

Transcript

Matters of Engagement podcast

Episode: "Equity and Diversity, with Nav Persaud"

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SPEAKERS

Nav Persaud, Jennifer Johannesen, Emily Nicholas Angl, Vina Mohabir

Nav 00:00

So you know, who benefits from talking about diversity? I think it's often not people who are affected by discrimination.

Jennifer 00:15

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

Emily 00:24

And I'm Emily Nicholas Angl.

Jennifer 00:27

In this episode, we attempt to take on a couple of challenging topics, diversity and equity, and more specifically health equity and barriers to health equity. This is thorny territory. And there's a lot of complexity, making these topics difficult to contemplate, nevermind actually discuss! But we're going to try.

Emily 00:49

So first, a little context. There's increasing pressure on government and healthcare institutions to address barriers to health equity, which disproportionately impact people who experienced systemic racism, and other disadvantage or mistreatment.

Jennifer 01:05

Right, and these barriers have always existed. But awareness has been heightened lately in the public consciousness by news coverage of recent world events. And we're now hyper-aware of race related health disparities and inequities, unequal access to health care for people who experience systemic disadvantage, and the lack of support for the health of indigenous peoples. Governments and healthcare organizations are under intense scrutiny for how they handle equity, health equity and diversity. And the stakes are really high.

Emily 01:37

So what does this have to do with patient engagement and partnership? Well, we think a lot. The goals of these programs include improving health equity and equitable access to health care for everyone. And the belief is that diversity among engaged patients - diversity representative of the people in Canada - is critical to helping achieve these goals. One of the problems is that engaged patients are mostly middle class, white, and female. There are exceptions of course, but there is a long way to go. So to help achieve desired levels of diversity,

there's a lot of focus on recruitment, outreach and accessibility, all in an effort to attract people from underrepresented groups.

Jennifer 02:25

We've been keen to talk through some of these ideas and assumptions as we think there are some interesting tensions to unpack. So we contacted our guest, Nav Persaud, for perspective and insight. We hope you find our discussion as illuminating as we did.

Jennifer 02:41

Please stay with us to the end for our new segment, "Patient Partner Reflections, brought to you by OSSU". We'll hear from Vina Mohabir, sharing her reflections on the topics discussed in this episode.

Jennifer 02:54

Dr. Nav Persaud is the Canada Research Chair in Health Justice, a staff physician in the Department of Family and Community Medicine at St. Michael's Hospital in Toronto, and an associate professor in the Department of Family and Community Medicine at the University of Toronto. He is also the champion for EDI - or equity, diversity and inclusion - for the Ontario SPOR SUPPORT Unit, or OSSU. And one of the authors of "[Fairness is Excellence](#)", OSSU's equity framework.

Emily 03:23

And actually, we're going to start there, with our discussion about the equity framework - which we've linked to in the show notes. The framework explains principles and practices for promoting equity and patient oriented research and equity related requirements for researchers. There's a short section on engaging patients and the public. And most of the document is about bringing an equity lens to the entire project, including topic selection.

Jennifer 03:49

We asked Nav how it's been received. What sorts of conversations have come of it? Here's what he said:

Nav 03:54

The document starts out by talking about the importance of health equity. And then the first topics includes selecting research topics and developing proposals. And really there the emphasis is on choosing projects that could actually affect equity or improve equity, make the healthcare enterprise more fair. But interestingly, since the framework has been released, I have received more questions about the more practical technical aspects, like designing, study recruitment, compensation for potential patient partners, etc. And I think all of those issues are important to address and important to think about and that's why they were included in the document. But I think doing those things without making the bigger changes is really an opportunity missed and I am a bit concerned that some might be reading the framework selectively and skipping over the first part, and just the sort of "yeah, yeah equity is important, got it". And then just looking at the technical, practical recommendations and saying, "Yeah, we can do a few of these things. And we can describe that. And then we'll be able to say that we are promoting equity". When really, I think the main message in the document is that we need to center equity and focus on it and not address it as an afterthought.

Emily 05:26

Yeah, this isn't surprising. People often feel kind of stuck. They want to do the right thing. But honestly don't really know what that's supposed to look like. Sometimes it's just: "Please tell me what to do and I'll do it."

Jennifer 05:42

Well, the framework is about patient oriented research, which, according to OSSU is the same thing as patient partnered research. So it maybe makes sense that it was received this way. It was likely read by people especially interested in patient engagement and partnership, which means they may indeed be more focused on things like recruitment and compensation. Nav acknowledged that those things are important, but that they probably are most helpful for people who already want to participate.

Nav 06:11

I think some of the technical practical solutions you alluded to there are helpful, like thinking about the time of day, that meeting should happen, thinking about support for transportation, childcare, etc. I think those can help people participate if they want to participate but I think the bigger issue is making bigger changes, so that people want to participate. And that it actually would make sense for them to participate because there's actually a chance that the project or the change in the way health care is provided could actually help people and help make the healthcare system more fair.

