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.

00:20
Jennifer: The topic for this episode wasn't really on our radar when we were planning out this season. But as sometimes happens, an opportunity comes along to speak with someone who's doing something interesting. Now, we're not always sure where the conversation is going to go or whether it's something our listeners will connect with. But in this case, we think the views of our guests will resonate with many people interested in patient engagement.

00:46
Emily: We're calling this episode, "Patient Experience as Evidence". And our guest is Miles Sibley. Miles runs the Patient Experience Library, which they describe as a national evidence base, an archive, for patient experience. Based in England, the Library was set up by Miles and his founding partner, Anthony McQuillan. And it contains an extensive catalogue of research publications and reports related to patient experience. We've put a link in the show notes, and you can find it at patientlibrary.net.

01:19
Jennifer: There are a few things we should mention before we continue. First, most of the contents of the Library are UK-based - about 80% of it. And we think this is because, like Canada, England has a public health care system. And there's a strong interest in including patient voice and patient experience in a way that we don't necessarily see in private health care systems. And therefore, there's an expectation of accountability. Our conversation with Miles is based on his experience and understanding of healthcare in the UK. But as you'll see, much of what we talk about is applicable to Canadians.

And second, the library is run independent of any health authority or service. They don't currently receive funding support - although they would very much like to change that - and they don't take advertising or sponsorship revenue. The founders have essentially bootstrapped the library themselves. So for the moment, it's a privately funded and operated project, but developed for public consumption.

02:23
Emily: And finally, let's clarify what we mean by patient experience. We should not confuse this term with patient engagement, patient partnership, patient-oriented research… the contents of the database is focused on research and reporting about what and how patients experience health care and health services. That material may or may not have been developed with patients or in consultation with

patients. So, while some of it may have included patients, and some of it may, in fact, be about engagement, that's not the focus of the Library. The focus is only patient experience as a category of research.

03:02
Jennifer: We spoke to Miles about the Library and talked about its purpose - what needs it addresses and so forth. And it raised some interesting questions that we haven't yet talked about on our podcast, but we think have relevance to patient engagement. One of the key underlying questions to all of this is: what qualifies as evidence, and is the definition to narrow? In healthcare, when we think of research, we think of medical research or biomedical research. And we also only include peer-reviewed published articles that come from people with particular training.

03:36
Emily: Yes, that's right. And Miles might explain it differently…but we think at the core, this project of the Patient Experience Library, and its rationale, are challenging those boundaries. So yeah, this conversation with Miles got us thinking about evidence and how it's used, but also about the healthcare, environment and culture in which this is all situated. Miles talks about a pervasive culture of dismissing or ignoring patient voices. And that the failure to investigate and learn from patient experience is both evidence of that, and perhaps the cause…

04:12
Jennifer:…which we think is pretty aligned with what we hear about patient engagement. That a culture of dismissal is what makes patient engagement required, and that the lack of patient engagement perpetuates that culture. But we're getting ahead of ourselves! Let's back up and hear from Miles. We asked him to tell us what gap the Library might help to address.

04:35
Miles: I set up the Library to … Myself and my colleagues set up the Library probably about five or six years ago now. And it was after I'd been working in a patient voice or patient advocacy organization, dealing a lot with health care providers and commissioning bodies, here in the UK, in England specifically, and realized after a while that healthcare is evidence-based. And clinicians and health professionals have access to all kinds of medical research databases, which are used as a basis for their initial training, and then their ongoing professional development. And also that kind of medical research evidence finds its way into clinical guidelines and practice protocols and diagnostic aids and so on. And that's what we call evidence-based medicine.

And I realized that here in the UK, our National Health Service - NHS, as we call it - it has all sorts of things in it strategies and so on about being "person-centered", wanting to give "person-centered care". And it will say over and over again that the patient voice and patient feedback is really important. And I realized that in this healthcare system that was awash with medical research databases, there was no equivalent for patient experience. And even though huge amounts of patient feedback is gathered, online, or through surveys, or through focus groups, or public meetings, and including academic research, as well - loads of it is published, but it was being published all over the place across hundreds of different websites. It's really hard to find, and a lot of it wasn't even cataloged. And after a while, it

would just kind of disappear. And I thought: why haven't we got, in a healthcare system that wants to be person centered, and wants to hear from patients, why haven't we got a research database and online evidence base for patient experience?

