

Matters of Engagement podcast  
Episode “Compensation – with Dawn Richards and Zal Press”  
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Jennifer: Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. This is Jennifer Johannesen.

Emily: And this is Emily Nicholas Angl.

00:19

Jennifer: The topic for this episode is compensation. We're excited for this one because we know it's on the minds of both patient partners and healthcare professionals. Like all of our topics, there are so many angles to choose from when it comes to narrowing down the focus of what we're wanting to cover. We think this episode touches on a few of them, but certainly not all of them. We encourage you to listen through to the end. There are some ideas here that challenge some of our established ways of thinking, whether you think patient partnership should be a paid role, or should be volunteer, or if you think there's room for both.

Emily: Okay, so our guests for this episode are Dawn P. Richards and Zal Press. Dawn is an analytical chemist by training, who works as a consultant supporting research and patient engagement, and who also lives with rheumatoid arthritis. Zal is the founding co-chair of the Beryl Institute Global Patient and Family Advisory Board, and is currently the Vice Chair of the Canadian Agency for Drugs and Technology and Health (or CADTH) Patient and Community Advisory Committee. They're also co-authors, along with Isabel Jordan and Kimberley Strain, of a 2018 paper titled “Patient partner compensation in research and healthcare: the patient perspective on why and how,” which was published in Patient Experience Journal. There's a link to the article in the show notes, and it's also open access. All of the authors identify as patients or caregivers.

Jennifer: The authors intended the paper to be a conversation starter. For people who work in patient engagement in some capacity, you could think of it as a primer, like “Compensation 101.” It provides vocabulary and arguments to help facilitate advocating for funds to compensate patient partners. The authors also felt it would be helpful for patient partners to be able to educate their own project or team members on the issues. And it seems it's gained some traction: Zal mentioned that as of May this year, there have been almost 4000 downloads from 74 countries. Now, I like that this paper was written in accessible plain language. For some journal articles, we do feel it's helpful to go through the paper and do a close reading. But honestly, if you're not familiar with all the common arguments about compensation already, you should just go read it. We won't do a better job of explaining it.

Emily: But for those who haven't read it, we'll give a quick overview. The authors start from the position that conversations about compensation are either not undertaken frequently enough or — if they are — they're awkward or uncomfortable. And they also feel the onus for making a compelling case for compensation shouldn't rest on the shoulders of patient partners. So they wanted to write what they call a practical and pragmatic guide, written from the perspective of experience patients and caregivers.

they base their advice on five key principles, which are equity, acknowledging different motivations, respect for vulnerability, supporting commitment, and removing barriers to participation.

Jennifer: The authors then provide guidance on how to undertake conversations about compensation. They have explicit advice, such as: start the conversation early and ask patient partners what their expectations are. They also raise issues that many people may not have considered. For example, for some patients receiving money may impact other social or financial support they're receiving. So you'll need to discuss alternative forms of compensation like gift certificates, or maybe sponsoring them to attend a conference. Their most practical advice is around thinking about actual fees, whether patients are compensated hourly or daily; or if there's a lump sum for a project, or perhaps an annual fee that covers a certain number of meetings. They go through a few helpful scenarios that would give readers just enough to go on to apply to their own situations.

Emily: And finally, they talk through some further considerations, which are mostly about logistics and planning. When you're factoring in compensation, you'll need to consider other expenses like travel. You'll need to develop a budget, consider organizational policies around issuing tax receipts, expectations around invoicing, whether you need written agreements and payment timelines. So that's the recap. While these are all, of course, helpful and valid points, we think that there's so much more to talk about. We use the article as a jumping off point to get to some much deeper questions.

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Jennifer: In particular, I'm really intrigued about patient partnership as volunteerism. It's sometimes framed as "personal preference" as to whether payment is provided, but that goes hand in hand, of course, with a level of privilege that not everyone has. And for me, I think, this goes straight to the heart of questions about why patients are engaged in the first place. I'm also interested in the idea of "partnership as labour." Zal raises some really interesting points in our conversation about whether engaged patients should be thought of as part of the healthcare workforce. And just to go back to that point about volunteering, there's a kind of status that goes with that. In some of the groups I've worked with, payment is framed as something you only give to people who need it. So there's immediately a divide between who is seen to need it and who doesn't.