Emily 06:51

Right. So it seems that Nav is differentiating between two things: making things more accessible through those practical solutions just mentioned, and changing the wider system so that people have more confidence that participating will actually have an impact.

Jennifer 07:08

Yeah, that's right. Questions of equity have much broader implications and have a much larger scope than questions about how to engage. It gets confusing to talk about because I think in patient engagement, equity is thought about in a couple of ways. The first is that engaging a diversity of patients will lead to more equitable health care. And the second is that engagement itself needs to be more equitable, to make it more diverse.

Emily 07:34

Yeah, engaging equitably, and focusing on equity. Well, they're not the same thing. And one doesn't necessarily cause or require the other.

Jennifer 07:45

I think that's why we noticed that in the equity framework, the section about engaging patients and the public was relatively short. We asked about that. From an equity perspective, where does engagement in research fit in?

Nav 07:59

If there's a focus on equity, then it could certainly make sense to want to equitably involve people who've experienced disadvantages in the research enterprise that would include patients and members of the public.

And I think, in my own work that I think is focused and centered on equity, I believe that it is sensible to engage people who are not clinicians and researchers. But I can also see others disagreeing. And I also just be eager to point out that I don't actually involve patients and members of the public in every single research project that I do. I mean, I think it's important. And I do it more than I used to, and maybe more than others, but I don't do it in 100% of cases. And I think there are some examples, such as knowledge syntheses or systematic reviews, where I think there's there can be less of a role for patients and members of the public. I guess others would disagree about this. But I don't think that patients and the public have to actually be involved in every single activity that a researcher engages in.

Jennifer 09:08

Well, I think Nav's right, that others might disagree! We heard Maureen Smith in the previous episode describe being a patient partner in exactly these kinds of studies, like systematic reviews. But maybe where they would agree is that in studies like these, the role for patients might look different than it would for studies where the need for patient involvement is more obvious.

Emily 09:30

Yeah. And Nav's also looking at all this from the perspective of someone who's seen the fallout from engagement done poorly, or sees what happens when there might be a desire from the researcher to engage patients, but the constraints of funding and timelines don't align with the vision. He takes a cautious view and prefers honesty to overstating the involvement of patients.

Nav 09:52

That is a really important point about being clear and honest about what was the role or what is the role of patients and members of the public. I think that sometimes, because of the pressures that we've been discussing, the role of patients and members of the public is overstated and maybe exaggerated. And it might be with the best intentions. Like maybe the researchers set out to listen to what patients are saying and to make changes. But I think there are some situations where there are other constraints, like the realities of funding and timelines, etc. And then research just ends up moving forward. It's uncommon that researchers intentionally ignore what patients or members of the public are saying, but I think there are situations where researchers just want to move a project forward, and then the views of patients end up not really making a big difference. So I do worry about it actually, in some of those projects, where there's obviously a limited scope for patients, but there has been some pressure to include them. You know, I wonder about how that would go. And I think it is much better to be clear about the extent to which patients have been involved or not involved.

Emily 11:10

Yeah, there are certainly those that will argue that there's no natural limited scope for patients. But either way, this is where frustration is probably felt on all sides - when there's a desire for engagement, but the project or funding or structure isn't set up to support it.

Jennifer 11:29

Well, while we were on the topic of engaging in research, we wanted to talk about diversity. In everyday casual language, diversity and equity are so intertwined. I think we don't often stop to question how we tend to

associate them together. So we asked: what about diversity? Is that an important consideration when thinking about engaging in research?

Nav 11:53

I mean, I think the main thing is, like, is the purpose of the project to promote fairness and equity? If that is the focus, then it could well make sense to involve racialized people and other people who have experienced disadvantage. You know, there are a lot of projects that don't have anything to do with equity or fairness, don't have anything to do with addressing racism. They are like, the usual research projects, testing one treatment versus another treatment. And then at some point someone has decided, it would be a good idea to seek out patient or public involvement. And then someone else says, if we're doing that, we should try and recruit people who are diverse. So then I think in those situations, people can just be taken for a ride and involved in something that is not likely to promote equity in any way.

Nav 12:49

It's perfectly fine for a racialized person or another person who's experienced disadvantage, to participate in a project has nothing to do with addressing racism, they might just decide they want to help out on a project related to cardiovascular disease or preventing heart attacks or strokes. And that would be perfectly fine, I think. But there's, I don't think... you know, that shouldn't be represented as a project that's going to be addressing inequities. We also just want to be careful about what people are told about what the recruitment processes is like and what the purpose is. So I think that's the main thing, like, is there an actual focus on equity or not?