06:38
Emily: Miles and his team gather reports and research related to patient experience from across the internet. Paywalled contents is off limits, and they try to avoid content with obvious marketing or political agendas. And they don't publish individual complaints against named organizations or clinicians. But the rest? They sift through it piece by piece. Each item is categorized and includes the short summary.

07:04
Miles: So some of it is academic studies and papers, open access papers from journals - very much are rigorously produced and peer reviewed, and they explain the methods and so on and so forth. And some of it is stuff that is produced by small charities or community organizations, that is much less rigorously produced. But for us, we take that anyway, because there's something about having the authentic patient voice. And sometimes some of the smaller organizations are simply not able to, to go through the kind of academic hurdles to get published. But for me, as I see it, people who speak from the heart and speak from experience are often telling truths that might not get picked up by more formal processes.

08:04
Jennifer: The focus, then, is on content that describes system level conditions or issues related to patient experience, and not on individual or one-off complaints handled at the organization level.

08:16
Miles: I think in terms of patient-centered practice, and really hearing from patients, I think, very often, that works very well, at the one-to-one face-to-face level - the point of care. So your clinician, or your receptionist, or your hospital porter - whoever it might be. Very often they're really good at talking to patients, hearing what they want, and responding. But at the system level, or the institutional level, institutions can't have one-to-one conversations with patients. So they need to hear from patients as a whole. And, and they need to do that on the basis of study, and survey, and, structured dialogue. And that's where the evidence comes from. And there's plenty of evidence being generated. But there's this problem that there's no systematic evaluation of what anybody's learning from that and how it's translating into practice.

09:28
Miles: I don't know whether this happens in Canada, but here in the UK, you often hear patient feedback described by some clinicians and health professionals - by no means all, but by some - they'll describe it as anecdotal evidence. And what they mean is that the kind of evidence they really like, which is your scientific evidence coming out of medical research, they like that because they see it as objective, rational, reliable - whereas patient feedback… they call that anecdotal evidence. And what they mean by that is, well, it's kind of subjective. It might be irrational and emotional, and it might be unreliable. And therefore it has a lesser place in the hierarchy of evidence and is seen as just not quite as good. Really, there's a couple of problems with that. First of all, scientific evidence and statistical

evidence is not necessarily reliable. There's all sorts of issues about how studies are conducted, and cultural assumptions and politics around that that can influence how study is done in the first place, and with whom and to what purpose and how it's all written up. But also, it's really easy for healthcare systems to manipulate their statistics. And there's evidence that they do so for reasons of trying to… because there are financial incentives linked to performance, or because they want to present a good picture their institutions performing well. So statistical evidence is not necessarily reliable.

11:05
Emily: Now to be clear, Myles isn't dismissive of quantitative research. He's simply aware that no research is free from influence bias, politics. So when patient experience research is described as subjective or anecdotal? Well, Miles doesn't think it's a reasonable point of distinction. But it does indicate what type of research is generally considered legitimate and what isn't. And for Miles, there's a connection here between how patient voices are being heard through research and evidence, and patient safety. We talked about a recent wave of avoidable harm related reports in the UK, which he thinks demonstrate the culture of devaluing or ignoring patient experience.

11:49
Miles: Here in the UK, we've had a whole series of very large-scale cases of failures in patient safety where there's been avoidable harm, and death. And in every single case, and these are all documented down the years, in every single case - what you have is situations where patients have been expressing concerns, sometimes submitting formal complaints and saying, there's something not right here. And this was not necessarily picked up by the inspectors and the regulators and the commissioners of those services. Often patients have to campaign for years sometimes - and then finally, there's a huge official inquiry, it all comes out. And what you then find is that not only has the institution been ignoring or suppressing patient feedback because it's inconvenient and uncomfortable, but sometimes records have been "lost" (in inverted commas), or even falsified, and there's been coverup and collusion. And this comes out in these official inquiry reports. So this whole idea that there's qualitative evidence that comes from what is sometimes also described as patient stories - the idea that that is somehow less reliable, or less valid as evidence, to me is false. And I think what you have to… of course, it needs to be critically examined and questioned, exactly as scientific evidence does. But it seems to me, to have a really robust evidence-based system, you need to put the scientific evidence alongside the human experiential evidence. And then you've got a complete picture.