Emily: And this then complicates the idea of compensation as an equalizer. Well, we'll have to dive into that a bit more later. But for now, let's get into our conversation. Something to note as we get started is that both Zal and Dawn have a lot of experience as patient partners. But Zal is more on the quality improvement or organizational side, and Dawn has more experience in research. We'll hear from Zal first. He's been pushing for payment for his time and experience for decades and gravitates towards assignments and working relationships that will compensate him appropriately. And he declines opportunities that won't. In our experience, that isn't a common approach. So we asked him if he felt like a bit of an outlier.

Zal: Often, in a lot of what I do... I often feel like I'm a lone voice, because there is no movement, right? There's no community that's really galvanized around, you know, the whole idea of patient engagement. There isn't patient leadership. That's, you know, well defined, that's aggregated, that's dedicated to a particular cause that, you know, mobilizes a community and rallies a community around a particular

cause. So it's really tough, you know, to sort of advance ideas within an industry or a sector where change moves at a pace that's about the speed of a melting glacier.

Jennifer: Zal was saying that in terms of negotiating compensation, patients are pretty much on their own. And he's right, there is no association or advocacy group that is pushing for certain demands on behalf of patient partners. This line of thinking leads to some really interesting and complex ideas. If we want to think about the idea of compensation as a cause, then there's a huge missing piece, which is an organized movement, advocacy in support of a collective demand. And this is really complex, because — as Dawn points out — in healthcare in particular, there's a real culture of volunteerism that can be altruistically motivated. And while some patient partners may buy into this fully, others may want to at least have the conversation about payment, but they're uncertain as to whether they should bring it up.

Dawn: Shifting it into a mindset of compensating people for... I will argue, for the actual skill and perspective that they bring to the table, has not been one that's to say, well established. And then I think there's this level of strangeness and awkwardness to be invited to be part of a team, and that door being opened for you. And then, you know, feeling like, "Am I... is it okay for me to even ask for compensation?" Like, it's one thing that they've asked me to be part of the team and I'm supposed to be grateful for that and I am — don't get me wrong about that — but then, you know, do I seem ungrateful if I ask to be recognized or compensated for my time and for my skills and perspectives that I bring as well? So there's all these things where, you know, normally people would look at that behaviour and go, "Wow! Like, how can you be asking for that?" Whereas my perspective is, "How can I not be?" Right? Like, you know, I'm as much a part of the team as everybody else.

Emily: Zal connects this modern-day culture of volunteerism with healthcare's historical origins as a faith-based charitable enterprise. He referenced a book by Tiffany Ziegler called "Medieval Healthcare and the Rise of Charitable Institutions: The History of the Municipal Hospital." There's a link in the show notes. Zal thinks this ethos of caring for the sick and needy hasn't changed much.

Zal: Our entire healthcare system is based upon a medieval model that promotes the thought that you're getting health care as a charitable act rather than as a matter of public policy. And as a consequence, you have to... of necessity, you are obligated to feel grateful. This is where I think, you know, it's sort of the source of people saying, "Well, you know, I want to give back." You know, "I don't feel comfortable taking compensation." Meantime, they've been paying a fortune for their healthcare, so, you know, there's an irony in that. But the reality is that we've been conditioned to believe that the whole enterprise is a charitable enterprise.

Emily: So this cultural legacy persists, but doesn't jive well with today's reality, where expectations of recognition have changed.

10:39

Zal: It was almost insulting, you know, when you get a \$25 Indigo card for taking an entire day off, and your parking costs \$27, right? But you know... [laughs] the intention, perhaps, was there, you know, to be fair, but they just didn't have, as Dawn says, they didn't have the tools they didn't really understand,

you know, the full background, you know, the real principles underlying the need to value a person's time and energy and effort and intellectual capacity.

Emily: Zal also commented that on the more consumer or commercial side of healthcare, like companies that make medical devices or pharmaceutical or retail companies, they're much more accustomed to paying patients for their contributions — not necessarily because they especially value the patient voice, but because they're already used to paying experts and professionals for their time, and in many cases for their support.

Zal: They understood it because of their experience in dealing with healthcare professionals and compensating healthcare professionals for their time and energy when they were used on advisory boards, etc, etc. So, it wasn't that they necessarily bought into the value of the patient voice, of having, you know, some sort of measurable value that said... this is what they were conditioned to do.