Emily 13:31

Well, that's raised a lot of important questions. This concern that Nav I've expressed that people might get taken for a ride... that they might be used symbolically as an example of diversity.... when in fact, they may just be there because they're interested in a project and want to help. They weren't expecting to fill some kind of mandate.

Jennifer 13:53

Right. And these things are rarely explicit. Often, there isn't an official mandate, but rather an implicit understanding that the group should aim for more diversity and better representation. That might sound reasonable. But in practice, it can get complicated. We asked Nav to comment on potential problems related to diversity and representation.

Nav 14:14

You know, my guess would be an individual does not provide input on behalf of others with the intent to represent the views of others to represent an entire community or an entire race (if you want to use the term race that way). You know, they'd be providing input on a specific project based on their own experiences, which obviously would be informed by their identity. But I don't think that most people would attempt to represent a larger group when they're providing input on a research project or on the way healthcare is delivered. But certainly, one of the reasons they might be there is because someone, a researcher or an institution, wants to say that they have consulted with racialized people or with members of a specific group - there might be a box that is checked as soon as that individual opens their mouth - that they could also have that perception that they

are being... they have been invited, or they're being asked for their view because they're a member of a specific group. So that could feel like a lot of pressure, if that is the perception. And it could also feel like you're being flattened, like, you are seen just as your race or your skin color, and not as like a more complex three dimensional person. And not all of your experiences and your views would be informed by your ethnic identity or your race.

Jennifer 15:55

So we've touched on a few things that are actually pretty common in discussions about patient engagement - meaningfulness, diversity, risk of tokenism. The challenges presented by each of these are not easy to solve, and people within patient engagement are working hard to address them. But patient engagement programs are of course situated within a wider context. Actually, within a context within a context within a context. There's the organization or institution, the wider community, the healthcare system, and the culture we're all immersed in. And I think there are aspects of this wider ecosystem that we just don't talk about enough.

Emily 16:33

Yep. We're talking about systemic barriers. We often use this catch-all phrase, but when it's used too often, it loses meaning. We're talking about racism, oppression, discrimination, injustice, unfairness - all the things that stand in the way of health equity, especially for racialized people and others who've experienced disadvantage. So there might indeed be valid reasons to try and increase diversity, and maybe deploy various recruitment tactics or make engagement more accessible. But from a health equity perspective, we need to ask more fundamental questions.

Nav 17:09

Why would a racialized person want to help the research enterprise when the research enterprise is racist, in many ways? You know, if you look at big research institutions, including in the large institutions that fund research in Canada, they are headed by white people, mostly white men. Some of the institutions involved in health research in this country have never been headed by anyone who wasn't a white man. And so now that there's attention to racism and equity, many institutions are looking to hire someone who is interested in equity, and that person is usually a racialized person. And they're also looking to engage with patients or members of the public who would give an appearance of diversity. But who is actually served by that? Could a racialized person or another person who's experienced disadvantage participating in that process just help to support an institution that's fundamentally flawed, that's historically racist, and currently racist? When we're talking about racism or oppression, we're talking about power differentials and money differentials. So it's important to keep track, to keep score, of who's going to be benefiting. And how much is a racialized person or another person who's experienced disadvantage participating just going to exacerbate a power differential or a money differential.

Jennifer 18:38

So this challenges some really well entrenched notions about diversity - that if we take a kind of multicultural approach to filling out patient engagement programs, then maybe that might help to push against or even reduce some of the barriers to health equity, like systemic racism. But as Nav just pointed out, it might actually make things worse. Increasing diversity for its own sake, without centering a focus on health equity? Well, it can

further exacerbate existing issues by making it look like there's been some kind of progress when there hasn't been. And sometimes not having diversity is the right approach.

Nav 19:17

You know, while equity or fairness makes sense... like everyone would want to be in an institution that centers on equity and fairness... it's not necessarily true that you would always want to be a part of a diverse institution where that would be beneficial to you. There might be, for example, benefits of being associated with an institution that focused on the health of racialized people. And that mostly hired racialized people. So that would not be a very diverse setting, but it could actually be an institution that promotes equity. So you know who benefits from talking about diversity? I think it's often not people who are affected by discrimination.

Jennifer 20:05

Well, this is consistent with a recommendation in the equity framework. It says that in some cases, it may make sense for certain groups to be actually overrepresented if they're disproportionately affected by whatever is addressed in the research project. And for projects that truly put equity at the center, it says: "engagement will clearly prioritize people who experience disadvantages". Which puts a different light on how we're even talking about diversity and engagement.

Emily 20:33

Yeah, that's really interesting. Currently, there's very likely an over representation of middle class white people who engage. And the effort is on adding people with different experiences and perspectives. But if we put together the pieces of what we've just heard, a key goal of patient engagement is to improve health equity. (I mean, it's more nuanced than that... but for the sake of argument, let's say just "health equity" broadly.) But if that's true, engagement should prioritize people who experienced disadvantage, not just add them in for the sake of diversity. That really changes things I think.

