:30**

It was very refreshing for me to hear Vasanthi speaking, to deliver such a personal account of what she's been so instrumental in shaping. I mean, I agree with what she said - that in Canada, we equate patient-oriented research with what we more aptly call patient-partnered research. That's different, because that's not what it means. And that's not what it means in other parts of the world.

**Maureen 23:56**

And that reminds me of my first master class that I took in patient-oriented research. It was a three-day course. There was a woman in the course who kept saying, "Well, you know, if there's patients who are participating in the research..." and she meant as subjects, "...of course it's patient oriented. How could it not be, that's what it's all about!" But it was a real eye opener to me, I thought we're all at different levels here. And we all have different understandings of what it actually means. So I like the term patient-partnered research because that makes it really clear and it separates us from the participants in the research.

**Maureen 24:35**

And the participants in the research are incredibly important. And for me, the role that I play when I partner in research is to make sure that everything that the patient participants are going to give to that study is meaningful, and is set up in a way to really get their perspectives and their feedback. That was interesting that that term "patient-oriented research" that CIHR adopted....and then kind of put their own spin on it. It does make research into patient engagement difficult because all over the world, we have a tangled web of terms.

**Jennifer 25:15**

Does "patient-partnered" automatically mean that research is patient-oriented in the way that it had initially been established? So I'm wondering if you have thoughts on that if, if it's reasonable to assume that if patients are involved, that research is by definition, therefore patient-oriented? Or if these are now kind of separate definitions that both need to be accounted for?

**Maureen 25:40**

If they're involved, and it's not tokenistic, and they really do have some influence over the over the study, then yes, I would say it will be patient-oriented. But I don't think that one necessarily allows the other. You could bring people on to fulfill your funders' request to have that, and not give them any shared responsibility or co design. So I mean, no. According to CIHR you need the two to get patient-oriented research. So the partnership is part of the patient-oriented research for them... but it's part of it.

**Maureen 26:22**

So in most of the projects that I partner with, if I'm a patient partner, and maybe I'm a co-investigator, I'm working with the researcher to bring in other advisors - other patient or youth advisors in the case of some of my research - to work with them. So there's different levels of the engagement, but they're all partnering in the research, but have different responsibilities. So I may be there from the beginning, like inception, right to the end. And an advisor might come in at key points in the research. And so that's like a multi layered approach. You're often going to see that.

**Maureen 27:00**

But in other studies, like if you're in a methodological study, for example, there may not be other patient partners, and that may be okay. So for example, if you're part of a systematic review team, you may just have two patient partners. So it has to fit in to the study. I don't think we do a good enough job in communicating that. Like, it's not black and white, there's all kinds of research. And I do adhere to that "nothing about us without us" principle. So that would be basically my short answer to: do patients really belong everywhere, as partners?

**Maureen 27:45**

For some studies, it's incredibly obvious that patient perspectives are essential. And we wonder how the research could actually be conducted without these perspectives. It doesn't even make... it doesn't even make sense. So that's often the case of disease-specific or service-specific research. It just makes sense that people with lived experience, you know, lend their expertise. And I'm not referring to them as end users, you know, or participants in the research... which of course, goes without saying. I mean patient partners, collaborating with researchers in the planning, you know, conduct, you know, analyzing and disseminating the research. So that's where we've made incredible advancements in the past decades.

**Maureen 28:36**

In other studies, it's not as intuitive. And that's where much of the work remains to be done. So many types of research fall into that category. So for example, preclinical and bench research, systematic reviews and other forms of evidence synthesis, methodological research, core outcome set development. And in the last five years or so, there has been much progress. But... and I hope, I believe that we'll get there in my lifetime... but there's still a lot of work to be done. So I've really noticed the progress in patient engagement in core outcome set development, which is an area of interest to me. So I'm involved in four studies, two in pediatric rare diseases and two in pediatric mental health. So the patient partners, who are co investigators, and the patient and youth advisors, which is that second level I was talking about, are there to collaborate with the researchers to ensure

that the patients and the parents who will participate in the process can do so meaningfully and that the outcomes matter to them.

