Transcript
Matters of Engagement podcast
Episode: “Understanding Legitimacy in Public and Patient Engagement, with Katherine Boothe”
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SPEAKERS
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Jennifer 00:02
You're listening to Matters of Engagement, a podcast examining issues at the intersection of health, healthcare and society. I'm Jennifer Johannesen.

Emily 00:12
And I'm Emily Nicholas Angl.

Jennifer 00:16
As part of our continuing series in Engagement in Health Policy, this episode gets deep into the weeds. Our discussion today is more like a case study exemplifying all of the thorny questions we asked about public or patient involvement. I love this kind of discussion, because it doesn't get caught up in some of the questions like “should we or shouldn't we”, or “how should we do it better?” Instead, we're going to step around some of these logistical questions and contemplate concepts around legitimacy.

Emily 00:46
Right. It's a word with a lot of complex ideas embedded in it. And in this conversation, we're looking at it from a number of angles.

Jennifer 00:55
And we'll get to definitions in a second. Let's first explain the context so we're all on the same page.

Emily 01:01
Okay, great. Our guest is Katherine Boothe.

Jennifer 01:04
She goes by Katie!

Emily 01:06
Right, Katie! Katie is an Associate Professor at McMaster in the Political Science department and a team member in the Public Engagement in Health Policy Project. She wrote a paper called "Redefining Legitimacy in Canadian Drug Assessment Policy? Comparing Ideas Over Time". It was published in 2021.

Jennifer 01:27

Okay, so what is drug assessment policy? Here, we're referring to the process that determines which pharmaceutical drugs will be paid for by funding programs at various levels of government. The programs have qualifying criteria, and a process by which they determine certain drugs that are eligible for reimbursement.

Emily 01:45
And this process is overseen by drug advisory committees made up of healthcare professionals, epidemiologists, health economists and other technical experts. And more recently, members of the public.

Jennifer 01:57
Yes, and Katie's research is specifically looking at the Ontario drug assessment process, as well as the Common Drug Review and the Pan-Canadian Oncology Drug Review, which are both pan-Canadian processes. Since 2006, each of these drug advisory committees have included patients or members of the public. And it's in this context that Katie wanted to better understand how adding lay members may affect ideas of legitimacy.

Emily 02:24
Okay, so that leads us back to the definition of legitimacy. Basically, Katie's research explores the degree to which public engagement is recognized as making a valid contribution to a policymaking process that typically relies on economic and scientific evidence.

Jennifer 02:40
Yes. So from there, we can ask questions like: how does contribution from the public sit alongside other types of information and evidence? And how is public input seem to affect the outputs of a typically very technical process?

Emily 02:54
In other words, does adding lay members to these kinds of committees increase or reduce people's trust that these processes will produce the so called right results?

Jennifer 03:03
Katie's work doesn't answer those exact questions! But her work does get us closer to homing in on some of the tensions and complexities.

Emily 03:12
Well, let's turn it over to Katie now. As usual, our guests do a better job of explaining their work than we do! We asked Katie to summarize the goals and the context for the paper.

Katie 03:23
The paper is asking about how and when people's ideas change, with their ideas specifically about public and patient engagement in drug assessment, in this case. And I was interested in this because the introduction of public and patient engagement to Canadian drug assessment, starting in 2006, was a big change. A big change to these institutions, which had previously only been made up of people I categorize as technical experts. So clinicians, health economists, sometimes health ethicists, and they form these independent bodies who apply

the methods of health technology assessment to consider the clinical effectiveness of new drugs and also their cost effectiveness. And then make recommendations to public drug plans in Canada about which drugs should be publicly funded for those limited groups of people who have access to public drug insurance. It's this kind of very technical specialized space. And in 2006, in large part in response to pressure from patient advocacy groups, and a sense that there's a democratic legitimacy problem with the way these recommendations are made, they started including patient and public members.

Emily 04:58
So Katie talks more about this idea of democratic legitimacy a bit later. But essentially, she's referring to the rights of people in Canada to contribute to decisions that ultimately affect them.