13:31
Jennifer: Miles pointed to several cases that have received a considerable amount of media coverage and public outcry. There's the case of Ian Paterson, a breast cancer surgeon found to have performed hundreds of needless surgeries. There's the case of all the harm caused by pelvic or vaginal mesh implants, where hundreds of women endured painful suffering and irreparable damage. And then there's what's been called the worst maternity scandal in NHS history, where some 1200 cases of avoidable harms and deaths are being investigated at one hospital trust. Now, it's notable that all of these examples center on female patients, but of course, avoidable harm and death are not exclusive to women. Anyway, Miles sees these sorts of cases where people have been speaking out for years and routinely ignored or dismissed as evidence of a wider cultural problem.

14:26

Miles: But at the heart of it, as we see it, it is because patient feedback is not taken seriously as a form of evidence - it is seen as anecdotal, is dismissed, is seen as unreliable - or these people have an agenda or they want to just get into litigation and get compensation and are just not believed. And sometimes as well, what happens is that there's a desire from the institutions to protect organizational and professional reputation, rather than get to the truth and stop the harm. So our report, Inadmissible Evidence, is really all about this double standard in evidence-based practice saying, "we have a problem here, folks", because medicine says it's evidence-based. It is as far as the medical evidence is concerned, but it's not as far as feedback from patients is concerned. And that is why over and over and over again, here in the UK, we have these scandals emerging and in every single case, patients have tried to speak up and they haven't been heard.

15:31

Emily: Miles mentioned the Library's latest report, which they published themselves, titled Inadmissible Evidence. It outlines some of the clues that these cases are not likely one-off anomalies, but rather tragic but unsurprising outcomes of the current healthcare environment. Miles talks about the importance of language and what it signals.

15:52

Miles: You know, this thing that when something goes wrong in healthcare, healthcare professionals spot something going wrong, "we'll file an incident report". That's what we call it, an incident report. When a patient does exactly the same – spots something going wrong and speaks up about it - it's not called an incident report, it's called a complaint. So straight away, you've got a cultural difference in how these things are observed. The professional is behaving neutrally and professionally and doing the incident report; the patient is complaining. And that word "complaining" carries with it connotations of negativity, and dissatisfaction and all the rest of it. So there's a language problem that reveals a kind of a culture. There's another one as well, which is this thing about medical evidence is seen as kind of solid and reliable, and some statistical evidence is called hard evidence. And patient evidence is described as anecdotal or soft patient stories, which, again, creates an inequality about how the evidence is seen and valued. And then the third thing around language is that when patient feedback, again, is sometimes referred to as "patient stories". But we never talk about "clinician stories" - clinicians are credited with the task of keeping records. So again, it is kind of given this feeling that this is objective. "As a scientific professional, I maintain a record. You, the patient, tell a story."

17:24

Jennifer: One part of the report that caught our attention was about "bad apples", referring to a tendency to blame rogue individuals who operate outside the norms. The report disputes this and says, in fact, no, it's not about bad apples.

17:39

Miles: So that's the overarching national culture. And I think that's why we say in the report, "there are no bad apples", because we can't take each of these failures one-by-one and say, "Oh, look, there's another rogue trust", or "Oh, look, there's another rogue practitioner". And in fact, in the report that came out earlier in the year - that prompted us to do our report, Inadmissible Evidence - the report

came out earlier in the year the Cumberlege Report around pelvic mesh, and other failures in medicines, and so on. There's a quote from that that says - and this is from Baroness Cumberlege, you know, one of our peers, highly respected - and she says, "The issue here is not one of a single or a few rogue medical practitioners, or differences in regional practice. It is system wide."

