Transcript
Matters of Engagement podcast
Episode: "Health Policy Series Kick-off!: A retrospective look at public engagement, with Julia Abelson"
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SPEAKERS
Jennifer Johannesen, Emily Nicholas Angl, Julia Abelson

Jennifer 00:02
You're listening to Matters of Engagement, a podcast examining issues at the intersection of health, health care and society. I'm Jennifer Johannesen.

Emily 00:12
And I'm Emily Nicholas Angl. In this episode, we kick off our Health Policy series and speak with Julia Abelson, professor and researcher at McMaster University in Hamilton, Ontario, and lead of the Public Engagement in Health Policy project. For transcripts and links, please check the show notes.

Emily 00:37
Hey, Jen!

Jennifer 00:38
Hey, Emily. So we're branching out!

Emily 00:43
I know. It's really exciting. It's been fun, you know, figuring out how we want to proceed and, and building a lineup of guests.

Jennifer 00:51
Yep. And to help us stay focused, we're going to embark on a series of, well... series. We're thinking of them as collections of episodes that loosely revolve around a theme. So except for the rare occasion, there won't be a required sequence. Listeners can jump in anytime.

Emily 01:09
Okay, so first up is a series on Health Policy. We have a range of questions we want to explore, including things like, who is involved in making policy, and how our public needs identified? How is public engagement defined? And who is included or excluded?

Jennifer 01:30
Even though we're moving into wider territory now, it's kind of amazing how engagement continues to be such a prevalent theme, especially when it comes to health policy. There's a significant downstream effect on how we all experience our health and health care. But it's also a fairly removed and non-transparent process.

Emily 01:49

Yeah, absolutely. Policy is made by politicians, bureaucrats, regulators, lawmakers, and influenced by a lot of different parties with special interests. There's a sense that people in charge aren't attending to the needs of so-called "regular" people. So like practically everywhere else these days, engagement is a hot topic.

Jennifer 02:13

Yeah, and it's important for both sides. People want to be engaged, and those in charge want to be seen to be engaging.

Emily 02:20

There's certainly a lot to consider not just how people interact with the healthcare system, but the extent to which the system is reflecting and serving the needs of people. So yeah, we're really pleased to be taking a deeper dive and making a whole series devoted to public engagement in health policy.

Jennifer 02:39

It's a pretty varied series we have lined up. We're exploring topics like Black community engagement, and COVID, use of health data, even the business and politics of engagement. And we're going to hear from a wider range of people than before community leaders and policymakers. And I guess what we might call "regular" people - members of the public, like you and me.

Emily 03:02

To kick things off, we're talking again to Julia Abelson. Julia was an early guest way back in Season 1, talking about evaluation and patient engagement practice...

Jennifer 03:12

Which by the way, was one of our most downloaded episodes. Julia is actually well known for her work in public engagement, as well as health policy. She's a professor at McMaster in the Department of Health Evidence and Impact and an associate member in the Department of Political Science. She's also Director of the Health Policy PhD program. She has a special research interest in public engagement in health system governance, and the analysis of the determinants of health policy decision making. So obviously, an ideal guest for our topic. We thought checking in with her would help point us in helpful directions.

Emily 03:48

And it really did. Julie is leading a team of researchers in a project based at McMaster University, it's actually called.... Public Engagement in Health Policy.

Jennifer 04:00

Sounds like a good fit!

Emily 04:02

Yeah [laughs] Well, the project aims to critically reflect on some of the political, economic and social challenges in public engagement and health policy, and consider what might be needed moving forward to address those challenges.

Jennifer 04:15

To be able to deliver on all this, they've assembled a diverse team of researchers to consider these challenges from different angles. We'll be speaking with a few of them in this series.

Emily 04:25

Yep. So we reconnected with Julia for a big picture conversation about some of the early insights learned in the project so far. One of the research themes in the project is looking back, reflecting on the evolution of engagement practices and health policy and seeing what can be learned from past experiences. And for Julia, it's not just a theoretical exercise. She's been a researcher in this field for, well, her entire career. And so she's seen some of these changes firsthand. We got to talk to her about her insights related to trends in engagement in health policy, and also discuss one of the projects first outputs - a case survey of government-initiated public engagement in health policy.