**Maureen 29:46**

So this week I had the privilege of participating in a Youth Advisory Group meeting for a pediatric core outcome set. A few months ago, the youth who are aged 12 to 17, had provided feedback on the design of an outcome survey. This week, they looked at the outcomes identified by the patients and caregivers, how the research team proposed to group them, and their definitions, to tell us if that made sense to them. Well, we learned a great deal from their invaluable input. And now we will make several changes to the outcome labels and definitions that will appear in the Delphi survey. So our parent and youth advisors play that essential role in ensuring that the parents and the youth can meaningfully participate in the process of selecting outcomes that are important to them. This type of research, you know, where the methodology can be complex, and the reason for participating is not as obvious - in this case, it would be an investment in the future research - benefits greatly when patient partners are part of the process.

**Emily 30:57**

So would you call that type of involvement, then, "partnership"?

**Maureen 31:02**

To me, they're... advising us. So it's a level of partnership. And it's not the same level as the co-investigators who are there from the very beginning. So they're advising, so yes, it is partnership. But as I said, how do you define partnership, right? There's no... that's the issue. There's no one definition for partnership. So when you say patient-partnered research, people can have all kinds of perceptions about that. And that's where we kind of run into trouble sometimes, because sometimes the patient partner may have an idea of what it looks like. And the researcher might have an idea of what it looks like. And that's why groups like, you know, the Support Units, are working to work with researchers and patient partners to, you know, to make sure that we're all on the same page.

**Emily 31:58**

So because of the way that it's defined in terms of like a continuum... let's say, from collaboration to kind of actual partnership... usually partnership is placed at the end of a sort of continuum.

**Maureen 32:10**

Right.

**Emily 32:10**

So one of the struggles I have with the whole term of patient partnership as the form of research, is that patient partnership is... it's sort of one way to involve patients, in my mind, so as co-investigators... but even talking to you the last time, you know, you cited a paper that said, you know: what's shown is sometimes the best way to involve people is to consult with them on this part or do this type of thing.

**Maureen 32:35**

Right, right...

**Emily 32:35**

Which to me then makes people call "partnership" something that it isn't. And in many cases, to me, could be done in a way that could... I mean, I could be argued against... but could be shown to be basically qualitative research with a group of people, where their understanding, their perspectives, especially with priority setting, stuff like that. Do you think it's necessary to be a bit more precise in the use of "patient partnership"? And what do you think the implications are of saying, "This is patient partnered research" and allowing it to be an umbrella for all of these types of things, even as you describe?

**Maureen 33:11**

Right. So that's a really good question, because that's the growing pains of something exploding, right? Like, "everybody wants to do patient engagement, oh yes". So you've got the growing pains. In the work that I do when I'm a patient partner - and I truly am a patient partner, because I'm often a co-principal investigator, or a co-investigator - I insist on transparency. So when we bring our advisors together, we put up a slide, and we show them the continuum of engagement. And we circle: "This is you". We don't pretend that they have all this power over the design of the study or anything else. Like, this is where you come in. And this is where we come in. I think that transparency is really important. That's sometimes lacking.

**Maureen 33:59**

For me, patient-partnered, you would want to have some patient partners who are there from beginning to the end. And then it's up to that study to determine whether they need to bring in smaller groups to advise them. I mean, that's really dependent on what it is that you're... that you're actually doing. And I think you'll see often that there's advisory group... like they'll bring in an advisory group, because patient partners often recommend that. I don't want to be... I don't want to speak for all these people. Like that's not anything I've ever wanted to do. I've made that very clear from, you know, from the beginning of my engagement. I'm not representative of a patient voice.