18:34

Jennifer: The Library itself obviously isn't going to single-handedly shift this culture that Miles is describing. He sees where other activities may also influence changes, including patient engagement or partnership in research.

18:48

Miles: I think any efforts to involve patients and public in medical research must be good, at least in principle. In principle, it seems to me you ought to be asking, and having a dialogue with people who experienced the illnesses, or are going to be using the treatments and procedures that you're developing. So just as a matter of principle, getting patients and public involved in medical research, must help to kind of broaden the research and deepen the understanding and improve the research design, you would hope, if it's done well. Now, of course, there is a question - because sometimes it isn't done well. And in fact, sometimes, patient and public involvement in research is driven more by the fact that is a funding requirement than via a really conscious effort to understand what people might be able to offer to the research process. So there's a bit of tick box or tokenism going on sometimes that is not welcome. As I say, as a matter of principle, it must be, it seems to me, a good idea to involve the very people you're trying to help and who understand their own illnesses in the process of researching those illnesses and possible treatments.

20:03

Jennifer: Miles spoke about a kind of simplified research pathway where there's an input, which is the process of generating research, and then output, which is the process of translating research into practice.

20:15

Miles: Now, that's about the kind of input side of research and how you get people involved at that end. But there's also something about the output side of research. And one of the things that we've documented over the years in the Library - and because there have been studies on this - is that when research is published, that's all well and good. But how does it then translate into practice? And what we find in patient experience work year on year on year, there are studies which indicate a gap between evidence and practice. So evidence is published. But for a start, nobody can necessarily find it easily because like I say, until we set up the Patient Experience Library, there wasn't even a national… a one-stop-shop for all this stuff that you could go to and find it easily. But also, because the task if you want to translate some of that evidence into practice, first of all, you have to actually see it and value it as evidence. And that takes us straight back to this problem of patient feedback and so not really being seen as having the same value as medical evidence. So that's the output and we're, "okay, how do we translate the research evidence into practice?", and it's not - in the case of patient experience evidence it's not done terribly systematically.

21:37

Emily: It's the case for any kind of research, medical patient experience or otherwise, that translating evidence into practice is a formidable task. It's a known issue that a lot of research just doesn't make it into the hands of the people who could best use it. This means it doesn't inform clinical guidelines or government policy or professional education. Nevertheless, when it comes to medical research, there are established ways of understanding and synthesizing existing research to inform priority setting what to fund and what direction to steer future research. Miles suggests that these existing models should be utilized for better understanding patient experience research as well.

22:17

Miles: Here in Britain, we've got a body, for example, called "NICE", the National Institute for Health Care Excellence, and they produce clinical guidelines and so on. And they have a priority setting process for research. So put very, very simply: they know what's in the evidence base, so they know what they know. And they know what they don't know. And they know what they kind of know but it probably needs updating. And with that knowledge they can work out where to direct the research funding and the research effort. They have a strategic overview, and they can steer the research accordingly, and bring in patients and public to help. And then when it's produced, they write the guidelines so the clinicians understand what to do with their research. It's really good. It's really systematic. On the patient experience side, nobody anywhere has a strategic overview of the evidence base. And what we see coming that the stuff that we gather into the Patient Experience Library is, over and over and over again, duplicate studies on areas that are already extensively documented.

23:30

Jennifer: Miles is pointing to a few things here. He's saying that by including patient experience research as part of the overall evidence base, we can reduce research waste and duplication, identify knowledge gaps, reduce harm and bad outcomes, by not only learning from what we already know, but also finding out what it is we don't know.

23:51

Miles: So one example would be in primary care - people are getting access to appointments just to see their local doctor. And there are endless studies on this. And every new report just adds more and more to the pile of reports, it doesn't really add anything much to the sum of knowledge. On the other hand, there are big gaps in the evidence base, sometimes around things like rare disease, and sometimes around things like health inequalities, and the kind of people in communities who don't have much of a voice are considered hard to reach so nobody bothers trying to reach them. But nobody has got a proper strategic overview of any of this. So all of this work that's being done year on year to research patient experience - it doesn't have any proper steer or prioritization on it. So there's a lot of duplication, waste and a lot of gaps. And that gives us a kind of evidence base, as a whole, that is not terribly robust.

