Matters of Engagement podcast
Episode “Evaluating Holland Bloorview’s Family Leadership Program: a Conversation with Aman Sium”
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00:07
Jennifer: Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

00:16
Emily: And I'm Emily Nicholas Angl.

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Jennifer: In our last episode, we heard from Julia Abelson, who gave us a perspective on evaluation as a researcher of patient engagement, and as a researcher who engages patients. This time around, we wanted to get an organizational perspective. So for this episode, we're going behind the scenes of Holland Bloorview Kids Rehabilitation Hospital, an internationally renowned inpatient and outpatient facility which is well known for its client and family engagement programs. Its history of including youth and families in decision-making spaces extends as far back as the 1970s, and it now has engagement built into its operating structure. Now a bit of disclosure here: my son was a long-time client of Holland Bloorview, and I think I was on an advisory committee just once back in the late 90s. And it was for exactly one meeting. I went, I sat and I left. And that was the extent of it. Things are quite a bit different now.

01:19
Emily: Our guest is Aman Sium. He's the Director of Client and Family Integrated Care at Holland Bloorview. In that role, Aman oversees or supports programs that encompass youth and family engagement in both research and for the hospital, as well as family leadership and peer support. We wanted to talk with Aman about their engagement programs and how they evaluate them. And to know how an organization as large and complex as Holland Bloorview thinks about quality and improvement of engagement. How do they measure it? How do they get feedback? How do they pick and choose what to prioritize?

02:02
Jennifer: We visited Aman at Holland Bloorview pre-Covid on a typically busy day at the hospital. We spoke with him in the Family Resource Centre, an open concept space with books and computers and lounge areas and staff and workstations. In this recording, you'll hear lots of friendly ambient sounds in the background. We started off talking about the trend towards patient engagement in general. It's becoming more commonplace for organizations to talk a lot about their patient engagement strategies. But I think we all agreed that the depth and quality of implementation may vary.

02:38
Aman: There is a lot of talk and a lot of like, flag waving around it because I think people and organizations know enough to know that that's what they should be saying. And then it shifts like this work for folks who are interested in serious about it because it becomes a bit more like guerrilla

warfare: like, who actually means it, and who just knows enough to know the language and key terms they should sprinkle in their strat plans and their speeches and their like, quality improvement priority setting with…

03:07
Jennifer: Holland Bloorview is not one of those organizations. They invest heavily in their patient engagement programs. They actually call it “Client and Family Engagement,” and they're proud of what they've accomplished. Let's take a quick look at their Family Leadership Program, then we'll carry on with Aman. First, there are the committees. There's the family Advisory Committee, which advises on hospital service delivery and functions as a resource for hospital leaders. It's what Aman calls a design space, and we'll talk more about that later. Then there's the Youth Advisory Committee, which also gives input, and it provides an opportunity for youth to develop advocacy skills. And there's the Children's Advisory Council, which is a forum for very young clients and their siblings to share their ideas on improving services. And then in a separate area, there's the Research Family Engagement Committee which works with the Bloorview Research Institute to help prioritize research, conduct reviews and communicate findings of studies and projects.

04:09
Emily: In addition to being involved in committee work, individuals can become Family Advisors, where they can participate in specific service or quality improvement projects. They can become Family Mentors – working directly with peer clients and families in a supportive or mentoring role. And they can become Family as Faculty, which means they’re part of an educational and professional development team that participates in clinician training inside and outside of the hospital. There are a lot of moving parts, and a lot of people! There are currently over 150 family leaders in all of these programs. Most are volunteer, with a couple of paid roles reserved specifically for Family as Faculty. Holland Bloorview’s commitment to engagement didn’t spring out of nowhere. Aman notes that it’s their unique position as a pediatric rehab facility that keeps the pressure on – they have long-term relationships with clients and families, which means there’s a lot at stake, and all parties are heavily invested in that relationship.

05:10
Aman: This is just the reality and uniqueness of pediatric rehabilitation. The rehab part means that we have long, long, long relationships with these families, right? So age, you know, 0 to 19, as an outpatient. Sometimes, like I said, up to 6-8 months as an inpatient. We have a lot of time to form a relationship, we have a lot of time to try and instill trust, I think that always shows itself in the quality of our partnership. And then on the flip side, you mentioned pediatrics, like you will not get, I think, more fierce advocates than caregivers in the pediatric context, right, who are often parents, for all the reasons you mentioned. And then the intersection of that, I think, is this big kind of part of why, why we feel that we're at the level we're at when it comes to partnership with families.