Jennifer 05:08

Yeah, I remember when that was published a couple of months ago. It's called "Trends in Public Engagement in Canadian Health Policy from 2000 to 2021: Results from a Comparative Descriptive Analysis." It got a lot of attention, I think, because it's maybe the only study of its kind....?

Emily 05:28

Well, it's certainly uncommon to conduct research on engagement that isn't just about the "doing." There's not a lot of looking back and trying to understand what has already happened.

Jennifer 05:41

Yep. And, well, this is familiar territory, the language and definitions around engagement are often quite loose. So figuring out what it is you're actually trying to study is one of the first things to address. Here's Julia:

Julia 05:56

It's interesting, because the forms of engagement are really… there are many of them. And there are shades of differences. And I think that's been one of the things that I've always found a little bit… Both interesting and, you know, maybe a little frustrating, because there's a lack of conceptual clarity about what are we actually talking about. You know, if I were to say, "I do work in public engagement" to 10 different people, they would actually interpret what I mean by that in potentially 10 different ways. People would have different views. So being conceptually clear about what we mean by that.

Emily 06:30

So these are pretty fundamental questions, like, who are we actually talking about? And in what context?

Jennifer 06:37

It's one of the reasons this kind of foundational work is important. It helps to establish some common ground, and like Julia says, tries to gain some conceptual clarity.

Emily 06:48

Yeah, I think we often talk in circles. So actually doing the research gives a much more solid footing for moving forward.

Julia 06:55

It's a lot about methods, right. And so I don't actually distinguish the methods from the enterprise itself. That's because I'm a researcher. I can't help but think about and that's always been my interest is, if we're going to… if we think this is important, this notion of engaging publics in some way and more or less interactive ways - all of these different elements along the continuum - what are the most robust ways that we can do this? And then we get into things around representation, or representativeness, inclusivity, transformative... you know, many of the different characteristics of... and again, some of the critiques of processes that don't have those elements, and where perhaps we should be going.

Jennifer 07:40

Julia said "publics," plural. Because often when we say "the public," we're not actually talking about every possible individual, but rather subgroups or categories of people. And you obviously can't include literally everyone, so there will inevitably be questions about who is engaged, and to what extent can you assume those people represent others.

Emily 08:05

Yeah, these aren't simple matters at all. The connection I'm making here, about what Julia said, is that the methods used for engagement really do both reflect and define the nature of the engagement. Unfortunately, I'm not sure a lot of people who do engagement realize that. I think it's common to pick a popular or easy way of engaging, but not necessarily consider the implications later.

Jennifer 08:30

I'm sure Julie has seen it all, or at least a lot. And of course, as a researcher, her focus is on observing and studying and analyzing. She's not typically involved in the engagement activity that she's studying.

Julia 08:45

I don't dictate because I don't make the decisions about how engagement, you know, is going to be positioned, lobbied for, policy documents, legislation, you know... I'm a researcher, and I respond to what I see happening in the policy sphere around engagement. So when I see a policy of government saying we are going to, you know, focus on patient partnered policymaking, research or whatever, I say "okay, that's interesting." So what's... you know, I'm looking for the underpinnings for it all. But I'm always thinking about it, to some extent, methodologically, whether, you know, that's maybe good or bad, but that is how I think. Okay, if that's going to be our plan, or kind of motivation, whatever has motivated that decision... I think we need to do the best job that we can with that.

Jennifer 09:38

So Julia mentions here thinking methodologically, which means to look at what's happening using established tools, methods and frameworks to gain a better understanding. It's so important to do this work, because often ideals around engagement are just so loaded with passion and emotion. It can be hard to see what's really going on when it feels like there's a lot at stake.

Emily 10:01

So, as a kind of witness or observer, Julia is in a position to note inconsistencies or discontinuities, where things just don't quite line up. We hear this a lot, actually, from researchers in the space, there can be a lot of misalignment mismatch of intentions. This is where some of the critique comes in.