Jennifer: Zal talks about those industries being conditioned to pay for services rendered. And for anyone who's had a job, this is simply our understanding of the nature of work. We do things that usually benefit someone else in exchange for being paid. And for Dawn, who already works in health research, this is her everyday reality.

Dawn: Given that I'm a self-employed consultant, that is usually one of the ways that I can make people understand why they should be compensating me for my time... is I professionally bill on an hourly rate. So if I'm going to participate in a project as a patient partner, I'm missing out billing other clients. And it's really interesting when I simply bring in that, you know, I'm missing work to be able to be here, people can usually... "Oh, okay, that one makes sense." But I also agree that it's not just about time, it's also about my experiences that I bring to the table, my perspectives that I bring to the table, and that's often, I don't think, recognized. So I do a lot of work in the research world. Participants in research projects are often not compensated for their time, and there are ethical reasons for that, but this is... we're not speaking about participation in a research study, we're talking about being partners in a research team, which to me brings very different connotations to the table.

Jennifer: Patient partnership has connotations of productive collaboration between team members who are likely to think of themselves as equals, and payment in this context doesn't seem out of place.

13:39

Jennifer: One of the things we wanted to get to in our conversation is this tension between volunteerism and compensation. Zal and Dawn seem to agree that patient partnership is real work with real benefits that accrue to the healthcare system, and for some, there are real costs associated with participation. It could be hard costs like transportation and childcare, or — like for Dawn — there could be opportunity costs of not spending time on something else.

Emily: Because of these and probably many more reasons, they agree it's not unreasonable to compensate patient partners. But we haven't quite sorted out the wrinkle that volunteerism throws into this. If asking for, or even pushing for, compensation is something important — if it is indeed a cause that needs widespread support in order to gain traction — how does volunteering factor in? If there's

room for both volunteering and compensation for essentially the same work, well, any notion of collectively advocating for widespread compensation may be undermined by the fact that some prefer to do the work for free. So we asked, “What are your thoughts on this?” Dawn doesn't see it as a black and white issue.

Dawn: So I... you know, this one's a really tricky question. I've thought a lot about this, right? And I don't know that I have a set, you know, “everything should be standardized,” or, “these should all be individual conversations,” I think. I think I recognize... maybe I'll call them the limits of them, of each of those different approaches. I certainly know for example, again, coming from the research world, there can be certain limitations on like, what the budget can be, and you know, within... though the Canadian Institutes of Health Research has guidance on compensation, they don't come out and lay out specific numbers around things. But for example, their Chronic Disease Networks that are related to the Strategy of Patient Oriented Research, have come out with a document and — full disclosure: I've been part of that because I worked for one of the networks — you know we did kind of standardize what the potential rates are if patient partners want to be compensated for their efforts around engaging within the various networks, and those are largely driven by, you know, having a set budget for things and coming up with amounts that seem like they could be appropriate for the activities that are undertaken.

Jennifer: Dawn is describing a process for figuring out compensation based on guidelines, budgetary constraints, and some reasoned thinking about the value of the work. But like many aspects of patient engagement and partnership, these are all considered from the vantage point of the organization, and it's the organization making the rules. And as outlined earlier, patient partners are in no real position to negotiate. I would think this is especially true if patients join projects, and then want to start the conversation about compensation. Because of this, the authors thought it was especially important to produce an article from their patient perspectives, even though it's aimed at organizations. Zal talks about it as a tool for capacity-building.

Zal: That's why, you know, at this point, I think it's absolutely critical to enable not only the professionals, the researchers, the healthcare providers, you know, with the principles behind it, but also to provide, you know, guidelines around having these conversations that patients, you know, have access to, and it's guidelines that represent their perspective. And that's really what's different about our paper, you know, is that it's written by patients, and if you want to consider it to be “biased,” you know, from the patient perspective, I'm okay with that! Because nobody else is providing, you know, a comparable kind of perspective. So all of those patients who, you know, would not normally have gone into a research situation and had the courage or the capacity — let's say the capacity better than courage — but the capacity to engage in a conversation, now have that capacity. To me that's liberating.

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Jennifer: For Dawn, writing the paper was also about taking some of the pressure off of patient partners to have to explain everything themselves, which can be exhausting. The paper gives patient partners a way to push some of the responsibility to the institution or organization, where Dawn actually thinks the responsibility belongs.