05:53
Jennifer: With all of these programs to manage, Aman is tasked with ensuring they run effectively, with an eye on quality of both process and outcomes. Given that engagement is embedded throughout the organization at virtually all levels, we wanted to get a picture of how he approaches evaluation of their engagement programs. We started with their annual survey:

06:15

Aman: … where we can anonymously, like, seek feedback from family leaders, like really different kinds of feedback. So we can break that down even further. There's like, kind of like process measures, right, where we, where the practices… do the practices make sense? Do the practices meet the goals? So we're trying to redesign a whole clinic, and all we did was send you a survey. That doesn't sound like a very good practice, like the methodology sucks and doesn't really match our goals, right? There's the experiential piece, like maybe you felt completely disrespected because the conditions in the room didn't let you talk. They weren't taking you seriously, your expertise wasn't valued or even understood as expertise, and then the outcome impact piece, which is, I think, the giant question mark we're all still playing with right?

06:57

Emily: It was interesting to note that we were there to talk about evaluation, yet the very things we imagined that a place like Holland Bloorview would have figured out – outcomes and impact – were still, as Aman says, a “giant question mark.” We do come back to this later… at this point, we carried on talking about the survey as an evaluation method. Aman says surveys can be helpful, but they’re not sufficient for painting a full picture of how things are really going. They also look to their embedded engagement practices which generate their own ongoing feedback loop. This has the added benefit of not having to wait for an annual survey to see how they’re doing. This might be easier to explain by way of example. Here’s Aman, talking about the work of their Family Advisory Committee:

07:45

Aman: Every year our family Advisory Committee selects two goals. So in addition to… you know, we have our monthly meetings… in addition to every project that will come to the family Advisory Committee for feedback, there's two sustained goals with what we call subcommittee work. Every meeting is just two hours in length, 30 minutes at that meeting is dedicated to some kind of continuity, to driving a goal forward month by month for the entire year, and the expectation is, it's hard for that to get lost. But not just that: we ask families to help vote on — not even really help — to vote on and determine what those goals are. And then the expectation is, if you decide — this is a real example — if you decide that you want to work on diversity representation, because you do not see the demographics of Holland Bloorview represented in this room, the, you know, last Thursday of the month, in the form of family leaders coming together to design things, make big decisions, families flag that to us. They said, “You're not doing your job, we need you to do better to recruit for diversity.” So we were doing that, like that's a process in and of itself, but we take seriously the challenge that they offer to the hospital to do better. So that means partnering with families and taking a year to figure out how we're going to do that.

08:56

Jennifer: Holland Bloorview went on to develop a demographic survey, which they matched against existing hospital demographics. This helped them identify gaps in representation, and informed how they were going to think about targeting recruitment for better diversity in the family leadership programs. For Aman, this kind of embedded feedback activity is an integral part of evaluation, and would not easily be addressed through a survey.

09:21

Aman: If we're relying on surveys, we've already failed. I think that's important. And that kind of evaluation that's, like, systematic and happens every three months, or whatever it is, is important. It's really, really important. We have to get that right. But we need to try to invite as much challenge and dissent as possible and not run from that or be scared of that, not try to sanitize family feedback in those meetings in the everyday of partnering with family leaders, because that's where we get the best feedback.

09:48

Emily: As Aman mentioned, the Family Advisory Committee selects 2 goals each year to work on – they develop a plan to address whatever they've selected and are given support and resources from the hospital to sustain the work over time. We asked for clarification on how those goals even get to the Committee, and what sorts of parameters guide their decisions. Aman explained that deciding on scope for the goals isn't exactly a blank slate. There are many things that patients might want that aren't under the control of Holland Bloorview. So instead, they narrow the scope of what the committee can consider, to what *is* within their control – by asking a basic question:

10:29

Aman: What is a pain point for you? That's how food was suggested. Actually, it was our inpatient clinical team that said, we're getting a lot of feedback or even a lot of concerns, like formal complaints, and we know the food sucks. That's something that we'd like to bring forward, to the family advisory committee, and then that lined up alongside 12 or 14, I can't recall, other suggestions that were suggested by other folks across the hospital community, and family leaders could vote on and choose from those options, but they could also add other ones. If we're doing this in like our respective corners, we know, we come together to say this is what's not working, and then we retreat to our corners where families are on one side and staff and leadership on another, and we just try to build things separately. That doesn't work either. So the expectation is that alignment, that alignment happens at those advisory committee meetings, those other broader priorities are brought there. And it's like priority setting. It's a priority setting exercise and the family advisory committee or council will bite off two of those big priorities.

