Transcript
Matters of Engagement podcast
Episode: "Deliberation, democracy and public engagement: a conversation with Kim McGrail"
https://mattersofengagement.com

SPEAKERS
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Jennifer 00:00
Hey Jennifer here! Before we start the episode, we just want to let listeners know about an upcoming conference hosted by the supporters of this series. And that's the Public Engagement In Health Policy Project led by Julia Abelson out of McMaster University. The conference is called: Reimagining Public Engagement in a Changing World. And it features keynote speaker Jamila Michener. And has panel presentations by Alpha Abebe and Rhonda C. George. both from McMaster; Joanna Massey, also from McMaster; and Genevieve Fuji Johnson from Simon Fraser University. The date is September 22, in Hamilton, and the morning sessions are open to the public. Both Emily and I will be there all day, participating in and recording some of the proceedings. You can learn more and register at engagementinhealthpolicy.ca.

Jennifer 00:52
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 01:02
And I'm Emily Nicholas Angl.

Jennifer 01:05
For this health policy series, our goals have been pretty open ended. I guess we could say that at the core, we're interested in better understanding the relationship between the public and health policy. But of course, that's very broad - almost so broad that we kind of have our pick of topics. For example, we could look at how health policy affects individuals and communities...

Emily 01:28
...or we can look at the ways that the public influences health policy, or maybe demands change.

Jennifer 01:35
Yeah, and then there's everything in between, like all the political, environmental, financial, and other factors that come into play. So I mean... to say "health policy" is almost to say "all of health care" - because it's a very complex ecosystem that can't be separated from its context in order to be understood.

Emily 01:54

And the notion of public itself is also a complex idea. We've talked about engaging the public before. But usually, we're actually talking about a subset of the general public, like people who live in a certain area or people who identify in a certain way.

Jennifer 02:10
Yeah, we don't usually talk about public at a very large scale, where the public literally means everyone in Canada.

Emily 02:19
Maybe the most obvious example of that kind of public engagement is federal elections. However flawed it all is, we see elections as an important aspect of democracy. But voting isn't the only kind of public engagement, obviously. I mean, a democratic society values the right to participate in civic life.

Jennifer 02:38
Yeah. And in Canada, we have all kinds of shared social and community services, like education, health care, policing, community services, all of the things that make up our ideals of Canadian society. These are some of the areas where people like to volunteer, as an expression of that right to participate.

Emily 02:58
Sometimes that participation is very local, like volunteering at an event or even running for school council. But it's not always obvious how people can participate in projects that have a much broader scope, like publicly funded federal initiatives.

Jennifer 03:13
I think that's because there just aren't that many opportunities, or maybe they're hard to find. And to be fair, I think it's really hard to figure it out beyond sending out surveys or maybe running some focus groups... ...or public advisory tables. But those can seem a bit exclusive or difficult to access for the average person. Well, it's these issues that lead us to our next guest, Kim McGrail. Kim leads a CIHR funded initiative, whose work in the health data space has implications for, well, everyone living in Canada. And they're keen to involve the public not just in getting input, but in providing guidance into key decisions.

Emily 03:57
And it's not so easy to figure out. Their work is complex, highly technical, and requires careful consideration of ethical and equity related issues. We're talking about HDRN, Health Data Research Network. They're a member based organization that...

Jennifer 04:16
[interrupts] Wait, hold on! Before we get into all of that, let's meet Kim.

Kim 04:21
I am Kim McGrail and I'm a professor in the School of Population and Public Health at the University of British Columbia. So I'm based in Vancouver.

Emily 04:29

Kim's background is in quantitative health services and policy research with a focus on health equity, which led her to an interest in health data.

Kim 04:39

Because I was a quantitative researcher, I got really interested in data. Because data are kind of the lifeblood of the work I do.

Emily 04:49

Kim was previously the Scientific Director of PopData BC, a large university based data center that provides population based health data as well as services to researchers. There are several of these data centers across the country and each with its own data sources.