Katie 05:09
The two questions I had, were: first of all about the effect this had on the pre existing technical members of the committee's. And that's the focus of this article. The second question was about how patients and members of the public view these changes that have now been in place for, well, 15 years ish. So the first part of the question, though, was focused on the changing ideas, potentially changing ideas, of these technical experts, for two reasons. First of all, because the change of the drug advisory committees was not initiated by the people who made up these committees - it wasn't initiated by the people who do the drug assessments - look at this evidence, apply these methods - it came from outside the committees themselves.

Jennifer 06:09
At the time, this must have ruffled a few feathers! Not only because adding lay members may have changed the group dynamics, but because it might have challenged the very essence of why we have these kinds of expert drug committees. Katie relates these tensions to ideas about legitimacy.

Katie 06:27
There's a very kind of specific, we might even say narrow, idea about what constitutes legitimate evidence when you have a process based on a Western scientific method and, you know, standards of biomedical research. You know, even bringing in some economics, it's still a fairly rigid set of criteria for what constitutes quote unquote, good evidence. And in many ways, adding public and patient members and asking for information from patient groups was a challenge to those standards of using the "good" scientific evidence.

Emily 07:14
So yeah, no surprise that adding lay people to previously expert-only processes is a challenge to the status quo and raises questions about how to proceed. But we're not necessarily talking about overt conflict or tensions. Katie's work takes a look at how different reasons and priorities may contribute to members potentially feeling that they're not actually aligned.

Katie 07:37
Even instances where everyone agrees, it seems like everyone who is involved in a particular activity agrees that public and or patient engagement is a really important part of the process. But they think it's important for different reasons. And those reasons aren't necessarily compatible.

Jennifer 07:57
So one of Katie's avenues of exploration is to try and understand what makes public engagement legitimate. Or, where does legitimacy in an engagement process come from? And once she started delving into explanations, more questions arose.

Katie 08:14
This is something that's been the subject of lots of interesting research and different ways of describing, where, for example, legitimacy comes from in a patient engagement process. Does it come from the process itself, the way the process is designed? Does it come from the outcomes of the engagement activity? Does it come from who is involved, like having the right people at the table is that what produces legitimacy? So there's different kinds of ways of thinking about where legitimacy comes from.

Emily 08:53
For Katie, a good starting point in thinking about legitimacy is to consider why do we involve patients and members of the public in the first place?

Katie 09:01
One reason that you might involve them (and us) is because they have a right to be there. You involve them for democratic reasons, because it's important that people who are affected by a decision are provided with an opportunity to contribute to that decision. So that's one reason and we can think of different sort of factors that would go into creating a democratically legitimate engagement process to do with: who has the opportunity to be involved, what barriers are there to participation, and how are those dealt with? What sort of opportunities do people have to make their voice heard and are those kinds of meaningful and appropriate? So that's one set of reasons and ways that patient engagement might contribute to the legitimacy of a health policy decision, for example.

Katie 09:59
Another type of reason is we should involve patients or members of the public because they have information that we need that we cannot get any other way. So when we're talking about drug assessment for example, drug advisory committees are saying: Okay, we've got information from clinical trials about how these drugs work. We've got economic assessments about what they cost relative to other drugs that do similar things. And we also need information about do these drugs meet patients needs? Right? What kind of outcomes are patients looking for in a particular therapy? And do these drugs meet these needs? Or, you know, how do patients understanding and evaluation of the costs and benefits of a drug shape a committee's decision about whether it should be publicly funded, right? The drug does this thing that it's supposed to do, for example, but it causes terrible nausea. Okay, that's, that's important information that you might not get from clinical trials.

Jennifer 11:09
Okay, so Katie spells out a couple of different reasons for engaging patients and members of the public. And often these reasons do coexist comfortably. We hear both reasons a lot: patients have a right to be there, and their information is useful. But as Katie mentioned, these reasons may not always be compatible or produce the

same outcomes. Katie describes how sometimes these differing rationales can lead to disappointing experiences.