11:24

Jennifer: This is where conversations can get a little muddy for me. Aman uses a lot of corporate lingo – words like alignment, and priority setting – It's a modern business-speak that makes sense in context, and internally means something specific - but for me, anyway, it doesn't reveal much about how these meetings unfold. Earlier, Aman had talked about the family leadership program as a place where pushback happens. Where dissent and challenge are invited and worked through. Now, having participated in committees where collaboration and alignment are said to take place, we both know that despite the best of intentions, these kinds of meetings aren't necessarily the place where dissent and challenge actually happen. We asked Aman if there are maybe other ways that they get a read on how things are going, that might give them a more complete picture in this respect. He agreed it's definitely a challenge, and we talked through some of their approaches, returning again briefly to the survey.

12:28

Aman: So if we're using an annual survey, and it's completely anonymized, we're getting like aggregated feedback. So there are questions on there that look at those three domains. Like, did the practices match the goals to you? So a process question, the experiential question that I referred to earlier, and then the outcomes question, and that always gives us a sense from the family leader perspective, did they feel like they shaped… The presence of family leaders had a real opportunity and did shape the outcome, or had impact in wherever the kind of deliverable was of a project, but then we weren't able to map it to specific projects. So if 85% of people said, yes, we don't know where the 15% is that we need to work on. Like, what projects weren't working, and who are the staff leads providing targeted support. So that's what I mean by "we need to work on it." And then I'd say the other thing that we do, where we actually get better feedback on this, or better mapping than the survey, is our family partnership specialists are often facilitating… they're matching family leaders to a particular, let's say, quality improvement project, but then they're in the background facilitating to help to orient family leaders to the project. This is kind of what the goal is, from the other… staff's perspective, is what we're trying to work on. But they don't just disappear at that point: they're often supporting in the background, both the staff and the family leaders, and by the end are able to anecdotally understand if family or feedback was completely omitted from, you know, whatever the deliverable was, and then that's used to support the staff with more targeted education. And that's kind of how […] we're able to understand family leader roles have impacted outcome.

14:02

Emily: Aman is acknowledging limitations of surveys. It's a fine balance, trying to get useful information in a way that's efficient and doesn't overburden the respondents through a lot of written responses or time-consuming interviews. It can also be quite resource intensive to extract qualitative data and do the required analysis. So to fill some of those knowledge gaps, Aman describes a kind of peer leadership model, where a family partnership specialist is designated as a link between staff and family leaders, to facilitate communication, to help everyone get the resources they need, and to ensure family leader input is appropriately incorporated into a given project. If anything is amiss, the specialist can report back so that the right support or intervention can be put in place.

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Jennifer: So that all sounds great... and it's still got a certain sheen – the lingo of productive collaboration - and again doesn't quite sound like the system of checks and balances that we were originally talking about... but in fairness, we may just be looking at things from different perspectives, like, is the glass half empty, or is it half full? Are we focused on complaints, or are we focused on improvement? And, you know, we should also acknowledge that Aman's actual job is to support and even promote their engagement programs — both internally and externally — and this carries a whole different set of expectations or assumptions than if we were talking to a researcher.

15:29

Emily: Recalling our conversation with Julia Abelson, she talked about the importance of being clear about the goals for evaluation. And given his role, Aman's focus is more on evaluating with the aim to improve the quality of family engagement. But still, Holland Bloorview is very involved in research, and so I would assume there is also interest on their part to contribute to the broader understanding of if

and how engagement might have impact. Going back to our conversation with Julia, we briefly discussed this idea of tracing or tracking inputs and outputs to determine the origins and pathways of a decision making process. This is something I had become interested in as part of some of the research work I'm involved with as well. So we asked Aman if they do any sort of decision tracking or mapping at Holland Bloorview.

16:21
Aman: Honestly — this might sound like propaganda, but it's not — uhm…

Emily: That's what all the…

Jennifer: You really really mean it!