**Emily 34:50**

So without you there, would it still be patient-partnered research? If they still got all those people and had talked to them and were transparent - "Here's where you come in" - and someone was really good at designing patient engagement, but they weren't a patient and did exactly that sort of thing, but they weren't a patient partner?

**Maureen 35:08**

I think that to be a patient partner... I think you'd have to be wearing that hat. I don't think that if you're working in a professional capacity, and that's your day job, that, you know, with that group, that you could call... You call yourself an advisor, you call yourself an engagement advisor. But I don't think you could call yourself a patient partner. I think patients want to... patients and caregivers... I think, want to keep that term for themselves.

**Maureen 35:43**

Patient partners are a diverse group of people, you know, who are motivated to be engaged for various reasons. And they have preferences for how they envision their partnerships. So how... Are they defining it as a partnership? I mean, there are so many questions around this, right? And so I'm always disappointed when I read "patient engagement best practices" or "guidelines for researchers" and they make statements like, "be clear about roles and what you expect". Wrong. Wrong. It needs to be a discussion. So what is feasible for both the researcher and the patient partner? And that's based on a number of factors. So I mean, there's one researcher with whom I've collaborated for a number of years. And when she first approached me, I really wondered like, what can I possibly contribute to this? But she had me when she said, "Maureen, we'll learn together." And I was like, okay! Like, there's no expectation that this is going to be perfect, we can kind of negotiate as we go along. So I think that part about trying to put patient partners also in a box, is also problematic.

**Maureen 37:02**

I can give you another example. I was working on a... I was working on a video for getting patients engaged in research. And they had given me this script, you know, to edit, and it said on the script, "oh, and at the end of the study, you can present with the researcher." And I said, "I think you should take that out of there. Some people don't want to do that. And you're going to turn them..." "Oh no, it's really important. We want to empower them." And so the intention is really good, right? Like, "we want to leave it in", I said, "Fine", I'm not going to fight every battle. So they bring in a pilot group, and they play the video, and the person says, "Well, if that's the case, I'm not joining, because I'm very shy, and I don't want to do any presentations." So you know, sometimes that goodwill doesn't suit that patient partner,

**Jennifer 37:58**

[fade in]...The researcher: they're not necessarily afforded that same kind of, you know, deciding where to slot themselves. You know, I think the real successful projects that we hear about often have a PI or a leadership team in the research project, who are very much drawn to doing collaborative work. And I think we sometimes encounter people who are in fields... or who just, frankly, have certain personality types... you know, where that doesn't come easily to them at all. And so the pressures of trying to enter this partnership space become frankly quite overwhelming. What could patient partners do - or people in leadership in patient partnership - what could you do to help bridge that gap and maybe build some capacity for researchers, so that they're not feeling like they've somehow been hung out to dry in some cases? Because I think that that can happen too.

**Maureen 38:52**

That's a really good question. I have a perfect example of that. So when the pandemic struck, there wasn't a lot of... there wasn't a lot of patient partner research going on at all. But I became involved with a project called COVID N, which brings together evidence synthesis from teams from all around the world and tries to, you know, put it all together. So there's no duplication of research on that. And I knew about it because of my work with Cochrane and I kept saying to the leads, you know: We're decision makers. So the whole point of COVID N is to make it easier for decision makers to have access to the research that they need, you know, quickly in the pandemic, because then, you know... We're decision makers too during this pandemic, like we're making decisions about public health measures and things that at a rate that the public has never made before. And they're, they're having an influence on our society and all kinds of people. We should be involved in this project.

Well, you know, open your mouth and ask for involvement and then the next thing, you know, you're the citizen engaged... Citizen Engagement Co-Lead!