Katie 11:36
In my work, I talked about that second type of contribution as being related to scientific legitimacy. It can be a real difficult one, because often... and again, this is specifically relying on on my research on drug advisory committees... often the majority of those committees are clinicians, or health economists or ethicists, and especially the clinicians, their whole professional worldview is built around a particular type of evidence, understandings about what good evidence looks like. And the type of evidence that the committees need and receive from patient group submissions and from patient and public members of the committee don't necessarily fit neatly into that understanding of that scientific technical understanding of what good evidence looks like. So then, how do you deal with that?

Katie 12:38
And that, I think, is a key place where people with a lot of goodwill, and a lot of interest in making this work, can still talk past one another. And say, "okay, well, the patient is here. And that's democratic. And so we've done the thing that we need to do." And the patient might say, "Yes, I'm here. But I don't feel like you're taking my evidence seriously." Right? Because there's this con... there might, there might be this conflict between how clinicians or people with technical expertise understand evidence, and the types of evidence that patients are being asked to provide. There's a sense in which "being there" might not be enough - democratic legitimacy might not be enough - but the scientific legitimacy part is just a real place for, I think, miscommunication, if the goals and standards aren't really clearly articulated.

Jennifer 13:47
As part of her research, Katie also interviewed representatives of patient organizations, who were given an opportunity to provide written feedback to the drug advisory committees. Now, these representatives weren't lay members of the committees, but rather members of the public who were part of patient advocacy groups.

Emily 14:06
The process for submitting comments to the committees was thorough and required quite a lot of work from the patient groups to meet requirements. However, as well established as the process was, patient representatives were often frustrated by the lack of insight into how their feedback was being taken into account.

Katie 14:24
This is an example of patient groups in this instance are being asked to fulfill a role related to scientific legitimacy. Right, like present us with evidence, a certain type of evidence, is what we need. And so then it's a question of like, are we asking patient groups to do qualitative research on their membership? Are we asking them to gather life stories? Are we like... what are we asking them to do? And so I think there's a lot of potential there for frustration, frankly. And this is in a process that has, like I said, a lot of institutional buy in and support. And so then when we move to other processes that maybe don't have the same level of buy in and resources

and support poured onto them, then the risk of patients and organizers not talking about goals, or not understanding one another's goals or not considering different forms of legitimacy, I think is even greater.

Jennifer 15:34
So there may not be a perfect way to reconcile this tension, which is why as Katie describes, it may be helpful to take a more nuanced approach.

Katie 15:44
I don't think that democratic and scientific legitimacy are necessarily mutually exclusive. But sometimes they are some aspects of them will be. And if there's if there's no effort to consider the ways in which that might happen, then I think there's it's kind of setting a process up for, for failure. And it's also maybe not asking all aspects of a process to do everything, right, to say, Are there different types of inputs that we need in order to make this decision? Are there different points in which we need feedback versus times when we need to really sit down and deliberate with patients or members of the public. And so I think just being a little more fine grained in the in the way that processes are matched with goals might be helpful.

Emily 16:54
So we've talked about legitimacy of engagement generally, and considered democratic and scientific rationales for engagement. So we can see that there are different reasons why people think it might be important to engage the public. And if we can articulate that better, we might have less frustration. But that's not quite the end of the story.

Jennifer 17:16
Not only does public input represent different kinds of legitimacy, but that legitimacy can have different audiences. In other words, we have to consider how different stakeholders view that legitimacy.

Katie 17:30
The paper suggests that there are probably different audiences for legitimacy in the case of drug assessment, we might ask is patient and public involvement legitimate in the eyes of technical members, which is what this paper was focused on. And I think that that's important, because at the end of the day, the technical members of the committee are really the ones who are responsible for implementing public and patient involvement. The committees are independent, and the way the process happens in the committee is the responsibility of the committee members. So if they don't have some understanding of patient and public involvement as a legitimate component of of the process, I think that that potentially limits how meaningfully it can be incorporated. Okay, so that's one audience for legitimacy.

Katie 18:27
You also need legitimacy in the eyes of affected individuals, groups and communities, because that's who public engagement is for, right. And if the process is not legitimate in their eyes, and they don't have the opportunity to understand how their input is being used and judge the acceptability of the way their input is being used, then it just becomes this, potentially, this extractive process with trying to like get better information for policy decisions out of members of the public or members of patient groups, without giving them that sort of

meaningful control over the process. The tricky part is the kind of legitimacy needs of these different audiences are probably going to be a little bit different. I don't think it's impossible to account for different legitimacy needs. But if you don't even understand that those needs are different than your you know, you're not going to do it.