Jennifer 21:13

Well, engagement programs don't feel welcoming to everyone. We know this, and people are trying to change it. But maybe that change won't happen unless it does actually look completely different first, where white middle class people aren't at the center. Getting creative with recruitment and compensation practices really can only go so far, if there aren't bigger structural changes. People who have experienced discrimination or the kinds of disadvantage we've been talking about who aren't engaging, well, they may not even want to enter the building.

Nav 21:48

Part of being honest and clear with people is saying: patients are not going to be involved at all levels. Like, there is a CEO of the hospital who doesn't look like me, it doesn't look like the patients or members of the public who are going to be involved. And decisions are made at that level, that affect the way we do things, affect the way we reimburse people, affect how security guards are hired. And these are all things that are ultimately going to affect the process. For example, we have had issues where patients and members of the public who have been involved in research projects have had concerns about the way they were spoken to by security guards when they were entering or exiting the building. There are certain things that I can do to help address those situations

- I can speak to people, I can speak to security staff, but ultimately, there are bigger issues at play that impact people in a very direct way. In the same way that patients receiving care at the hospital are affected by the frontline staff, the staff they would interact with on a daily basis. Likewise, patients and members of the public engaged in research or in the way care is delivered are going to be affected by those higher level decisions that they frankly, do not have a direct role in making.

Emily 23:02

There's only so much that can be accomplished when there's a wider system in which the people involved, or engaged, have little control. It's not just about what else is happening. It's about who's in charge, who is authorizing or making decisions? How is money allocated? Who gets hired.

Nav 23:22

Taking again the analogy for the leadership of the hospitals or the CEO, hospital generally have a lot of people who are qualified - like doctors, nurses - who have the credentials, and many have now done MBAs, etc. So there'd be a lot of people who would meet most of the technical requirements for being in the leadership. And yet still, the leadership of hospitals is fairly homogeneous.

Emily 23:51

Yeah, the lack of diversity at the top is very hard to justify. And Nav makes the same point about engagement. The lack of diversity is not for lack of people in general, there are plenty of so called "diverse" people.

Jennifer 24:06

Yeah, we tend to focus on recruitment or outreach to address the diversity problem. But there are other valid reasons why engagement lacks diversity, including the fact that some people just don't want to engage with a healthcare institution, and may never want to.

Nav 24:21

You know, likewise, when it comes to patients or members of the public, there are a lot of people who've experienced disadvantage, who could be involved in designing research projects and helping to design healthcare. And so I would be very surprised if someone tried to claim that they are just not out there. You know, if racialized people are not interested in being involved, we should ask why what needs to change about these institutions? You know, is it because they don't feel safe in these institutions and you know, when they get an invitation from a certain hospital they think about poor treatment or racist mistreatment that they or a family member received? And if so, I mean, it would make perfect sense for them not to want to volunteer their time to help that institution. So, I think we want to try and understand: if it's true that racialized people don't want to be involved, why?

Jennifer 25:22

I can imagine people listening to this and saying, "Well, we do have EDI programs to answer these questions and address these issues." Maybe so. We're not really qualified to comment on the effectiveness of those programs. But we do know that there are experienced advocates, experts, academics - people like nav - who can guide organizations towards better approaches to equity.

Emily 25:46

Right. And based on his experience working within and for organizations with varying levels of commitment to equity, we wanted to know: what makes for a good, or bad, approach to EDI and improving health equity.

Nav 26:01

In terms of red flags, one would be if the institution or the researcher has really never done anything related to equity or fairness, and now there is a sudden about-face and a sudden increase in the interest in equity. And you could say, well, "but people are changing and learning isn't a good thing if someone you know, wants to do that?"... I think the other part of it is you can work with people who have been active on these issues and trying to improve equity. And I think that would be one of the hallmarks of a project or a group that has put some thought into this, is that they are working with people who have done this before. Like, imagine if someone said, like, "we're really interested in developing new statistical techniques to analyzing health data. And you know, we're looking for public input on that." And they hadn't spoken to involve any statisticians. Like, you'd wonder, you'd say, "Do you even know what you're talking about? Like, have you put any effort into this already, yourself before you have thought to involve other people, and potentially put others at some sort of risk, or at least put demands on their time?"

Jennifer 27:13

Yeah, this makes a lot of sense - to bring in people with actual experience, rather than trying to muddle through on your own. And if we think about patient engagement, this is also useful advice. In some cases, it's probably more productive and potentially less risky, to consult with community leaders or to partner with community groups, instead of trying to individually recruit people into engagement who have particular experiences or backgrounds.

Emily 27:38

Yeah, but forging these kinds of relationships or doing the work that someone might advise? Well, you can't rush it. And it might be unpredictable and hard to control. Given that structures, timelines and budgets don't really account for this, well, as Nav says, even just trying can seem sufficient. Even laudable.