Dawn: I think it's really interesting how, to date, there's been this onus placed on patient partners who are already, I don't want to say disadvantaged by being the only... usually the only patient partners at a project or at a table, but you know, they're already in a minority amongst the team, and then you have to flip up your hand and ask about the budget for compensation, or has it even been considered, right? So I think we kind of came at it from the perspective of, it would be optimal if it's the healthcare providers and the researchers or the organizational individuals bringing this to the table first. And again, I haven't given you a really good answer as to how it would be different if we wrote it for patient partners, but I guess part of it is, to me, we've written it for patient partners to simply be able to flip over to someone and say, "This is a conversation we need to have. And here's some helpful guidance about it."

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Emily: Okay, so we've established that compensation for patient partners is non-standard at best, and that often, patient partners themselves have to bring it up to the project team. This means that these patient-authored guidelines would surely be helpful to alleviate the pressures on the patient partner and would provide some good starting points for organizations to start to get their heads around it.

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Jennifer: I think it's useful to pause here to consider something we don't hear discussed very often: Are patient partners performing labour that should by rights be compensated? They're obviously not punching a clock, nor are they really likely accountable for their contributions. I'm not aware of a time a patient partner or advisor was taken to task for performing badly. But still: if it's so valuable to organizations, if patient contributions are potentially improving care, saving money, building goodwill — why should this be measured differently than the contributions of the paid employees?

Emily: If you listen to our interview with Francine Buchanan, you may recall her saying something similar — that patient partners are recruited to help improve healthcare services and delivery, yet, there are also executives who are hired to improve healthcare services and delivery. And one gets a salary, and the other gets paid parking. This isn't lost on Zal, who quoted Carl May, a medical sociologist from the UK:

Zal: ... and he says, people with chronic conditions are now explicitly conceptualized as part of the healthcare workforce, are delegated tasks by the system and given performance targets. This can create new inequalities. I think this is really kind of telling: what he's saying here is that when we're not just... you know, patients being involved in research and quality improvement and all that, you know... aren't just volunteers in this. I mean, they are part of the workforce. So, you know, how do we really understand that, and how do people actually reimagine themselves within the context of being part of that workforce?

Jennifer: Carl May's work talks about the burden of treatment, about how patients with chronic illness are often tasked with self-care and self-empowerment through various interventions, technologies and treatment modalities, performing tasks and having responsibilities that had previously been assigned to healthcare professionals. And there's a [link in the show notes](#) to a paper of his that exemplifies these arguments. So it's reasonable to think of patient engagement and partnership as being on a broader

patient continuum. After all, the only way to become a patient partner is to first be a patient. And it's not a stretch to apply these ideas. According to May, and referenced here by Zal, healthcare offloads certain care responsibilities to patients with chronic illness. In patient engagement, we could say that healthcare offloads certain decision making and administrative responsibilities to patient partners. So, in this light, should the work of patient partners be considered wage labour? Like with most topics, there is not unified agreement among patient partners. Some would say yes, and I think many would say no. So we asked Zal and Dawn how we might reconcile this tension. Here's Dawn:

Dawn: I've seen this attitude of, "If you don't want to do it for free, like you don't have to be here!" Right? Or I have seen, in instances where people do ask for payment, "Well, we'll just go to the person who is happy to volunteer," right? And you know what I, I say to each zone... I fundamentally believe, and in the work that I do this is always a conversation that happens, it's: we have to talk about compensation. And if we're going to ask people to, you know, give their time, expertise, opinions, perspectives, it's at least a conversation that happens, whether or not they want to take it or their circumstances allow it is another thing, but for me, it's like, this is part of the process of engaging people. You know, I just really feel like, there will always be the people that, to your point, "I'm just happy to be here. I'm happy to give back," and I say, that's great.

24:38

Emily: Dawn went on to say that she thinks there's room for both models, and that there's plenty of work to go around to accommodate the different types of relationships, paid and unpaid. The key thing for Dawn is that patient partners are involved in a discussion and they contribute to the final decision. Now Zal, on the other hand, sees the work of patients as work that should be compensated, but he recognizes in the current culture, people have different preferences. And for Zal, there needs to be more effort in building capacity and supporting a culture shift. But when asked about tensions between patient partners, the lines for Zal are drawn a bit differently:

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Zal: The notion of tension is really an interesting one, to tell you the truth. And I've been on countless committees — Dawn's experience is more oriented in the research community, my experience is more in you know, patient and family advisory work within healthcare institutions, hospitals, etc, long term care, etc. You know, on these committees, I think there's... you know, [when] you boil down, what does that tension look like on a committee, you recognize that there's tension between those who are actually committed to the work of the community and those who aren't necessarily committed to the work, who are more interested in, in just the glory of the work and the honour and the position. And so there's a, you know... there's a tension on a lot of those committees, that leads to things like, you know, attendance requirements, and fulfilling other kinds of criteria in order to maintain membership on those committees. Oftentimes, people don't appreciate how much work actually goes into those committees.

