

Conference: [2nd Evidence-Based Research Conference](#): The place of Evidence-Based Research in the Evidence Ecosystem

Title: "Involvement of end users in research when planning new research (EBR)"

Speaker: [Jennifer Johannesen](#)

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**Jennifer 00:05**

Hi, thanks so much for tuning into this presentation. It's been a little while since I've prepared a talk like this. And I'm always glad to have an opportunity to share some critical ideas about patient partnership in research, especially to a new audience.

**Jennifer 00:20**

A quick note before I start: I'll be making a transcript of this recorded talk and providing it to the organizers of this conference. But if you're watching this video and don't see a transcript - and would like one - please email me at [jen dot johannesen at gmail dot com](mailto:jen_dot_johannesen_at_gmail_dot_com) and I'll send it to you. I'll also be posting this on my blog at [johannesen dot ca](http://johannesen_dot_ca).

**Jennifer 00:43**

I've written and spoken quite a bit about the topic at hand, focusing primarily on some of the rationales and implications of bringing patients (or end users) into the health research process. My work doesn't delve into improvement per se. I don't have a lot to talk about when it comes to how to make things better or more meaningful, or more impactful, or whatever the measure of success may be for a given project. I'm more interested in questions that traditionally spring from the social sciences, like why and why now, who benefits? What are the harms? And what is the cost?

**Jennifer 01:20**

To help give some context to this discussion, I'll first share a couple of things about myself. First, I'm Canadian. And this matters for this discussion because our healthcare system has a strong culture of patient engagement and participation. My work stems from close examination of the evolution of engagement in a place where it's reached some maturity as a practice. And second, I speak from both personal experience and academic study. I've been an engaged patient for decades, starting from my first pregnancy about 25 years ago. I then went on to study bioethics and have embarked on a decade long quest now to push against establishment ideas in healthcare. I like to think of myself as an outsider. But here I am doing things that firmly locate me on the inside! I can't reconcile this, so I'll just leave that to remain a contradiction.

**Jennifer 02:21**

So, Canada... I've lived all of my life in and around Toronto. All of my healthcare and health research experiences have been here, and have been experienced through the lens of a middle class and non-Indigenous upbringing. Non-Canadians tend to think of us as having a single national health care system like the NHS in England, but that's not quite right. Each province or territory has its own health authority and health insurance plan. So care and coverage differ from region to region.

**Jennifer 02:52**

In the case of health research, we have a national funding body called the [Canadian Institutes of Health Research](#) or C-I-H-R, and they have a national [Strategy for Patient-Oriented Research](#) known as SPOR, S-P-O-R. Now, the definition of patient 'oriented' research has evolved over time to essentially become synonymous with patient 'partnered' research. Which means the goal is for patients to be involved in research at all levels. Not just as participants, but as advisors and planners, co-investigators, co-authors, maybe involved in ethics review. And all the way from framing research questions to implementation, evaluation and knowledge translation. CIHR-funded health research projects require that applicants state how patients are planned to be involved. And this carries significant weight and funding decisions.

**Jennifer 03:48**

Now, beyond involvement in just health research, we also have a culture of “patient engagement”, where patients are involved at all levels of healthcare service design and delivery. This includes patient advisory committees, patient project groups, patients as trainers in medical education, and patients on hiring committees. Whether required by funders or simply part of cultural expectations, the ethos of engagement is deeply embedded throughout every aspect of healthcare. My critique of patient engagement and partnership arises from this context, where there's not only a push from patients to be part of decision making, but a mandate from governments to include patients in health research.

**Jennifer 04:35**

While many researchers have come to accept and even embrace the shift, it's worth noting that the impetus for mandating the inclusion of patients across the board did not seem to come from the research community. The demand for a mandate to include patients comes from funders, administrators, policymakers, and of course from a subset of patients who are interested in engagement. It's for this reason that I think of it as a social or cultural phenomenon.