Nav 27:59

It does seem like sometimes when it comes to these equity or diversity initiatives, the bar is very low, and the standards are very low or non-existent. You know, I think there's sometimes this attitude that any attempt to promote equity, or to include people fairly deserves a medal, even if someone does it very badly. If they're at least trying, then that's better than nothing. But in fact, I think a poor attempt can be much, much worse than nothing. I think sometimes it is better not to dress something up as addressing equity. It's better if some projects don't try to include a diverse array of patients or members of the public where it's not likely to go well, and where there's not resources, and you know, the expertise or skill and in dealing with some of the issues that might arise, then it might be better not to do it, rather than doing it badly. And obviously, there are always going to be risks, and like no situation is going to be 100% safe. But I think I have seen some situations that went badly and probably could have been avoided if things had just been different from the very outset.

Emily 29:10

Yeah, it's such a common refrain, that something is better than nothing. It's often not for lack of trying by the people who are directly involved. As Nav pointed out, it can be because initiatives are underfunded or support is minimal, or that people tasked with EDI initiatives are inexperienced or have been given a limited scope of action. It can be really frustrating for all those involved.

Jennifer 29:36

Well, I think the part we have to say out loud is that these constraints could be adjusted if people wanted to adjust them. And we should also wonder if these diversity efforts actually make an impact on health equity at all, especially if the focus doesn't reach executive or leadership levels of the organization.

Nav 29:56

It's already against the law to hire in a discriminatory way. If a hospital or university said, "We just prefer to hire members of leadership who are white, like, we just like having a white CEO. And we like having white vice presidents of this hospital," - that would be totally unacceptable. And I'm sure would open them up to liability and someone would sue them over that. So, I don't think there are any institutions that are saying that right now. But if you do look at who's leading hospitals and universities, across this province across this country, it is mostly white people, mostly white men. You know, these institutions are not doing a good job at hiring fairly. So it would be odd now, when it comes to patient partnerships to say, "we're going to have a very high standard. And when it comes to these, like mostly volunteer positions, where people are not paid or paid very little, we're going to ensure that the recruitment process is totally fair. And we get a lot of racialized people involved, for example, or we get a lot of people who have disabilities involved now." So why would you apply that to patient engagement or public engagement, but not to hiring the CEO or the vice president of the hospital or university? I mean, if it's true that you want to involve people at all levels, then you know, find a new CEO. Find new vice presidents for the hospital.

Jennifer 31:23

We asked Nav directly. Do you think that, what you just described... is it on purpose?

Nav 31:30

Yes, I think it is intentional. I think there is a desire to maintain the status quo. If you're in power, in a position of privilege, you're going to tend to want to hold on to that power and privilege. And if people are saying they're concerned about racism, they're concerned about inequities, then you might feel some pressure to do something. You may not want to make a fundamental change. So then you make a change that's not very important. And you know, that's not likely to threaten your position of power, it's not likely to threaten the status quo. And one of the things you can do is invite a panel of patients who are quote "diverse", and take a picture of them and put it on the cover of a brochure. So that when people ask you about what you're doing to promote diversity, you say, "we have these people come in once a month, or whatever, and we listen to what they're going to say, and we record it and we take notes, and we have a potluck at the end of the year." So it's a way to do this anti racist pantomime, without necessarily making any real changes. And in many cases has zero financial implications for the institution. Like at least if you think about the hierarchy, changing the leadership of the hospital, that might have some big implications. Then there'd be like changing the management and

changing the frontline staff. And then I think the safest thing to do would be to make changes in these advisory committees or patient panels where there would be basically no risk and no financial or power related dynamics at play here.

Emily 33:18

I kind of think of this as a sort of chicken or egg problem. Like, what should we do first? Do we prioritize the bigger issues and the smaller ones will kind of fall into place? Or at least once we do address them, it will be within the context of a more equitable system? Or should we start smaller, like increase diversity and patient engagement? And will that maybe have a ripple effect? Or maybe we do both at the same time? We brought this up with Nav and his answer was very... realistic.

Nav 33:51

Yeah, I think it makes more sense to focus on the bigger issues. I think you can always frame a best case scenario where maybe, even if we just engage this one patient who's experienced disadvantages, they will inspire employees, and they will inspire the board and the institution will eventually become better. You know, if you look at the history of many of the institutions we're talking about - hospitals, universities - they've had similar approaches over 100 years or longer. So I think you have to be realistic about what will be the impact of a diverse patient panel, for example, and think about all of the other layers in the institution - the employees, the leadership, the executive, the board, and just be realistic about how much of a benefit there will be to striking this diverse panel.