Emily: So Zal mentioned not only the actual committee work, but the other obligations that come with it, like travel time, or childcare, managing home and work life, and finds that people may not fully understand what they've signed up for.

Zal: Oftentimes, that you know, the burden of, of this work isn't fairly shared, to tell you the truth, and I've seen that time and time again on committees that end up just functioning as a result, you know, with a lot of... let alone tension but, you know, the strife among committee members that can evolve from that. Moving towards some kind of fair relationship among all patients, you know, is really what's the important thing, but only if people are going to recognize that you know, a non-compensated position doesn't enable a person to actually contribute less.

Emily: And certainly Zal recognizes that there are extenuating circumstances for some, and that accommodations need to be made. But you can see what he's getting at. I've heard people say they prefer to stay as volunteers as they don't want the responsibility they feel comes with payment, that they need to stay flexible with what they can give. But in the context of this overall conversation about pay for work, Zal thinks there's value in shifting how we understand the power of money to create a shared commitment or obligation.

Zal: You know, I think that it's really important to understand that, just because you say, "I want to give back," that's great. Well, you know, then give back and participate! In the notion that Carl May talks about where you're actually part of the workforce, and you, you're being compensated for that because you are working according to the criteria that all the other workforce members are working towards. And that's a shared commitment, and that's a shared obligation, and I think there's value in that, in understanding you know, that kind of, you know, perspective.

28:46

Jennifer: Regardless of whether a patient partner receives compensation or not, at the heart of the patient engagement relationship seems to be a strong desire on the part of the patient to contribute to something they think is important. So compensation could be seen more as a form of thanks and recognition, and less as a straightforward trade of labour for wages. And in Dawn's experience, even when there is payment for patient partners, it's nowhere near the rate of the other professionals, however you might try to calculate it. So for Dawn, one of the more important things to focus on is that patients feel empowered to have these awkward conversations.

Dawn: Typically, the patients at the table are getting paid such a fraction of what everyone else is getting paid, whether it's researcher, healthcare administrator, even trainee, like I'll be honest with you [laughs], if we're really going to make that argument about, you know, a patient having more power because they are or aren't getting paid when it's like such a fraction of the budget compared to everyone else, I do really believe that it's about the space that's built — whether you're paid or not — to be able to have a safe conversation. And to feel like the value that you're bringing is going to help the team and, you know, all of those things that you're sitting in the corner with, that you're afraid to talk about, because you don't know enough about the context of the project, or where people are coming from, for you to be comfortable enough to actually just talk about that. You know, that's so much more important than... the compensation thing to me, like just melts away.

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Jennifer: Dawn is referring here to a culture of openness and transparency, where people can say what's on their minds and bring up tricky topics like compensation. Now, throughout the conversation, it

was clear that Dawn was supportive of patient partner compensation and in fact has the compensation discussion herself, but she he also believes that money doesn't solve communication or culture problems and recognizes that money can, in fact, complicate things.

Dawn: You know, we somehow equate being compensated to be there... I've often heard this too as well, "I can't... I can't actually say the things I want to then because I feel like, you know, I have to tow the party line," or "I have to agree with everyone." And I guess for me, that just seems like such a sad state. Because again, to me, that ties to maybe a bit about the power thing and maybe a bit more than anything about creating a safe space, to be able to really bring your perspectives and ideas and feedback, and I don't think that payment makes that go away or makes that be clear. I think that that's a fundamental part of whatever team you're part of.