**Jennifer 05:06**

Now allow me another minute or two to share my personal experience which led me to all of this. My first engagement experience was very early on in my own intensive health care journey. I had a son Owen - his picture is right behind me - who was born with multiple severe disabilities and health conditions. Owen died about 10 years ago, when he was 12. Now, his issues started very early. He'd had procedures in utero and then was born at 28 weeks. I'd had a frankly terrible interpersonal experience during the diagnostic ultrasound. And when Owen was still in intensive care, one of the doctors asked if I would be willing to share my story at an upcoming sonographers' conference. Now, this was mere days after Owen was born. I was still in shock and traumatized. But I actually didn't care. In fact, this felt like a gift - a way to make sense of what had happened and to talk openly about my experience and to maybe impact others. And I was just so flattered! I prepared that talk for weeks. I spoke nervously to a roomful of specialists and researchers, and was met with much applause and teary eyes. And I was hooked.

**Jennifer 06:24**

I took every invitation after that, that I was offered - speaking to medical students, and writing articles, delivering lectures, sitting on advisory committees. And I helped design a patient survey for a study on which I was listed as a co-author. Now at the time, it was all volunteer, and it also became a significant part of my identity. I didn't use this term at the time, but I have friends in similar situations now who call themselves "medical moms" or "medical parents". And that usually entails a deep dive into the medical and technical ins and outs of our children's conditions. And I think to a large extent also includes volunteer work and advocacy, peer support and health system improvement, and sometimes contributing to health research.

**Jennifer 07:09**

In this respect, being a patient engaged in your own care, and being a patient engaged with the healthcare system, become quite enmeshed. And because of our culture of engagement, engaged patients in Canada are often involved in many different kinds of projects across the healthcare spectrum. Now, some may have preferences or particular training, but most engaged patients I know participate in both organizational improvement and health research. And in fact, often, organizations with research activities or affiliations share the same resource pool of engaged patients.

**Jennifer 07:45**

Now over the years, my son's needs and concerns became ever more complex and requiring specialized attention. And at the same time, like my fellow medical moms, my activities as an engaged patient continue to increase. But at some point, on both trajectories, my energies really started to wane. I grew more skeptical and more fatigued. The change or improvement that was promised on both sides was never realized.

**Jennifer 08:15**

On the clinical side, our physicians were certainly expert and caring, and always gave me room to make decisions. But over time, I started to see that medical care is not delivered in a vacuum. It was not purely about science or medicine. There was a *perspective* with lots of assumptions about disability and deafness, neurodevelopment, how to measure improvement and success, ideas about inclusion and special education. I also noted that there were plenty of assumptions about how much work I was expected to perform as my son's therapist and personal support worker and parent. And all of it was based on assumptions that were never articulated explicitly. And frankly, maybe not even known to any of us - it was just in the air that we breathe.

**Jennifer 09:03**

I think generally, we understand that healthcare service delivery is both an art and a science. And I would also say it's economics and politics and culture. And we kind of know this, I think, right? We see these other aspects come into much sharper focus in times of stress, like in a pandemic, when we must ration care, triage emergencies, rank how much we value cognitive abilities and physical function. As individuals, we also see this when we experience a long-term chronic illness or disability. The economic, political and cultural assumptions that we're all immersed in really start to reveal themselves. So yes, we received excellent medical care. But as I grew tired of performing as a medical mom, and

as my son failed to achieve any of these heroic physical feats we set before him, I really felt the weight of these unreflected assumptions.

**Jennifer 10:02**

And then on the other side, there was engagement. Which for medical moms like me, was a concurrent and intertwined experience that was inseparable from my intense healthcare experience. I felt that regardless of how personally rewarding it occasionally felt, my inclusion was always tokenistic. Or maybe *symbolic* is a better word. My presence served a purpose well beyond my actual contribution. Which is not to say that I didn't have occasional impact! But that would have been incidental. Maybe a happy accident. The point was simply to have a patient involved regardless of what they were able to contribute. The value of my presence was simply assumed. Now, there was more to it too, which I've addressed in other talks, but I'll just mention here: engagement gave me a safe space in which to channel my discontents and my advocacy energy; I was gently coached and guided into being helpful and productive; and occasionally pressed into service for free communications or administrative work.