Jennifer 34:56

Okay, so what I'm getting is that diversity in patient engagement, for its own sake, may not have the impact one might hope for. Which I think for some might be hard to hear. But here's another maybe even more challenging thought: could the same be said for patient engagement in general? I mean, it's thought that by adding diversity in the form of patients and patient experience to health system improvement or health research, that that itself may lead eventually to improved health care and health equity for everyone. It's a bold claim. And we ask Nav what he thought:

Nav 35:33

I think this idea is maybe related to like this very wide definition of, of equity or diversity. And there are actually many health research documents that have been published, that have extremely broad definition of diversity, to include things like diversity of different medical specialties involved, like diversity of thought, diversity of different academic disciplines. And then they'll say also, and, like diversity in racial and ethnic groups, etc. And like, usually with ellipses at the end, like you know, "all that stuff". And I mean, thought about that way, the concepts of equity and diversity are like almost totally meaningless. You might be promoting that meaningless, empty, large concept of diversity by just including members of the public because they are going to have a different perspective from doctors or from nurses. But there are historic and current inequities, like differences in life expectancy based on whether you're a racialized person or not, differences in whether or not you're likely to be killed by an intimate partner if you're a woman or a man. These are things that have been around for a long time. They're big problems today. And they're very different from you know, the difference between having a medical anthropologist and sociologist involved in your project. You know, that's a totally different issue.

Maybe that is important, I actually don't know. But it's not at all the same thing as involving people who experienced disadvantage.

Nav 37:19

I mean, I guess I've been saying a lot of things that might come off as negative. You know, let me also say that I am a researcher. And so I have a certain view that health research can help to address inequities and can help to address health inequities. And I also think that engaging patients and members of the public can improve health research and can improve health care. The concern is really if people are being taken for a ride on projects that are not truly ever going to address equity, but there is this desire to have this equitable veneer on things.

Jennifer 38:06

Hey Emily.

Emily 38:07

Hey Jen.

Jennifer 38:10

So throughout this whole conversation, we've talked about two concerns for patient engagement: improving health equity, and increasing diversity. And we spent some time with Nav understanding that the connection between the two is maybe not as strong as we might think, or hope. But there were some additional questions Nav raised that I think we should talk about, and that is: who benefits when we focus on diversity?

Emily 38:35

Well, let's retrace our steps. First, there was a lot to take in. I do think that efforts to increase diversity come from a genuine desire to improve patient engagement. And improving recruitment and accessibility will make it more tenable for people who want to participate. That seems logical. At the same time, we know that there are people from some communities or backgrounds who are not joining patient engagement programs in the same way that other patients are, for reasons we've gone over. However, if we zoom out and look at the wider ecosystem, health care leadership looks just as homogeneous as patient engagement, even more so. While there's pressure to increase diversity everywhere, efforts to change seem concentrated in areas where there is less decision making influence and power, and therefore less risk. Areas like patient engagement and partnership,

Jennifer 39:29

Right. And because patient engagement programs have a lot of symbolic value to an organization or institution, it's actually really important to show diversity. The high bar Nav talked about is perhaps not just because it's an easy place to affect change - or at least easier than diversifying, say hospital leadership - but because it's a very visible place to show change. Patient engagement programs demonstrate institutional values like inclusion, collaboration and community involvement. So if there's anywhere that needs to look diverse, it's there.

Emily 40:05

Well, organizations can take steps to minimize the risk that their efforts end up being purely superficial. As Nav said, it's important to consult with people who have experience and expertise helping healthcare organizations address equity issues, including approaches to patient engagement and community consultation. This doesn't get into the question of how communities might want to engage. I mean, we're still focused on institutional goals. But at least it can help avoid major missteps.

Jennifer 40:33

Yeah, engaging with communities tends to mean seeking feedback or input, or as we've been discussing, trying to recruit so called "diverse" individuals into patient engagement. Institutions and organizations likely benefit from this in all kinds of ways. But this may not actually have the community impact people might assume.

Emily 40:55

Well, all this makes me realize just how much more thought we should be giving to these ideas about recruiting for diversity. There may be valid reasons to do so. But if we're not clear, or we're only focused on tactics - well, as we heard earlier, it could be an opportunity missed to focus on equity. And even more important, it could cause harm or even work against efforts to improve health equity.

Jennifer 41:20

Okay, lots to think about. Let's leave it there for now. We hope to get more into these ideas in future episodes. Thanks to Nav Persaud for speaking with us and for his patience in explaining things to us not once, but twice. Please stay with us for our new segment, Patient Partner Reflections, brought to you by OSSU.

Jennifer 41:47

And now for Patient Partner Reflections brought to you by OSSU. The patient partner providing reflections on topics discussed in this episode is Vina Mohabir. Vina is an experienced patient partner and a member of OSSU's Patient Partner Working Group.