Julia 10:21

I could also be critical and say, "I don't think that's a good way to proceed, because I don't think you'll be able to achieve true partnership. I think it's, you know, a false starting point," because in the way that our health care system is structured with tremendous power differentials and the way society is structured.... I mean, are we really thinking that we are going to have this notion of some kind of true partnership? So this is where we get into the politics and the contested notions of partnered anything, right? When we're talking about extreme power differentials that are unlikely, in my view, to change, you know, very, very soon or quickly. So I'm trying to better with what we have with what's kind of in front of us and try to, you know, encourage people to… well, if you're going to do this, think about these principles [and so on] but also having some critical foundations with like, are you really... you know, can you really even call it that, given the realities of what our current structures look like?

Jennifer 11:26

This is one of those themes that yields a lot of interesting ideas for critique, how power is held and shared or not shared, and how that affects notions of so-called "true partnership," however, that's defined. So we have a disconnect between what we're calling something and how that actually looks in practice. But then we have almost the opposite thing happening too, where we just keep doing the same thing over and over, but call it by different names.

Julia 11:56

I mean, I see lots of different labels being used, right? Terms being used to describe things. Sometimes I see a label being used to describe something that isn't any different from what we were doing before, but it's a new label, right? I think we have lots of examples of those. Sometimes it's truly an attempt to shift some ways of doing things. And maybe by labeling it in a way, you're sort of aspirational, we're trying to move in this direction.

Emily 12:29

Yeah, I definitely see this. I can't comment on whether it's aspirational or not. But I do see a lot of repackaging of things done before. And conversely, borrowing terms or labels, which have a lot of history behind them, maybe to give something a certain appeal or connotation.

Julia 12:47

One thing that's coming up an awful lot, which I think is it has been for some time, but it has continued to come up in the context of this project is, again, back to labeling and back to, you know, concepts: community based participatory research, CBPR. A well-known approach to research – a long, long history. And some would argue, maybe some of the principles of patient-oriented research are very… you know, there's overlaps and people have asked that question, "What's the difference? I do this…" Or the even the concept of community-engaged research, which may be a new term. And yet community based/participatory has a lot of the principles or, you know, co-design to some extent, or experience-based co-design versus some other co-design. So, for me, it's, you know, it's important to know, because, why would we just start over when we could just take some really good ideas that have already been around and help.

Julia 13:44

And I also think that things are cyclical, right? So we do see things that were... you know, a lot of the public engagement stuff that I was involved in a long time ago... we're starting to hear people talk more about publics and communities again. We kind of went through this "It's nothing about public, it's all about patients now. Patients, family, care, you know, we're not interested in public, it's all about patients." Now we're coming back to maybe it's about communities and publics. I'm like, wow, we were talking about that a long time ago. And again, not just me but many, many other people.

Jennifer 14:19

Well, part of the work of Julia's team is to indeed look back and take stock of some of what's come before.

Emily 14:26

The team just published what they're calling a case survey. It's an analysis of public engagement trends over time, starting with the Romanow Report. It's a white paper that was commissioned by the government - the commission was led by Roy Romanow, and it was called The Future of Health Care in Canada.

Julia 14:45

So we took the paper, you know, the Romanow Commission, kind of as our starting point - the Future of Health Care in Canada - because there was a lot of... public engagement was a big part of the contribution to the commission work. And it actually seeded a lot of the public deliberation work that I and many others have gotten involved in since then. In many respects, you know... the feeling was not a lot has changed in the sense that we're still looking at pretty passive, pretty indirect, pretty kind of "put it out there." And maybe if someone finds the website, and [fades]

Jennifer 15:20

Yeah, so the case survey was really interesting. We're just going to pull a few things out of the abstract here - and we really encourage listeners to take a look. The link is in the show notes. No paywalls, and they've done a good job of making it fairly accessible language-wise. The basic idea was that they hoped to identify trends in engagement approaches in health policy by collecting examples of government-initiated engagement activities from the year 2000, up until 2021. And they were looking for particular information like type of engagement,

target population, selection method - this is all the methods stuff that Julia was talking about - and they also wanted to see whether these activities took stated or explicit steps to include marginalized populations.