Aman: [laughs] But I really mean it genuinely. I think a part of why… a part of why we don't is because this is all relationship based, right? So I'll give you an example of what we track. We will track all the decision points in a project, right? So we recently replaced… we have horrible, we had horrible kind of like sleeper beds beside the beds in the inpatient units, like really uncomfortable, they're actually causing injuries to caregivers, like actively causing injuries. So we know we need to change these. Okay, great, we fundraise, we have… our foundation has nicely secured donor dollars to replace them, but we need to design them, because they were actually… they looked like good chairs, right, but they were… but we know that we need to partner with families to design chairs that are not going to cause injuries, that are comfortable to help them sleep, because we know that sleep is a huge indicator of caregiver participation, etc., etc. So we can track all those decision points, right? Right from how many chairs do we need to get, which was one of them, to what are the fundamental features of the design and family leaders going to the factory in Mississauga to sit down with, like, the design team there with our vendor and the foundation staff and clinicians on the inpatient unit and other family leaders to design the chairs, which family leaders led, to the colour, to what the rollout and implementation should be, to how are we going to promote these new chairs amongst families…

17:49
Jennifer: This process Aman is describing – where families are swept up in a collaborative co-design project – it carries a lot of forward momentum, and as Aman explains, has its own vetting and weeding process. Staff will continually observe, ask, listen, get feedback, then refine or iterate on how they engage families, and how they educate and support staff. It's what's known as a continuous quality improvement model, which originated in manufacturing and other industrial sectors, and migrated its way outside the factory setting in the 1970s. It is now ubiquitous in many sectors, including social services, healthcare, and education. It's defined as a process of 'constant evaluation', where learning and change happen in incremental and continuous steps rather than all at once. It struck us though, that this example of the chairs was a bit of a low-impact and low-risk exercise. Not because the chairs aren't important and not because investment is low – I'm sure it wasn't - but because we wondered how necessary it was to enroll families in this elaborate exercise. Surely, comfortable bedside chairs already exist. And if not, a good product designer would be able to do a bit of research about this user group and figure it out. Now certainly... product testing and feedback should be part of product development,

but is a full co-production exercise – one that includes visiting the factory - required to produce the desired outcome of having appropriate chairs?

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Emily: Listening back to our interview, this question came up and we kept circling around it, but we didn't really ever get to an answer... I think what we can glean from this though is that the very question of asking whether family engagement is necessary, either overall or for a particular project, didn't seem to be part of "evaluation." I'm not saying it necessarily should be - it just might explain why this sort of reflection didn't come up... And we could also consider that this chair design exercise had more than one goal. Designing a suitable chair is one goal for sure, and maybe, simply including families in designing something is another. And if so, then well, mission accomplished! So let's switch gears, and think about the broader context in which family leaders are invited to participate in decision-making. Key factors for Aman include scope (which we mentioned earlier), and whether there's political will internally to make recommended changes.

20:31

Aman: What is within the authority and influence of this hospital community to actually change? So when and if my favorite family leader, who will say this at every meeting, says, "We need a provincial electronic health record!" there might be — there might be, right? — advocacy that Holland Bloorview can do from an organizational level in the context of bigger systems conversations to push that, because we do want that, sure. But I would colour that outside of the sandbox for the most part, right? So what do we have the authority and influence to control as a hospital community? That I think is the scope you're talking about now. I think a different question, and the real money question is, what do we have the political will to change? And I think that's the zone where we try to work in the most. What's the ambitious layer and level we can work at, so long as it's in within our control. So I hear your point earlier, how we priority set our kind of, you know, family partnership projects is a couple things, and there is a low hanging fruit.

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Jennifer: When Aman told the story of the bedside chairs, I used the term 'low-hanging fruit' to suggest it was 'easy pickings' – to indicate that I thought it wasn't exactly a controversial project. Here, Aman's using the term again partly to tease me – and to acknowledge that some priorities are brought to the committee already having been pre-selected by hospital leadership or clinicians. The committee is given a list of the things the hospital already knows it need to do. But that's just the starting point. As Aman explains, the committee can also add to it:

22:02

Aman: …. you can work on these or — and here's the important part I think that differentiates more ambitious partnership from what typically happens — or, you can identify a pain point that exists that's not on this list, and let's talk about how feasible it is together. And then let's take it on, because the right people to make the decisions are in the room: the CEO's in the room, board members are in the room, family leaders are in the room, clients and families who have active care experiences are in the room. And an example of that… so I'll give you an example…

22:27
Emily: An example of an ambitious initiative that came from the family advisory committee was the proposal to expand clinic hours to weekends and evenings. At one of these priority setting exercises of family leader brought up the point that people can access other services like banking during non-work hours, and caregiver shouldn't have to take time off work or pull other kids out of school to attend therapy at Holland Bloorview. So they listened and they decided that this was worth pursuing.