24:47

Emily: Miles and the Library team have set out a big task for themselves. And despite the lack of support and funding thus far, they've managed to accomplish something remarkable. They're aware

that they're pressing against the tide, and that there are a lot of intervening factors. But at the heart of it, Miles says that while there are indeed challenges, it's not really that complicated.

25:11
Miles: All we're saying is that we want to get patient experience evidence taken as seriously as medical evidence. That's it. That's all we want. And that's incredibly simple to do. And the reason I say it's simple is because medicine has a model for generating evidence and building it into evidence-based practice. And all we have to do is follow that model. But to do so requires a cultural shift, whereby we end this double standard in evidence-based practice.

25:49
Jennifer: Hi Emily

25:50
Emily: Hi Jen

25:53
Jennifer: I like this conversation, because I think some of the ideas that Miles raised adds some interesting dimensions to our discussions about patient engagement. I'm thinking in particular about the culture Miles describes where patient experience isn't taken seriously, whether it's in the form of qualitative research or through formal complaints processes, or in the telling of patient stories. His project is about amplifying the patient voice and also pushing healthcare and medicine to take it seriously. And I think for many, this is what drives the need for patient engagement and partnership. Now, whether it's an effective approach, or creates enough pressure to drive a culture shift? I have no idea. But it sounds like both here in Canada, and in the UK, there's a recognition of there being similar conditions. So, what were you left thinking about after our conversation?

26:47
Emily: When Miles spoke about a hierarchy of evidence, I certainly understood what he was referring to. In general, when it comes to evaluating evidence in healthcare, qualitative research is like the poor cousin to quantitative research. And now consider qualitative research about patient experience… well, that drops it down a notch. And then non-research reports or publications about patient experience? They don't usually count at all. I think Miles and the Library team are doing something really interesting. But it also may feel like an uphill battle, given the established ways of appraising research, and also cultural resistance.

27:26
Jennifer: Yes, I think so. The Library's mission is to make patient experience evidence as accessible and as relevant as medical evidence. And I think they're managing the accessible part really well. But the relevance? It has to come from a system wide change. And so far, I think, we're not really primed to think in these terms.

27:47

Emily: I sometimes consult on projects where they want to engage patients to understand their experience of… something. And it seems wasteful and also negligent to not be looking at similar work that's already been done. And I'm not necessarily saying that this would replace the need to engage again, but at least we'd have more reference points. In my experience, this isn't common practice. And engagement seems to be one of the few areas in healthcare where we feel confident to proceed without looking at previous reports or research.

Maybe this is a chicken and egg question. Maybe we don't look at the evidence base because there's just not much there. And what little there is, well, to Miles' point, it can be hard to find. And it can be particularly difficult to find clear reporting on the details of engagement and research that included patient partners. It often seems referred to as an aside or as a sort of pat on the back, but isn't often treated with the detail and nuance it deserves. It's another tricky aspect of engagement. Once we consider the patients as no longer "subjects", but as "partners" or "advisors" or "co-designers", there's less clarity about how we report on what the impact of their involvement is. And it muddies the water in terms of what the research ethics board might require. There are some efforts to improve this - some tools to help guide and to standardize reporting. (We've put a link in the show notes.) But I don't get the sense that they're widely used, probably in part because it adds a whole new aspect to the research to keep track of and to record.

29:27
Jennifer: Yeah, okay. It sounds like what you're saying is that if there was one, a central repository, you would find it useful. But that's assuming that engagement activities were captured and documented and placed in the repository. It's really interesting to me that engagement seems to be so untraceable in terms of what's happening now, but also its origins and its evolution. There's just not a lot in the way of theory and research. And I guess it makes sense in a way. You know, we talked to so many people who say that the process is what's important in engagement. There's a focus on communication and relationships and trust, which are all definitely important. But it always keeps things in "the now" and so context dependent. And because of that, probably not everyone would see a need to treat it as a science in its own right. A field of practice, perhaps, but less so a field of academic study or scholarship.