Jennifer 19:37
So even though the idea to include public input didn't come from the technical committee members themselves, Katie speculates that the rationale of scientific legitimacy is gaining some traction.

Katie 19:48
I think there is this kind of growing realization that the information was incomplete the information In the committee's were using to assess drugs was incomplete when they didn't have access to information directly from patients either sort of filtered and assessed by these public members or patient members, or directly in a submissions that they get from patient groups. So it's still very messy process, still are all sorts of questions about like, what are reasonable expectations of these patient submissions. Still questions on the technical side about is this actually good evidence. Questions about, you know, we're asking these under resource groups to potentially do qualitative research on their members. And that's problematic. But I think there's a growing realization among technical members, that it is important and necessary. Not just as a token. We have to make this process look better, by pointing out that there are patients on the committee, but we can make better decisions if we have this information from patients that comes to us on the committee.

Emily 21:16
And as we might suspect, the lay members of the committee felt that their addition was an important step forward for including patient and public voices in the process.

Katie 21:25
I didn't get to do the expanded round of interviews. But from the preliminary interviews I did, patient and public members of the committees were really, really sold on the value of being there in those rooms on those committees.

Emily 21:45
But it enthusiasm was less from patient groups who still felt left out of the process.

Katie 21:51
The greater difficulty was patient representatives who are on the outside of the committees who didn't have access to, you know, the specifics of how the decisions are made, or the way their information is used, or evidence that they were having an impact. I think that was a greater source of frustration. So therefore a greater potential legitimacy gap. Because the patient representatives who put together these submissions on specific drugs that affect their condition, they don't get to talk to technical members, you know, and hear about the impact that their information has. And you know, maybe in some cases, that would increase the legitimate the legitimacy of the process in their eyes, and sometimes, maybe not. But they don't have access to the same information that I was able to get through these interviews. [fade down]

Jennifer 22:51
So we've talked before about engagement activities being somewhat clubby, where especially selected so called "regular people" now become part of the inside circle. And as Katie describes, they're the ones most enthusiastic about being included. But for people on the outside of this process, like members of those patient groups, well, they might not have as much confidence in decisions because the process isn't transparent to them.

Emily 23:18
Yeah, I mean, we generally tout how important it is to include patients and the public. But when it comes right down to it, participation is necessarily limited to a finite number of people. So the general public, people who are potentially most impacted by policy decisions, well, they may not care who's at the table if their needs aren't being met.

Jennifer 23:39
Yep. And this is the kind of tension that Katie identifies in her work, noting that understanding the legitimacy needs of different groups is really important. Maybe not to solve everything, but to manage expectations.

Katie 23:53
And I think that that's a potential moment of disconnect in reconciling these different legitimacy needs. I think, legitimacy in the eyes of patients and members of the public is important for a few reasons. It's important, you know, just because, in general, we would like - I would like - policymaking to meet certain democratic standards. And I don't think it can meet them fully without some types of engagement. And the other thing that I think is, again, maybe like this is a little more instrumental, but if the people who are being engaged, if the patients and the members of the public and the communities who are being engaged, don't think the process is legitimate, and don't, you know, have a reasonable amount of confidence that the work that they do is to to engage with these policy processes meaningful... why would they continue to do it? You know, eventually, you have to reach sort of a point of exhaustion. And that I think is really detrimental to the process as a whole if people opt out of engagement because they don't think it's legitimate.

Emily 25:17
So, despite the tensions and frustrations Katy uncovered in her work, she's still committed to the idea of engagement, especially when it comes to both drug and health technology assessment. In particular, she thinks that patient and public voice is essential for helping to determine what gets covered through public funding programs.

Katie 25:35
I gave you the research story of why I think this particular type of engagement is essential. So maybe I'll give you the personal story to my youngest child... [fade down]

Jennifer 25:45

Katie's daughter has type one diabetes and now wears a continuous glucose monitor. It allows her parents and other caregivers to keep track of her glucose levels in real time.