22:57
Aman: Makes sense! Now is that revolutionary? I wouldn't say it's revolutionary — I would definitely say it wasn't on our radar going into that conversation. No staff were entering that room thinking, we're going to totally change our clinic hours. We're going to the room thinking, let's get new bedside sleeper beds for inpatient units. But that's what we identified. That's what was voted on. So that's real direction setting and priority setting. The majority of families in the room said, Forget all the other stuff you brought, that's a priority! We need evening hours…

23:22
Jennifer: There's no argument from us that this process clearly empowers those who are assembled to have influence over what gets decided. This raised a few more questions, though. Emily, you picked up on something interesting here.

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Emily: I asked about the gap between the committee saying, this is what we want, and the hospital saying, okay, let's do it. How do they actually validate this is a real need for the wider community?

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Aman: So let's think of that as like the creative incubator, right? Like that's… our family advisory committee is where we're inviting new priorities to be set by families like that one, and we're also sharing with families other priorities that were kind of floating around the hospital. And we're asking them to priority-set and direct us for the year. The step in between is the vetting. So it's not quite evaluation of the engagement process, but it's important… data becomes very important still for us. So we have… there's a reason why the family leadership program, right, that engine for engagement and all its staff, all the priority setting we're talking about, and Client Family Relations — or Patient Relations — live inside the same program here. Because that's a really important link. So when someone says, we've got to overhaul our clinic hours, we're going to the data. That community, that space, that family advisory committee space, that's the design space — but if we're going to throw our weight behind why we're choosing that topic, it's not just the 10 people in the room, it's also the data, it's the surveys, it's our experience scores, it's our Patient Relations process and the compliments but more importantly, often the concerns or the complaints, and do they validate us spending a year throwing our weight as an organization and community behind this? So that I mean that's what we did in that example. And we saw the data validate…

24:58
Jennifer: Emily, in this conversation, did we ever really get to the bottom of why they don't just start with the data? If the data is there to validate this, why wait for families to bring it up?

25:09
Emily: We didn't circle back to this, but I think this is where the priority-setting came in. I mean, they probably have a laundry list of 100 things they want to do, and somewhere along the line, someone has to whittle it down and pick. Well, if the families helped do it, there's probably less questioning about it later. I think it's one of the reasons why this kind of co-design work is so popular. You can always look back and say, “Well, we made the decision together,” or, “Patients helped make the decision,” even if it was just the committee deciding and not say, a community vote.

25:46
Jennifer: Interesting. Another question arising from this part of the conversation related to Aman’s comment about the “10 people in the room.” This was in reference to the family advisory committee — the number may not actually be 10 — but anyway, we were wondering how to think about the influence these particular people have. They've self-selected to serve on this committee, which means they're not nominated or elected, or hand-picked for some reason, and they may or may not have specific interests or skills. And they may individually have their own ideas about what they're there to represent. So I guess the question is, on what basis do they get to have such influence, and on whose behalf?

26:29
Aman: … so there becomes so much focus on the outcome impact, like the back end, right, that we're not even talking about, like representation — which is evaluation — like we should be evaluating who is in the room and who's omitted, because it's not acceptable to participate in engagement structures, processes, relationships, because we're so eager, often, for folks who are interested in this work to jump to the value for money side, but we're not actually thinking about… yes, the 10 people built something really cool, but who are the 10 people and do they match the demographics of who should be in the room? So I think you're right, I think it's a part of the same conversation and an important piece because it is evaluation. So I'm not proud of the fact that…

27:12
Jennifer: For Aman, who is at the table is critical to the evaluation discussion, because it's a marker of some kind. It's an indicator of whether they're doing something right. And this brings us back to the point we keep returning to, which is that the way successful engagement is defined seems to hinge not on outcomes, but on process and the experience of engagement for those involved. Now I keep finding it strange that all these engagement practices get put into place without having a clear eye on what a good outcome is supposed to look like. But I'm starting to realize that my own expectations aren't quite aligned with what's happening here. What we're seeing time and again, is that the underlying belief is that engagement must happen, and it must be seen as fair and accessible. validating, and representative. If these things are in place or are, you know, constantly being worked on, then whatever outcomes happened — those must be the right ones.