30:26
Emily: Right. But however we want to look at it, I do think it makes sense to at least track what's happening across the field - catalogue it and learn from everything that's been done so far. Even if what we learn is about engagement trends, new approaches and how practices evolve. Certainly, there are published case studies and occasional ethnographies… sometimes interview-based research papers that examine engagement…. but similar to Miles' point, there are probably plenty of engagement related reports out there that are recorded in some fashion and not shared, because they don't count as evidence.

31:04
Jennifer: I think when it comes to organizational or quality improvement type engagement, this might actually be a harder sell to promote a culture of sharing this kind of internal reporting. But when it comes to engagement in research, yeah, I would say it's definitely a gap. Engagement seems to now

be baked into the infrastructure of research. And, you know, maybe mentioned in the final publication, but it's not considered part of the findings or research output. Now, to be fair, engagement in research sits in a funny place. It's considered to be part of project management, or maybe part of governance or part of administration. And at the same time, it's also said to be this all-important addition to the research process, which influences direction and analysis, knowledge translation, and probably research outcomes. And then layered on top of that, is that it's all about relationships and trust among individuals. So it's just not easy to account for this in existing scientific methods.

32:05
Emily: Exactly. And if engagement is seen as an end goal in-and-of itself, well, this means you can't reasonably use research in place of your own engagement activity. You're required to do the engaging yourself, every time. And this perhaps explains the heavy emphasis on process-related research about engagement - because we're so busy with the "doing". Well, anyway, let's tie this back to the discussion with Miles and some of the challenges they face with the Library. Its Miles' observation that there's a culture of dismissing patient voice and patient experience for all the reasons we discussed with him.

And I think we could speculate on a couple of additional reasons. First, patient experience may be seen as a moving target. People's priorities and context constantly shift. And any one study is from a specific place and time. I can understand the impulse to want to redo a study even if you did it just a year ago. But it's also possible that it's used as an excuse to not have to act on previous findings. It's a known stall tactic at all levels of government. Just keep commissioning studies and people will forget. It's a lot to overcome. But I think Miles appreciates the magnitude of the task.

33:27
Jennifer: Yeah, I think they're choosing to be optimistic and keeping their eye on the horizon. They know they won't shift things all by themselves, but they do want to play some kind of role in making change. And they're doing that by showing what's possible.

From the healthcare side, though, I think the lack of inclusion of patient experience evidence didn't happen because of an oversight, or because someone forgot, or because they just didn't know. On the contrary, I think medical research and in fact, the entire medical establishment, is deliberately exclusive in order to maintain its legitimacy. We have deeply rooted practices and understandings about how research is supposed to be conducted and ways of determining what counts. And that's not easily disrupted. Yes, we're now inserting patient partners into the process and it would certainly be fair to call it a disruption! But it's by no means settled, and power imbalances continue to present challenges.

My main point is that systems that exclude or minimize particular voices aren't broken. They're functioning exactly the way they're designed to. Powerful or dominant systems and institutions work very hard to stay powerful and dominant. So in this respect, it's not surprising at all that Miles and his colleagues have yet to convince the national health authorities to support a project that is seeking to elevate patient experience evidence to sit side-by-side with medical evidence.

Now having said that, I think there is value in doing what they're doing. In a way the Library is like a fly in the ointment, demonstrating that a few hardworking people on a shoestring budget can put

something of value together despite being told repeatedly by various healthcare entities that it would just be too hard and expensive and complicated. They're not just proving them wrong - they're calling their bluff. And they're not the only ones. There are all kinds of people out there advocating and applying pressure from both the inside and outside the system to try to reconfigure public health care around the needs of patients. With enough critical mass enough of these projects, who knows, maybe a culture shift is possible.

35:48

Emily: Thanks to Miles Sibley for giving us so much to think about. Please visit patient library dotnet to browse the library, learn more about their work and access their latest report in admissible evidence. We'll provide links in the show notes. And as always, if you have any questions or comments, you can reach us through our website at mattersofengagement.com.

36:13

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 belongs solely to the producers or their guests, and are not to be considered endorsed by also the Government of Ontario or CIHR.