Emily: It's really interesting, this idea that people might feel constrained by compensation. It's definitely something we've heard before. And for Dawn, this is an indication of a power imbalance, or perhaps a lack of what she refers to as a "safe space." In a follow up conversation with Zal, he also had some thoughts on this. He says, if he's been paid for his thoughts and ideas, they should come freely and unfiltered. He thinks it's his obligation to speak truthfully, however disruptive that might be. So we asked Dawn and Zal if they had any final thoughts, not to neatly wrap things up, but to leave our listeners with something to think about. Here's what Dawn said:

Dawn: Right now... it's so ad hoc, right? The conversations about compensation are so ad hoc. We leave it to the individual researchers and patient partners and then, you know, all of those institutional people and researchers have to go jump through multiple hoops within their own institutions to figure out what they can do, what they can't do. And wouldn't it be nice if you know some of those barriers went away for them? That, you know, at least organizations were willing for this to be a typical part of the conversation? Again, I'm not saying everyone wants to be compensated, I firmly believe that's up to individuals, about whether or not they want that to happen. But it would be nice if we could

33:12

move past, "Oh, isn't this an interesting conversation?" to, "Yeah, let me go see how I can help you do that."

Jennifer: Zal also spoke about removing barriers — economic, social, educational — some of which the authors suggest that compensation can help to address. But Zal also sees another angle that is perhaps informed by his work experience outside of healthcare as a business person. He understands something quite fundamental about how the world works, and it's that "money talks."

Zal: And I think that's really the critical part of what's underlying this need for compensation — that we're moving the needle, not necessarily among patients in terms of getting them to be activated within the work — they're activated to being within the work — but how do we activate the organization to support that work in a meaningful way? And until an organization has a line item on the budget, it's not something that's really triggering the attention of the senior leadership. Without the attention of senior leadership, the commitment of senior leadership to the priority of patient involvement in everything and every decision that the organization undertakes, then we're not going to quite get there. So that's kind

of how I look at it, money's the trigger, and once that engagement happens at senior leadership level, that's when we see organizations actually changing, we see progressive change, and we see better outcomes within the organization. That's unquestionable, there is evidence to support it. This is why we've written this paper: it's about changing organizational culture in order to enable valid and authentic patient and public involvement.

35:12

Jennifer: Hey, Emily.

Emily: Hi, Jen.

Jennifer: So, even though they agree on quite a bit, I'm really struck by how their approaches to thinking about compensation are quite different. They do both want to see some forward momentum towards compensation being more widely taken up, or at least more widely discussed. But Dawn seems to look at this more from a personal or interpersonal angle. What I heard is that patient partners need to be better supported individually to have these challenging conversations, and that institutions need to take up more of the responsibility to initiate them. But overall, she was supportive of the idea that patient partners should have the option as to whether they accept payment.

Emily: Mm hmm. But Zal was more hardline about it. If I can try to summarize, he sees compensation as earnings for work he performs, and also sees it as a way to encourage people to care more about the work of patient partners. So that's patient partners themselves. He said, being part of a workforce helps to create a shared commitment and obligation. And then he's also referring to senior leadership. So there's kind of a "put your money where your mouth is" aspect to his outlook.

36:26

Jennifer: So between our two guests, we have a couple of different viewpoints that touch on a few of the common ideas about compensation. And, you know, as with many of our topics, it's tempting to just chalk things up to a difference of opinions and preferences and leave it at that. I mean, you know, honestly the details — like how much, and under what circumstances, and when to give a gift card — these are all things that can be figured out by reasonable people. But when I *really* went through this interview in order to think through this episode, I was so struck by a question I hadn't given much thought to before, and that is: what is the relationship here between the compensation discussion and gender? And I'm not talking necessarily about women's views and men's views, although there's merit to unpacking that, too. But I'm talking about how gendered the whole engagement space is and the implications this might have. Now, I don't have numbers. I don't know if anyone really does. But I do think women outnumber men by quite a large margin. That's what I've seen. Is that your experience too?

Emily: Yeah, definitely. Well, I mean, there are certainly men, and we've had a few on this podcast. But I would say there might also be a difference in numbers between patient partnership in research, and engagement on say, patient and family advisory panels. But yeah, generally it's mostly women.