28:17
Emily: Back to Aman’s point: Although we haven't yet defined what sort of representation they're after, whatever that is, they want more families involved. And it matters very much how accessible and desirable the engagement opportunities are. Holland Bloorview draws patients from a very wide catchment area, not just affluent Leaside where they're located, and we wondered just how big the pool of potential family leaders really is, given the diverse needs and experiences of their clients and families.

28:48
Aman: … and I think there's going to be — rightfully so! — populations who don't feel safe inside of a hospital space or to enter into some kind of engagement relationship with Holland Bloorview because they're thinking well, why, I don't trust you as an organization, to receive care, let alone like design something with you for the next year. So sure, I think that's… I think that's true, but I don't think that could be… I don't want that to become a copout for why we're not doing the work. So we have also…

29:11
Emily: The work Aman is referring to is the work of attracting more people into the family leadership program, and figuring out why some families either can't or won't be involved.

29:20
Aman: … push-pull, I think we need to push ourselves into communities and listen better and listen more deeply and actually physically go into communities with no other ulterior motive [than] to kind of talk to folks about what would it take to make family partnership something that they believe in. And I think we need to put more… I think we need to think deeply about accommodations, and how to make it more accessible physically here, right? So that that's where I'm going with the compensation, food, childcare, easy practices that we do anyways in other parts of healthcare, that we don't often think about, or don't always think about in regards to family partnership.

29:53
Jennifer: Aman is now talking about outreach, but recruitment into family partnership is just one vector that Aman would like to see enriched. The other vector is addressing clinical health equity.

30:04
Aman: I think it's okay for a goal to be, how do we make family partnership as democratized and accessible as possible. And then it's okay for a different goal — without these necessarily intersecting — to be clinical health equity: how do we get clinical services to people who need them? And what does that kind of accessibility look like without us expecting, or even wanting them, to become family leaders?

30:26
Jennifer: This is an interesting distinction. At Holland Bloorview, family partnership is the space where new ideas are proposed, where projects get taken up and priorities are set. And clinical health equity, which is addressed by the Equity, Diversity and Inclusion Office, is concerned with understanding and addressing barriers to accessing services. And the two areas often work together. Ideas generated by

the Committee might require validation through data. And data generated by the Equity Office might require some kind of action that can be taken up by the Committee. This distinction is important because I think both of us were wondering, where's this other work of outreach, health equity, accessibility…? And how do they validate their projects and priorities as set by the committee?

31:15
Emily: We talked a lot about health equity in this conversation. And some of the issues facing Holland Bloorview's clients and families, including social determinants of health and structural and environmental barriers that would prevent them from accessing services. Aman gave examples of projects out of their Equity, Diversity and Inclusion Office, including for brain injury support and autism diagnosis.

31:38
Aman: They did mapping of our in-house, kind of like social demographics, who's using our services, they mapped that onto our city's demographics and said, where are there massive gaps? Like, who are we not seeing? And they can actually, like, almost like a with a heat map present where are those swaths of geography and the populations that live within them that Holland Bloorview is not serving, even though we should be. And their probably primary interest right now is figuring out how to make these services… like figuring out why that's the case, number one, and if there's anything we can do as a hospital to make some of these services more accessible, including bringing them into communities. Now…

32:12
Emily: With families so embedded and programs so intertwined, it can be a difficult exercise trying to extract specific elements for examination. So talk of representation and diversity can feel a bit abstract or theoretical. Part of that is because we didn't hear a clear definition of goals for representation or diversity. Like, are we talking about gender, race, income, level of disability, age? At points, it sounded like all of it was fair game and all of it was relevant. But just keeping the question alive and dynamic was maybe a goal in and of itself. And that's not a criticism necessarily, it's more an observation of how slippery it can feel. Maybe once you pin it down, you're already missing something. While Aman isn't exactly specific, he does have a frame through which he sees representation. And it's one of perpetual learning and improvement and inclusiveness.