**Jennifer 11:04**

So why have I spent all this time describing all of this? Because I think in places where involving end users in research design is not yet common practice - where engagement and partnership does not yet have widespread adoption - the idea of feels novel. And rings true. It seems obvious that it's the right direction to go. And it's also such a fast-moving train, it would be near impossible to stop. But I suggest that it's never too late, or too early, to consider what else might be at play and to challenge some of the assumptions that go by unexamined.

**Jennifer 11:42**

Through all of my reckonings, I have not lost faith in the healthcare system. Quite the contrary. Rather, I would say have broadened or shifted my understanding about what I think is happening. Yes, there is research and science and medicine and evidence and treatment. But there are also human beings involved. Which means politics and agendas, power and control, management over bodies and ideas. Which, of course, is the case everywhere. In all of our institutions. Maybe [this] even is the point of institutions. The bottom line here is that it is not just *science* driving healthcare and health research. The very fact that, in this conference, we're delineating "evidence-based research" from, I guess, other kinds of research...I assume this means you probably understand this. But we rarely consider what these other levers are - the ones that get pulled to direct improve or otherwise impact society. In some cases, levers get pulled to make service delivery more manageable and predictable, efficient and safe. And these levers are things like policy nudges or ethics review or triage procedures. In other cases, levers are pulled to settle people down. To calm unrest, to foster contentment and to manufacture satisfaction. To deliver a good experience. And these levers include patient experience programs, patient centered care practices, patient feedback mechanisms, and quality improvement programs. We use the language of business which gives it a bit more "oomph". We treat patients like customers. Try to innovate and continually improve.

**Jennifer 13:22**

Now, when it comes to healthcare and health research, these levers are not deployed to support or nurture science, but rather to appeal to a demand for progress, competitiveness, efficiency, and also

reputation, legitimacy and influence. And this is where I think patient partnership finds itself. Not as a way to improve research, but a way to address something else.

**Jennifer 13:46**

I call it a phenomenon because it's obviously happening and we can't always say exactly why. I call it an ideology because it's a belief system that comes with its own circular justification. It's also really modern in the way it can be flexible and malleable. It appeals to our sense of patient rights and advocacy and even activism. There's a sense of identity politics. Ideas of populism, where out of touch experts need to hear from "real patients", and where we tussle over contested ideas of expertise and power, and the ways in which democratic societies express or govern themselves.

**Jennifer 14:25**

Involving end users in health research. It's such a simple and obvious idea! Yet embedded is a lot of complexity, if one chooses to look. I do try to chip away at some of these ideas, but I just can't hold it all in view, especially all at once. And there are many waves that swell and crash and then dissipate - it's hard to hold on to. And as I talked about earlier, it's very hard to separate a person's experience as a patient - which may have been life changing and extraordinary - from their desire to try and help improve health research or healthcare service delivery. Casting doubt on the entire engagement enterprise? It's a tricky business.

**Jennifer 15:09**

Now, in all of my inquiries into this phenomenon of patient engagement, especially here in Canada, I've had a lot of thoughts and theories. But there's really only one thing I feel certain about. It's that it's not about the science. There was no evidence to suggest we should include patients in the way that we're doing it, before its popularity surge of the last 10 to 20 years. The idea came first. And now we're trying to catch up to explain why we might want to call it a good thing. And on that point, there is indeed a growing body of research about engagement and partnership. It tends to center on matters of implementation and quality. Meaning: was it done well? Did patients and researchers enjoy themselves [and] appreciate the experience? Did they feel they learned something from each other and was it fulfilling? Did the patient partner feel valued and heard? And did the researcher communicate well, and invite everyone's perspective? And maybe the question that's most relevant is: did the engaged patients change the course of the research or act as a catalyst in some way? Was it "meaningful", the holy grail of engagement? Now, as I said, casting doubt on the engagement enterprise is tricky. Even I hear how cynical it sounds, when I suggest that meaningfulness is unimportant, or that claims of impact seem arbitrary.