**Maureen 40:00**

So the reason I'm talking about this example was that it took everything that we knew about patient engagement and turned it upside down. So we were trying to get people involved in rapid reviews - some of them were being done in three to five days. But they were doing these rapid reviews to provide evidence to decision makers for very important decisions that were going to be part of guidelines and policies that are going to affect us all. But there was no patient, or public, in this case, input. So here we have the situation now where we have all this, you know, information on patient engagement and training and all that - none of it is going to help them. So a lot of these researchers are people who do systematic reviews, you know, they may have had patients you know, at the end, on peer review - but have never worked with the public especially. And yet in the space of two weeks eighty citizens signed up to be part of this pool.

**Maureen 40:58**

So now we've got a problem because we've got this ideal, but it doesn't work. So everything that we know about - you know, creating relationships and negotiating with people and all these things - are not working. So we've got to be really flexible, and we've got to adapt to this environment, because I'm determined that we're gonna get... we're gonna put some of these, you know, members of the public or patients, we're gonna pair them up with researchers. Most of the researchers that who engaged us had never worked with a patient partner before. Ever. So you know, we created a 10 hour mini course and the whole course is basically saying, "Okay, these are all the things that you're supposed that normally you would do to have a good patient partnership. Yeah, none of that's going to work." So we had some guest speakers. And I remember when one of our course participants said, "Oh, so what did the research team do to accommodate your schedule?" And the answer was: nothing! They had a week, they were working 24 hours a day. And we found out from there that there are certain people who are willing to do this work quickly, on a time schedule that's difficult. And without, you know, having all those you know, feel-good feelings of, you know, training and all that. And that desire, that desire is there. I've learned a lot from that, because I actually got to work with researchers who were not used to working with the public. So you know, the bottom line is that it's nice to have all these ideals that we strive for. But boy, if we're not able to pivot really quickly and adapt? That whole ideal of patient-partnered research is not necessarily going to work. And that kind of applies for some of the projects where you're talking about, where researchers don't know quite how to fit that in. I think it's because it's not maybe long term, and it's not as collaborative. And I think you're exactly right - the people who are attracted to it are often the collaborators. And you know what, there's some great researchers out there who aren't collaborators. And they have to come at it, you know, at their own pace. And we have to help them, and be really patient.

**Maureen 43:31**

In all fairness to researchers, I can only imagine that it's going to be nerve-wracking to collaborate with patient partners with whom you've got no prior relationship. So it can certainly go wrong. So what? You know, you learn something. And you get back on the horse. But the truth of the matter is that I really believe that in the research enterprise, patient partners are often held to a higher standard than other members of the team. So for example, if a researcher has a negative experience with, say, a biostatistician on the team, you know, they chalk

it up to being the wrong fit for the team and it won't result in concluding that there's no value in partnering with biostatisticians. But when it's a patient partner, it's often a different story. I've heard many times "I tried it, it didn't work". So there's a lot of pressure on patient partners to get it right. And, you know, one would think that scientists would appreciate the value of trial and error. But there's often, you know, there's not having that patience, no pun intended, with you know, with: we're going through a process and learning and maybe refining it for your next study, you know. We could do this next time, instead of saying "well it just didn't work." So that's where I think there's an impatience now. "We've got to get this right." And I think I think that takes time.

**Maureen 44:59**

And we're just starting now to really evaluate its impact. That's just really, really beginning. And I applaud that, and I wait for those findings. But while we're waiting for that, I've had a few patient partners share a personal impact of their partnership with me, not to mention my own positive experience. And that sustains me on those on those days that I find tough. And then there's always this bigger picture. So that excitement about emerging patient partnerships, like in areas where patients didn't go before, like in bench research, for example. And all these innovative strategies that people were coming up with for patient engagement and for participation in research, you know, that that will serve Canadian society, and you know, that potential to revolutionize and democratize health research. I have to say that all of those things are very appealing to me, just on a human level.

**Emily 46:09**

A big thanks to the Vasanthi Srinivasan and Maureen Smith, for participating in this episode. If you have any questions or comments, please contact us through our website at [mattersofengagement.com](http://mattersofengagement.com).

**Jennifer 46:32**

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