33:12
Aman: For me, it's a matter of, I'm not looking for *the* representative. I don't think an organization should be looking for *the* representative — and you're right, that's like a, that's like another layer of like, almost "good intention tokenism" in and of itself — you're looking for a perspective that comes from the spectrum of perspective that that community represents. Like you're not here to speak through some sort of like monolith of… "And here's brain injury in a nutshell!" And now reflect that in the minutes. It's, here's *my* kind of journey and experience of brain injury, and my feedback is coming from my slice of that experience. I'd say the same thing probably applies to broader diversity. It gets very tempting to alleviate ourselves from the responsibility of consciously recruiting for, and being mindful of, the diversity of family leaders, because we know that it'll never be exhaustive, and because they'll never be a consensus.

34:04
Jennifer: A few times in our conversation, Aman acknowledged that things are imperfect or perhaps inconclusive. But it's important to not let that get in the way, because like many engagement practitioners and patient partners, Aman believes in the fundamental *rightness* of engagement. And Emily, I don't know if you've encountered this before, but there's something about this evaluation discussion for people who are really and truly enthusiastic about engagement that they find kind of irritating. And I've seen this mostly with patient partners in particular, that questions of measurement can produce a bit of eye rolling and a bit of, “Aren't we past this yet?”

34:43
Emily: I think where this comes from is that lack of evidence is seen as a cop-out or a bad excuse to not invest in it. Many arguments to justify engagement don't easily lend themselves to evaluation of outcomes and impact.

34:58
Aman: I used to hate… I used to, like, really overcompensate and hate and push back against conversations about evaluation of patient engagement. And I think a part of my… I don't know, maybe even resentment? That might be too strong, but I'll use it… as a part of my resentment or at least hesitation, I think is a common feeling still. And then — this is like not scientific but... [laughs] at all! But I think so many of us have just seen it work. And because we've… our only experience of doing the work as a family leader, or like a staff partner, or whatever, is you've seen it work, it's like: wow, I'm going to evaluate it. Like we don't need to know, in greater scientific terms, the degree to which it works, or, you know, what percentage of people say it works and all this stuff, because we know it has. Evaluation is suggesting that this doesn't work and is not important. And de-emphasizing evaluation is a way to push against that. And I'm not saying it's right, because I've evolved even myself from that, but I think I think that's a huge thing, right, like a part of the resistance or frustration with some of the evaluation conversation.

36:02
Jennifer: Aman realizes that to satisfy a lot of diverse interests, you do have to evaluate how things are going. So here's where he's netted out:

36:10
Aman: Yeah, we need to evaluate in all those domains we talked about: the process, the experience of those involved, the outcomes, to understand, okay, everyone on here is saying it's working and putting up posters and talking with engagement… now: what are the designated kind of factors, enablers, what are the things that our evaluation is telling us makes it work? Because everyone out here is telling us it works. So I think that's another helpful way to explain the necessity of why evaluation is important.

36:48
Jennifer: Hey, Emily.

Emily: Hi, Jen.

36:51
Jennifer: We've pretty much debriefed as we went. So what are your key takeaways from the conversation?

36:57
Emily: I guess what stands out for me is that a month working within a specific context where engagement is assumed to be the right thing to do. So his task is to kind of reverse-engineer the justification. When he said that evaluation as a way to look back to see what makes it work, it's like they embarked on this journey that didn't really have a destination other than to involve families. And now that there's interest in quantifying the value, some of the tools and frameworks can be deployed to explain how certain actions or conditions led to other actions or conditions… and I don't know, it still feels a bit vague. There's a sense that it's all supposed to just sort of explain itself.

37:43
Jennifer: Yeah, I agree. It felt like we concluded our conversation on a really satisfying note. But listening back now to Aman saying, we just know it works, I still find myself asking: What is it? And what is works? Because of all the goodwill that the programs generate it almost feels impolite to still be confused. Anyway, let's leave it here for now. Maybe at some point we can reconnect with Aman and carry on with some of this discussion.

38:15
Emily: Much appreciation to Aman Sium and Holland Bloorview Kids Rehabilitation Hospital for giving us an in depth look into their client and family engagement programs. If you have any suggestions or comments, please get in touch through our website at mattersofengagement.com.

38:34
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.