Vina 42:03

Hi, my name is Vina Mohabir.. And I'm here today to provide reflections from OSSU's Patient Partner Working Group. My views are my views alone and only reflect what I think. It does not reflect my employer or OSSU. I'm tuning in today from Treaty 13 Territory in Toronto. My pronouns are she and her, and today before we begin, I'd like to tell you a little bit about myself. I've been a patient partner in research for almost 12 years now. It began as a teenager after an injury I sustained that left me with damage to my eye, chronic migraine and trigeminal neuralgia. Later on in life, I experienced a spinal cord injury that led to severe complications, and a long recovery process as well. Throughout this entire time, I was engaged as a patient partner in research. And what I contributed, it always felt meaningful to me. And I'm very lucky to have had those experiences because I know patient partnership can vary, depending on where it's done and how it's done.

Vina 43:13

Today, I'd like to provide reflections on equity and diversity and inclusion. Before we begin this, I feel like it's really important to bring up intersectionality. I am a disabled woman of color. I am the child of immigrants who came here and lived in poverty. I'm still highly privileged. I was able to attend post secondary school, obtained

degrees, I have a full time job, I am currently homed. I'm extremely lucky to have the things I do have. Which is why equity and health equity is very important to me. Because I know had I been born into a different family, this would not be the case. And this is the reality for many children living with chronic pain just like I did. Many teens living.. and youth living with pain just like I did.

Vina 44:10

Listening to this podcast, I had a very strong reaction, because it can be hard to hear that patient partnership doesn't matter the whole way through the research process. It's hard to hear that sometimes patient partners are just there to check a box. And that's the way some researchers see us. It can be really hard to hear those kinds of things, especially when it takes a lot of time, energy and effort to be a person living with a health condition to continue to engage with the healthcare system, when at some points it would really just be easier to stop engaging. As Nav mentioned, you know, the way security looks at you or the interactions that you have before even reaching the researcher can really colour the way the way you feel about an institution.

Vina 45:04

And it can be really difficult because when you're looking at some of these opportunities, it's hard to know exactly whether you'll just be in a group photo and have lunches a few times a year. Or if you would be making the differences that you hope you would be making. I've been extremely lucky, because from my point of view, I feel I've made changes that have impacted other kids with chronic pain in the health care system. And that's what I mean by turning my pain into my purpose. It can be hard because I've been a partner on systematic reviews, and I felt like my contribution mattered. But to hear the viewpoint that sometimes those contributions don't matter as much, it can be really disheartening, because it takes again, a lot of time and effort and energy. And for those of you in the chronic illness or chronic condition community, it takes a lot of spoons, takes a lot of energy to engage. And it can be really disheartening to hear that.

Vina 46:16

I feel, especially in projects related to equity, I felt that pressure to represent my community or make changes that could help other people with brown skin, and who don't look Eurocentric or white, or benefit from a system of colonization, white supremacy and racism, and misogyny. And I do believe that it's time for healthcare providers to realize that we have to make statements like this. Because this is a reality of many people.

Vina 46:52

It doesn't mean that, or at least I feel like it doesn't mean, that you shouldn't engage in research. Now, it may not change who's the CEO of the hospital. But these changes make small, even small care changes can make all the difference in people coming through that same clinic. It can make all the difference when you gave feedback that these forms should be translated into different languages. From my point of view, that's a significant change. Because all of a sudden, that individual walking into that office feels a lot more comfortable and ready to engage with the healthcare system. These may not change who the CEO is. But these are the day to day changes that you can keep impacting as a patient partner in research.

Vina 47:42

I've helped with interventions. I've helped other teenagers, especially teenagers from families of colour, realize that it's okay to talk about your illness, or condition. It's not a sin nor it's not bad karma. And this is a really widely held belief in the South Asian community. Even sharing my story, and the hospital that I work with giving me that platform to share my story, would hopefully make a difference for other women of colour, or people who identify as women, to come through the clinic and have a different experience. I think it makes a difference when I ask healthcare providers to make sure they ask people for their preferred pronouns and preferred name. Those things matter. And those are some of the ways that I've informed care. And the way I see it is making healthcare more equitable at an everyday level.

Vina 48:40

I've also been a part of larger policy changes or conversations around policy changes. And again, I didn't feel like the token minority or the token "brown girl" in the conversation. I felt like my views were heard. And I think the key thing when you're engaging in patient partnership, is if you as an individual feel valued, if you feel respected, if you feel heard, those things are what matters in patient partnership in research. Now, this could be about as simple as informing kind of where research is going next and starting to think about, you know, key terms for systematic review. Those things matter, and that is partnership in research. And what's wonderful is I've worked with researchers from that beginning phase, all the way to seeing large scale implementation and resources being created for individuals. And seeing that knowledge translation happen from a systematic review that I started on. Again, this may not be the most popular view but I truly believe patient partnership in research changes research.