Jennifer: Right. And though there is some ongoing work now to understand exactly who patient partners are across Canada – but for a while now I think it's commonly understood that engaged patients are mostly white, mostly middle aged, mostly middle class, and this, of course, informs the push for more diversity. But social privilege isn't the whole story, I don't think. As Zal pointed out, the historical roots of healthcare are as a faith-based charitable enterprise — a way to both take care of those in need and also express your faith or goodness through action. And we definitely still see traces of this today, but with a pretty gendered slant, I think. SickKids hospital, for example, still operates a charity called Women's Auxiliary Volunteers. But it's not always stated so explicitly. We see other types of volunteering and fundraising like galas, and bake sales, knitted garments for babies... I mean, obviously there are exceptions, but it does seem to be primarily women organizing and performing these duties. And I would also have to say it's not just any women: it's women with time and opportunity. There's a social currency to performing charitable acts, which goes all the way back to the origins of modern healthcare. Now, I know I'm making some loose connections here and it would take more work to bring some of these ideas together. But I could see this being a good research project, looking at the role of gender and volunteering in healthcare, and seeing if there's connection to current implementations of patient engagement.

39:33

Emily: It's an interesting vector of thought to pursue. It might help us explain why discussion of payment for what's thought of as charity makes some people uneasy. I think that uneasiness is felt on both sides, from patient partners and from institutions who sort of expect patients to volunteer.

Jennifer: Well, and it may help to explain why offering payment as a way to remove barriers hasn't exactly fixed the diversity problem. If engagement is seen as giving back, and there is social privilege attached to it, I can see how some communities just wouldn't be interested for any number of reasons. In some cases, money just simply isn't the problem, or at least isn't going to fix the problem.

Emily: Well, that complicates things a bit. But I'm intrigued by this line of thinking. I've also encountered a large number of patient partners, probably the majority that I've worked with, that frame their engagement as a way to give back — or maybe it's more commonly to help make things better for others. In fact, that's why some people say that they don't want to accept compensation, because they feel it would no longer than be an altruistic act. There's actually a study out of Alberta that looks into motivations of people who participate as patient advisors. Over 60% of them said the role that best describes them was “volunteer.” It's an interesting study overall and definitely worth checking out. So we'll put a link to it in the show notes. But okay, so back to the paper at hand: the authors want to make compensation a more normalized part of the dialogue, which makes a lot of sense in our modern culture where value and money have a strong correlation. But they're up against a long legacy of a culture of charitable giving, which is tangled up in ideas of class and privilege, which has exclusion and disenfranchisement baked into its design. Trying to shift this culture is going to be a long-haul sort of effort.

Jennifer: Yep, I agree. And one last thing, on the institution side, to Zal's point: money functions as a pressure point, a way to, let's just say, “encourage” institutions to deepen their commitment to patient partnership, by making it a more significant line item on their balance sheets. I just wonder how much of

that pressure institutions would be willing to withstand. Now just imagine if all engagement became “fee-for-service.” Would there still be enough political will or interest on the side of the institutions? I think this is just as challenging a culture shift for them — with this idea of volunteering, institutions are set up to rely on it, and they get a lot of social currency by generating or attracting patient supporters. It's an integral part of their operations. So again, not surprising, there might be resistance, or at least some discomfort with thinking about compensation for patient partners.

42:31

Emily: So before we wrap this up, I would like to swing this around to look at it from yet one other angle, perhaps more on a practical level. And it's that the way we frame the argument for compensation has direct bearing on what the model looks like. So again, the authors list equity, different motivations, respect for vulnerability, commitment, and barrier removal as reasons for compensation. But each of these will have different implications. Okay, for example, if we look at barrier removal, we have to identify who is experiencing barriers and what sort of compensation would be appropriate. If we look at equity or power imbalance, well, then we're into discussions of expertise and credibility and what's considered fair or comparable wages between all parties. If we consider commitment, then we would need to think about levels of pay related to expectations.

Jennifer: You know, it really seems like we keep running into the same problem no matter what topic we're discussing. And that is: what is the purpose of engaging patients in the first place? And what exactly are organizations trying to accomplish? If these goals were made more explicit, then a connection between value and compensation would likely become a lot clearer.

43:57

Emily: Well, let's leave it here for now. A big thanks to Zal Press and Dawn P. Richards for joining us for this episode. And also thanks to their co-authors, Kimberly Strain and Isabel Jordan. We know we only covered a fraction of this topic, and we hope to revisit other aspects about compensation in a future episode. In fact, if you have suggestions, or you want to leave a comment about this episode, please get in touch through our website at [mattersofengagement.com](http://mattersofengagement.com).

Jennifer: And we're also featuring listener comments in an upcoming episode, and would love to include your thoughts! You'll find the details on the contact page.

44:38

Jennifer: 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 and are not to be considered endorsed by OSSU, the Government of Ontario, or CIHR.