Katie 25:55
...she wears a little device on her body, it measures her blood sugar and five minute intervals and sends it to her phone, and also sends this blood sugar monitoring information to my phone to my partner's phone, when she's at school to her nurse's phone. And...

Jennifer 26:13
This means her daughter doesn't have to constantly disrupt what she's doing to get her blood tested.

Katie 26:18
...In order to keep her safe through the night, we would wake up, you know, we would set our alarms for kind of three hour intervals to get up to wake her up to poke her finger to check her blood sugar....

Jennifer 26:30
And it relieves everyone of the hyper vigilance that comes with watching for symptoms all the time. The monitor itself alerts them when her blood sugar changes

Katie 26:38
...more insulin. So it changed our lives when she was tiny. And it also now supports her independence as a seven year old because she can play soccer...

Jennifer 26:48
The device is expensive, and at the time was not covered by public funding. So Katie got curious and researched the assessment history of the device.

Katie 26:58
...little device very important to our lives, also very expensive. I read the rationale for not extending public funding...

Jennifer 27:07
Katie discovered that it had been rejected for coverage because it wasn't found to sufficiently improve A1C levels, which is a diagnostic marker measured in the blood.

Katie 27:18
...so an important measure, but in no way captures all the other impacts of living with diabetes. If you ask any parent of a little kid with type one diabetes, what is the value of of a continuous glucose monitor to them, they're probably not going to say lower A1Cs. I think the only way you could capture this would be asking people who live with diabetes or asking people who care for people with diabetes, because there's no randomized control trial that captures the value of not waking up for three finger pokes tonight.

Emily 28:05
So, you know, one of the things we talk about on this podcast is whether any particular individual experience should inform policies and decisions that potentially affect a much larger number of people. So Katie's story opened up a huge conversation for us, and we weren't sure we wanted to include it.

Jennifer 28:24
In this case, though, we felt that Katie's story illustrates how policy priorities and individual interests can differ, maybe even conflict. Reducing the number of deaths is one legitimate way to ration or distribute funding. And this is maybe, probably? what they were assessing for with the glucose monitor. But for people who actually live with diabetes, this measure just may not be sufficient. So Katie's story here really captures this tension.

Emily 28:55
Right. The question that's brought up for us is certainly not whether her concerns are relevant. But whether engagement is an appropriate, or at least sufficient intervention to surface this kind of information. What about other forms of research that actually study patient preferences or patient reported outcome measures?

Katie 29:16
Yeah, that's a good question. It's certainly one that I started to get a sense of there with the idea that you could make patient evidence or information more legitimate by fitting it in to a more traditionally scientifically acceptable box.

Jennifer 29:39
So, yeah, Katie has a point. Understanding patient preferences through research is considered more scientifically acceptable, and therefore more legitimate. And I do find myself thinking, Well, what's wrong with that? Now, I agree, it would be ideal if funding assessments took a variety of factors into account. But I personally would trust the process more, if I thought it adhered to a scientific approach and wasn't overly influenced by select individuals who happen to be on a committee at the time.

Emily 30:15
Katie's work acknowledges exactly that tension. Prevailing ideas of legitimacy come from scientific methods. Inserting members of the public into the mix potentially up ends all that.

Katie 30:26
My hunch is that it's not an either or question or answer. It's a "both and" question for a couple of reasons. First, for sort of legitimacy reasons in that I think people who want to contribute to health policy decisions should have some options in how they want to contribute. If they want to be part of a research team, and you know, learning about how to collect qualitative information and express it in these social scientific methods, then they should have the opportunity to do that. And if they would like to have access to sort of a more unmediated opportunity to talk to decision makers or to influence decisions, they should have meaningful opportunities to do that, too.