**Jennifer 16:34**

The truth is that I'm actually aligned with some of the goals of patient engagement. Health care and health research *should* address the concerns and interests of those who are most affected. If I were in charge, I would certainly choose relevance over irrelevance. If there are ways to steer research closer to meeting patient needs and solving their problems, or to being communicated better or to be more readily taken up by patients and the public... I'll go on the record as saying "I'm on board".

**Jennifer 17:03**

But here's the thing: we already have established research methods and process to do these things, some of which I know the EBR community advocates for. Including comprehensive literature review, qualitative or mixed methods research, community-based research approaches, and various priority setting and outcome measures exercises. We know that we can gain a rich understanding of patient needs and interests through existing research methods. So, let's consider what else is gained by adding partnership into the mix.

**Jennifer 17:38**

The first thing that comes to mind is that partnership provides an opportunity for a potentially satisfying participatory experience for the individuals involved. And often meaningfulness is measured by looking at things like interpersonal or group dynamics - not at, say, whether partnership impacted society, or whether the assembled group in any way represented the interests of a broader spectrum of patients, or whether non-engaged patients endorsed the contributions of engaged patients.

**Jennifer 18:11**

Another reason we might add partnership, instead of just doing research, is that saying "patients were involved" is a bit of a shorthand. It's a way to signal to the outside that a particular study or project *thinks of itself* as being patient-oriented. It suggests a spirit of collaboration and says something about intent - but nothing about quality of implementation or practice.

**Jennifer 18:37**

And finally, partnership provides ready access to patient perspective more quickly and easily than doing research. The risk here is that this proximity to patient thoughts and ideas - and also the loose way we use the word "partner", which brings with it notions of equity and equality - well, it just might feel sufficient. The need for literature review or a survey or a focus group or some other research method that would validate an idea? Well, it may just feel less urgent if you have real patients in front of you, giving you answers.

**Jennifer 19:12**

Now, let's take a moment to acknowledge that there *is* real value in talking to patients and that much can be learned. Thinking about this point, I'm reminded of a paper titled, "[Learning from patients: constructions of knowledge and legitimacy in hospital-based quality improvement programs](#)". The first author is Paula Rowland. Now this paper isn't specifically about involvement in health research, but I think it presents some useful ideas.

**Jennifer 19:39**

In this qualitative study, the authors argue that organizations don't learn directly from patients per se, but are learning from what they call "constructions of patient subjectivities", which could be a way to describe what animates a patient's legitimacy as an advisor from the perspective of the organization. In the paper, they identify three constructions:

**Jennifer 20:02**

The first is "process informant", where the patient displays legitimacy by providing details and insights about organizational process or practice. And then there's "vessel of meaning", where the patient relays

a (usually) carefully crafted story of their experience as a patient in an emotive way, generating an affective or emotional response. And finally, there's a "critical friend" - I think of this construction as a kind of dialogue partner or trusted confidante, who may shed light, discuss challenges and help to sharpen the focus of a project.

**Jennifer 20:38**

These are not necessarily roles or types of people. These are *frames* through which to view how patient knowledge and experience gets organized and presented as legitimate in an organizational advisory context. Now, these kinds of analytic frames, I think, are useful, because they can take us past assumptions about what is happening. We know engagement isn't science. But it also isn't magic. If we demystify what's happening, if we stop romanticizing it, we can perhaps move our attention from the seemingly magical powers of patient knowledge and experience (which you'd think by some accounts get conjured just by assembling patients in a room), to the extractive nature of what organizations are asking of patients. We can use the word partner all we want, but rarely is there a partnership or equity in terms of decision-making, influence, power and compensation. It's much more likely that patient partners are playing a supportive role, subordinate to the research and institution. And that they have been enrolled to satisfy agendas that are both seen and unseen.