Emily 16:08
Okay, so looking over the details here... Okay, so here are some highlights. They found a predominance of feedback-oriented engagement....

Jennifer 16:17
….so not really partnership as it's commonly defined….

Emily 16:21
Okay, and self-selection recruitment methods....

Jennifer 16:25
….so they were essentially just looking for volunteers…

Emily 16:28
Okay, and engagements that include multiple populations were favored over single or targeted populations. And only 1 in 10 mentioned marginalized groups.

Jennifer 16:40
Wait, do you mean focused on….?

Emily 16:43
No, it says mentioned.

Jennifer 16:46
Okay.

Emily 16:46
And a lot of reliance on passive and indirect engagement, especially at the federal level.

Jennifer 16:54
Well, I have to say, none of this really comes as a surprise.

Emily 16:57
Yeah, I don't think they were surprised either. Although, there was one interesting thing that really stood out. And it's that at one point, it's like the federal government kind of kicked into action, and initiated a flurry of public feedback engagements.

Jennifer 17:12
So when they say feedback engagements, did they say exactly what that is? Like, how was that defined?

Emily 17:19

Well, they describe it as a fairly shallow but broad form of engagement, like a one-time call for comments on something specific. And it's usually narrowly framed.

Julia 17:29

One of the caveats with the case survey analysis is that we happened to stumble upon a very large number of cases at the federal level, because in 2015-16, they put in place this very formalized public feedback platform. They put it out for every single issue that they're seeking public input on. It's interesting, because it's very formalized and very transparent in the sense that it's all there, if you find it, and you can have all kinds of... you know, provide your input on many, many issues. But you have no idea where it's going. It's very transactional, and very one way. It's interesting. And that's one trend, like why? So our questions are, why was that even set up? What was the motivation for that? So that's follow up work we do.

Jennifer 18:17

Right. So the team noted a flurry of a specific kind of engagement activity, which in itself raises more questions for the team. They did actually find some more deliberative work being done at the provincial level.

Julia 18:30

But then at the provincial level, of course, we know of many of our cases that were very in depth. Very much more of an attempt to... over longer time periods.... using multiple approaches, you know. I'm thinking some of the mental health engagement processes that we looked at, have much deeper, more long term and more thoughtful and kind of interactive types of engagement. Where they're using feedback consultation, as well as maybe they're bringing a group together to deliberate around things. So very mixed.

Emily 19:02

So lots of interesting food for thought. And that makes sense. The case survey isn't meant to necessarily answer how or why, but what - to actually collect some data.

Julia 19:14

And so that's why it's hard to kind of make very broad conclusions from this. And we don't want to. It was merely I think a helpful exercise to see what's out there and to actually use it to generate new research questions and also to point to some opportunities for institutional change [fades]

Jennifer 19:32

So we should mention in our conversation with Julia, she acknowledged that they were relying on essentially publicly available information. And there's a lot of engagement activity that isn't publicized or recorded in a formal way. So they're aware this could create some gaps in what they're studying.

Emily 19:50

Still, what they did find generated some useful insights.

Julia 19:54

The other thing that I think was interesting, perhaps, you know, what we would have been expecting and did find is the pan-Canadian, right? So this is largely the health technologies, this is CADTH, they're the ones... [fades]

Emily 20:04

CADTH is Canada's drug and health technology agency. They develop recommendations for the optimal use of things like drugs and diagnostic tests and various devices and procedures. They have a public engagement process.

Julia 20:18

They're the ones doing the kind of in depth... the deliberative... like really bringing it into their, you know, every aspect of their decision-making process. But again, are you more.... and I'm kind of stealing my student's thunder on this a little bit, because she's looking at exploring this with long term care.... the further out you get from the actual decision making, location, and who's making the decision, the more likely you are to be open, maybe, to more thoughtful, interactive, inclusive engagement. The stakes aren't so high, right? When you're looking at "we're going to make a decision." And you know, these are going to be tough decisions, and how are we going to engage publics.... maybe feedback consultation, we'll do that broad based stuff, superficial, but maybe we don't want to have them so close. To actually informing the decision. That's a big part of where we think we're going to be going with some of these more in-depth case studies.