Katie 31:34

I think the key is, and I don't think this is where either the research world or the engagement world is right now... but I think the key would be to have both those types of opportunities be accessible, to have reasonable demands on the people who want to be engaged, and to engage people with an eye to issues of equity and inclusion. So they're not, you know, so neither one is restricted to people with certain resources of time, or money or education or privilege. Because I think both are valuable ways to get different kinds of information, necessary kinds of information, into the policy process. I think the process itself should be flexible enough in its understanding of legitimacy, to accept information, both from research that focuses on patient reported outcomes, for example, and from hearing submissions directly from patient groups. I think that they're different avenues, and they might turn up slightly different issues.

Jennifer 33:07
Okay, so this is where it's getting a little bit murky for me. I know that Katie's thinking out loud to some extent, and there's a lot here to agree with, like doing research on patient priorities, and also hearing from patient groups. The part I'm struggling with a bit is the part about patients having a right to participate in conducting research, at least to the extent that Katie's describing here. And also the idea of individuals having unmediated opportunities to influence decisions. It feels like a shortcut or maybe a backdoor, to granting influence to only certain people.

Emily 33:45
Yeah, I mean, there's plenty of potential risk here, which I think is why it's important Katie also mentioned equity and inclusion, to help ensure that influence or participation is not limited to people with certain privileges.

Jennifer 33:58
Yeah, for sure. It's clear Katie is grappling with these questions too, and doesn't think of it as all or nothing. I think what she's talking about is having the appropriate kind of engagement at appropriate times.

Katie 34:11
I think both are potentially valuable and the way that they fit into the policymaking process at different stages.... like you might not have both things all the time in every instance.

Emily 34:29
We asked Katie about where this work fits for her today. What's next?

Katie 34:36
First of all, the work I did on drug assessment has led to a lot more questions about what legitimacy is, who it is for. You know, I started the research project, being primarily interested in how institutions change. And I'm still interested in that. But I think the framing of the types of questions that I'm asking has changed. And I think that comes into the work that I'm doing with the team that is maybe a little bit more critical of some of our shared assumptions about what we're studying when we're studying public engagement. Like, are we trying to advise folks on the, quote unquote best way to engage different groups at different times? Or are we kind of taking a step back and saying, What do existing processes of public engagement tell us about legitimacy and about

power? And about equity? And I won't speak for everyone on the project, certainly, but for me, how can we study them with sort of a more activist lens in saying if what we're observing in our research are failures of legitimacy or failures of equity? How do we describe what we're seeing? And sort of direct our research goals to, to better understanding and maybe improving them?

Jennifer 36:50
Hi, Emily.

Emily 36:52
Hey, Jen.

Jennifer 36:54
I'm glad we had a chance to talk more about legitimacy. It's such a central theme to so many aspects of engagement. It helps explain why there's often tension around engaging patients and members of the public in scientific or technical processes. The reasons why various parties engage can be very different.

Emily 37:12
Yep. We talked quite a bit about scientific and democratic rationales for engagement. What I found particularly interesting here was considering how these rationales can actually be in conflict. And can lead to frustration and people feeling like their needs aren't met.

Jennifer 37:31
I also got a sense of some of the insider outsider issues we've talked about before. Katie's research showed that members of the public who were on the technical committees were very much bought in to public participation. But for members of the public, who were part of patient groups, submitting comments to the committees? Well, their response wasn't as enthusiastic.

Emily 37:58
And like we said, I'm not sure it mattered to them that there were lay people on the committees. They just wanted to know how their requests were going to be addressed.

Jennifer 38:07
I mean, focusing on equity will help to promote more fair distribution. But then again, who exactly identifies as being marginalized or disadvantaged these days? It's a bit of a moving target.

Emily 38:20
It gets complicated quickly. The public, by definition, is going to be very diverse and may not be aligned around common goals. The more influential political or special interest groups may get the most attention and resources.

Jennifer 38:36

Yeah, I'm really glad that Katie described the shifting lens and their research, maybe less than thinking about how to engage and more about looking at current engagement practices, and what that tells us about our views on legitimacy, and ultimately on power.

Emily 38:56
Big thanks to Katie Boothe for thinking out loud with us and sharing her work.

Jennifer 39:08
Matters of Engagement is written and produced by Jennifer Johannesen and Emily Nicholas Angl. If you have feedback, ideas, or just want to say hello, please get in touch through our website at mattersofengagement.com.

Jennifer 39:22
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