**Jennifer 21:52**

So if you're doing evidence-based research, where does patient partnership fit in? It exists on an entirely different plane from the research itself. To ask if it's evidence-based is to miss the point of why some think it should be a new standard for research. And to me, it's a contradiction and not reconcilable. And yet, the phenomenon continues to take hold and shift and grow.

**Jennifer 22:16**

You may have heard accounts from both researchers and patient partners about how partnership experiences can be impactful and transformative, individually and for the project. So even when it's hard to specify impact, I actually believe it. Why not? When interested and engaged people come together over a common purpose, creative and productive things can happen. So it's reasonable to ask: *why not* surround yourself with dialogue partners, or invite someone to illustrate patient impact with a real life story, or seek advice from someone who can shed light on something you don't know? Sure. I can see why it's argued that mandates and frameworks and contracts are what allow these moments of learning and connection to happen more frequently. So, let's go on the assumption that hearing from or consulting with individual patients is a reasonable part of a researcher's process.

**Jennifer 23:12**

But let's keep in mind two things. First, I think these consultative practices should only be taken up with the knowledge that they do not replace evidence-based methods for grounding work in a scientifically rigorous process. Whatever ideas come from these encounters should be validated in the literature or through further research. And much like any sort of data collection method, there should be an analytic process through which patient input is understood, and contextualized - which I suppose makes it start to look more like research! In other words, patient partnership should not be considered sufficient for understanding or addressing patient needs and interests.

**Jennifer 23:55**

And my second thought is that, while these may ultimately be useful practices from an organizational or institutional perspective, there is very little about patient partnership that is, in fact, patient-centric. Patients are invited to participate at the behest and the timing of institutions and researchers under terms and conditions not of their own making. Viewed in a certain light, we could see that programmatic inclusion of end users in the research process provides: a rich source of free labour; easy access to opinions; and a way to signal virtuous intent.

**Jennifer 24:34**

Patient engagement practices have been around in Canada for a little while now. And patients are sensing the hollowness of some of these initiatives. There are increasingly loud patient voices calling for fair and respectful treatment, remuneration for their work, and to be provided with training and skills to feel they can actually contribute in a way that is productive. The burden seems to have fallen to patients to push for improvement and to not be seen as symbolic. That seems upside down. What if it was flipped? What would a patient-centric endeavor look like? I think it would mean discontinuing the mining and extracting of value from patients based solely on lived experience. We have research to do that. Instead, we could understand the patient collective as a stakeholder group, who have a shared and vested interest in seeing research funded and conducted with transparency, equity, distributive justice, with a focus on community priorities and impact. Personal fulfillment would take a backseat, with involvement centering on priorities and interests determined by a patient collective.

**Jennifer 25:48**

I've said for years now that engaged patients *should* have agendas. They *should* be politicized. They *should* make things uncomfortable. And some do, but they usually can't keep it up for very long. Patient engagement and partnership programs rather successfully absorb or deflate those energies, training and socializing patients to be cooperative, collaborative, and non-confrontational. And this approach is far less messy - and it's kind of the Canadian way. But it also serves to keep the patient voice in check. It's one of those non-science levers that gets pulled in aid of other interests.

**Jennifer 26:29**

We're at the end, so I'll try to summarize into something salient! The programmatic involvement of end users in health research is not and never was about the science, nor is it based on evidence. Project to project there will certainly be occasion where involving end users would be appropriate and helpful. But if we look at it through an EBR lens, we'll come up short. It's perhaps more instructive if we think of it as a social and cultural phenomenon, even an intervention, that is not neutral or organic or grassroots. Or magic. As partnership and research becomes more and more prevalent, don't be afraid to ask unpopular or difficult questions. Maybe even just starting with: why?