Jennifer 21:21

Yeah, that's really interesting. I'll be curious to see where they net out on all of this. Maybe it's also not so much that the stakes aren't high, but that the impact isn't immediate or highly visible, and therefore, it seems like lower stakes. Decisions made early in a process can entirely shape what's to follow. So I would argue that the stakes maybe are quite high.

Emily 21:46

I suppose an argument could be made for deliberation early on in a process, like Julia's describing, and then intentionally deploying a more efficient and broad-based consultation later on, as something gets closer to market - well, using the example of CADTH. It just wouldn't be possible to deliberate on literally everything.

Jennifer 22:06

Yeah. And that actually came up in conversation with other project team members, that it's perhaps not reasonable to think that every part of a process is going to be a full-on partnership with all stakeholders. And I think you've said this before too, Emily, that, as a consultant, you sometimes see engagement where it just doesn't really belong.

Emily 22:25

Yeah. And maybe more common is that engagement can be used inappropriately or without a real goal. This leads to another question we had for Julia, which is that, well, how does she feel when she observes false starts, misalignments and confusion? The case survey was maybe a bit unusual for her in that it was a very high-level

inquiry using public records. But as a researcher, she often is more immersed in the work of engagement. And I wonder... it must be challenging to hold back on making recommendations.

Julia 23:00

It's analysis, right? That's where I come back to my role - analyst versus advocate. I mean, of course, there is some advocacy to this in the sense of I firmly believe in the importance of, you know, publics meaningfully contributing to shaping policy decisions that are made, that they are going to be affected by, right? As recipients, as users, as, you know, people who are, again, this idea of shareholders and users, whether current or future, of our health system. So I firmly believe in that, and those are kind of democratic values that I hold. But I try to separate that from, "I'm going to advocate for a particular way of doing this." Hopefully, my contributions are more as a researcher and analyst of these things. And by analyst I mean, in lots of ways. Analyzing the political structures, analyzing the methods we use, and, you know, lots of different ways in, to that analyst role. To hopefully inform and improve.

Jennifer 24:03

Yeah, this is really interesting for me to hear. I admit that for me, and how I've thought about my work, the line between analyst and advocate is a little less clear. One of the things I've thought about a lot is the fact that I've been critiquing patient engagement practice, in particular, for a long time. And I'm still seen as a kind of advocate for improvement. It's kind of why I'm keen to step back a bit from patient partnership as a topic. I don't really feel comfortable being seen as an advocate. I totally get Julia's distinction, though. As a researcher, she's not actually telling people what to do or how to make it better. She's, as she said, responding to what's in front of her and providing analysis. And then of course, people can do what they want with that information and knowledge.

Emily 24:52

Julia's delineating between analyst and advocate, but she's also clearly acknowledging her perspective and her desire to contribute things improving.

Julia 25:01

We just "do" and we don't think about why we're doing. Now, some people are doing because there are these incentive structures put in place to say "you have to do" not "why you have to do." So to be fair, I think partly it's maybe a deficiency or lack of the proper underpinnings for something being set up in the first place to explain why, right? Or what we need to think through to make decisions about whether you go ahead or how you go ahead, or that there's a whole kind of history before this or that these principles look a lot like those principles.... I do think there's a lot of doing and just: how do we do it? How do we do it? How do we get that off our plate? How do we move on to the next thing and say we did it? And I guess, yeah, I mean... like this is going to cause me to really reflect because what is, you know, what does that say about this field - if we can even define it as a field? So again, that's a whole other.... that's very existential around this for a Friday! [laughs]

Jennifer 26:04

Well, even if you're not listening on a Friday, I'm sure this is all still relevant!

Emily 26:10

Indeed! Big thanks to Julia Abelson for connecting with us again. We'll be back soon with more episodes, including more conversations with team members from the Public Engagement in Health Policy Project.

Jennifer 26:22

Super, let's leave it there. See you soon Emily!

Emily 26:26

Bye Jen!

Jennifer 26:31

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 26:45

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