Vina 49:56

And although again, it doesn't change who the white CEO is, it does change small day to day experiences in that healthcare system that need to be changed in order for people to engage in care. I can't change systemic barriers. I can't change the history of colonization, I can't change the misogyny. I can work very hard in my allyship. I can read, learn from others, I can unlearn and relearn. But I can't change those things as an individual. It takes us working together to change those things. I would love to have conversations where we do talk about making larger systemic changes, and evaluating... again, some of these systems in place. Because they do need to be evaluated. They were created for a very specific kind of person to thrive and they are thriving.

Vina 50:55

A lot of questions were raised about practical concerns on how to increase equity, diversity and inclusion in patient partnered research by utilizing tools like compensating patient partners, so they're compensated just like everybody else on the research team, for the time they spend on a project. Although these don't address these higher systemic issues, I think for some of these researchers, it's a start. It's a start to them thinking - just thinking about engaging with different people. And while again, this is a baby step, it's still a baby step in the right direction. And in my experience with the health care system, it's all about those baby steps building up to make those larger changes. It starts out with conversations like this, even just trying to wrap their head around patient partnership in research. But it's encouraging. It's a good sign.

Vina 51:57

I mean, some people would say that patient partnership isn't needed for basic science research. Why would you need a patient partner if you're looking at mice models, and you know, a whole bunch of other factors? Well, majority of researchers only use male mice. Now, as someone who identifies as a woman, this can feel very problematic considering how many studies begin with mice models. Now, this is something small, but this is a way to increase equity and health research. And sometimes by partnering with the patient, they might bring something like that up. They might make you think outside of your viewpoint with their intersectional three dimensional perspective.

Vina 52:48

Now, do I think patient partnership should be something done, just to check off the box? Just so you know, a funding agency will grant you funding? No, I don't believe that's what patient partnership should be because that is not patient partnership. But I'd encourage you to keep thinking about what partnership looks like, and how this could be done within your practice. Or in your research. There are tons of resources out there for you to access. And just like you would encourage patients that you work with to access resources, I'm going to challenge you and encourage you to do the same. I also think if you're somebody who is passionate about equity, diversity and inclusion, you'll take time to learn about anti-black racism. Learn about what Asian Canadians experience. Learn about what the Indigenous peoples of Canada experience on a daily basis and why Land Back is vital to moving forward. These are all large conversations and I understand that. And when you are engaging with these communities, if you are thinking, hey, "Vina would be great for this because she's a disabled woman of colour..." - you really have to think larger than that. And think about me as a human, my experience, and how that will impact your research. I am by no means representative of every Guyanese Canadian woman who is heterosexual and cisgendered. I am by no means representative of that community. I can only let you know what I believe based on my own lived experience. And luckily, my lived experience does give me some insight into this. However, no matter what it is coloured again, by my own biases and perspectives.

Vina 55:01

This is all important when you're thinking about engaging in patient partnered research. I hope that this, or these reflections, have helped out in some way and provided a little bit of a different view on some of these topics. I think if you are a patient partner or you're somebody interested in getting involved in research, I'd like you to know that, in my view, even if all you start with is informing a systematic review - that matters, that's important, even if all you're informing is that the security guards at the hospital need to go through anti racism training. That's important. It matters. our lived experience matters. And it's up to us to make small changes, to start fueling the larger systemic changes. We can't continue to go on the way we have, completely ignoring anybody who isn't white, cisgendered, has some level of education, high school degree or higher, has high levels of health literacy. We can't. Because those are not the only people interacting with our healthcare system. Those are not the only people in our society. We're a much larger group. And research should recognize that and reflect that.

Vina 56:31

And I'd encourage you again, if you're coming up with samples that are not representative of your community, talk to your community and figure out why. These are important conversations that need to be had. And equity can't be... an equity framework is wonderful. But again, it's larger advocacy and activism. You can no longer

afford to be apolitical when we know about social determinants of health. When we know how this impacts individuals. We can't continue to stand by while we have racism and homophobia and transphobia. We have to have a two pronged approach. We have to approach systemic factors as well as day to day factors and barriers to interacting with the healthcare system. These are just some of my reflections from today's episode. But I hope you enjoyed hearing them. And I'm always happy to continue these conversations. Thank you again to the hosts for this opportunity to provide some feedback based on my lived experience. And I hope this resonated with some of you.

Jennifer 57:53

Thanks to Vina Mohabir for participating in this episode. If you have any questions or comments, please get in touch through our website at [matters of engagement.com](http://mattersofengagement.com). This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl, with generous financial contribution from the Ontario SPOR SUPPORT Unit, or OSSU, which is jointly funded by the Government of Ontario and the Canadian Institutes of Health Research, or CIHR. The views and opinions expressed in this episode belong solely to the producers or their guests, and are not to be considered endorsed by OSSU, the Government of Ontario or CIHR.