Jennifer 05:05

Right. The problem though, is that until recently, it's been hard for researchers to link data from multiple data centers together. And that might be useful if you actually want to understand population health patterns beyond a particular region or area. And it's hard to do because each data center is subject to different local governance rules and privacy laws. As well, each data center has its own way of collecting and categorizing information. So linking or combining data can be difficult.

Kim 05:35

We have this long history of really good health data use in this country, but it tends to be province specific. It's an Ontario study, or it's a Nova Scotia study, it's a BC study. And there's so much left on the table if we only do things within our individual provinces. So there's a lot more that we could learn by looking at differences in the way provinces organize and deliver health and social services, if we were able to use data from multiple places to understand what's working well, what's working not well. But of course, we also want to use health data at a pan-Canadian level, so that we can say something about Canada as a whole. As opposed to just the provinces and territories that make up Canada.

Jennifer 06:15

Well, Kim is now Scientific Director of a newly formed CIHR funded network, Health Data Research Network, or HDRN. Their aim is to link or unite data centers to support multi regional research and multi regional use of data.

Emily 06:31

Which is all great, but it's more complicated than it sounds. Because the thing is, they don't actually extract data or hold it themselves. They're kind of like a consortium of member organizations. And together they co-develop algorithms, services, methodologies....

Jennifer 06:49

So yeah, it's pretty technical. And also, the collaboration is pretty specific to what they're trying to create. So it's not exactly obvious what the public would have to say, and why they would need or want to be involved. So we asked Kim.

Kim 07:03

if you think about the health data space as a giant socio technical system, we're not just talking about organizing and sharing data. This is not just like a functional... "if we just had the right IT in place we could do this really well." We really wanted to think about all of the other things that have to go around that. So one of them is this kind of social and legal implications of data sharing. So one of them is simply: can we move data across provincial and territorial boundaries and share them? Another is: should we, even if we can?

Emily 07:34

Okay, right. So these questions are of public interest because we're talking about health data getting moved around and used in ways that an initial individual consent form may not have covered. So yeah, it's definitely a matter of public interest, especially now.

Kim 07:53

And then, of course, with the pandemic, there's been a lot of additional conversations around community involvement and needing to represent community values and bring communities in more directly to these conversations. If you're going to have a really good, highly functional data health data system, it's going to have to involve communities, people, patients in one way or another. It's also going to have to do things quite differently to support Indigenous data sovereignty, because that is a rights-based conversation at this point.

Jennifer 08:28

I can understand the argument as to why public consultation should happen. But that's a lot of ground to cover. And I suspect that most people wouldn't really know how to contribute to this sort of dialogue.

Emily 08:40

Yep. And this is usually the moment where we start to hear about patient partners or engage patients. But for Kim, that didn't seem like quite the right approach.

Kim 08:51

This isn't about involving a patient and doing a research project. We don't do research projects. But what we want to do is involve the public in discussions about health data collection and sharing and use. So we've established a Public Advisory Council, which is still kind of formulating and evolving ...

Jennifer 09:13

Okay, so actually, this part is fairly common. HDRN has a Public Advisory Council, which is made up of interested members of the public. Now, it was a little hard to pin down exactly what they do. But as Kim said, they're in the process of figuring it out.

Emily 09:28

It will be interesting to see what sorts of things they're eventually involved in. Ken mentioned that they're shifting the role of the council to become more of a governance group and not a working group.

Kim 09:38

So we don't expect these people, the people on this council, to be the ones that give us all the answers and do all the work related that we need to be have involvement from the public. But they can help us either, you know.. in some cases do things, in another cases direct us to needing to have a broader engagement or involvement somehow.

Emily 10:01

Kim gave an example of what that broader engagement might look like, describing one of their white papers.

Kim 10:07

…to work on a Health Data Social Licence White Paper. And what this really is about is not a definitive answer about what is acceptable, but looking to what the literature already tells us about public expectations, attitudes, desires, ambitions related to health data. And then taking that to a broader group of the public to ask: What do you think of these requirements? Do you have some additional requirements? What are the absolute minimum things we have to think about when we're talking about, again, collecting/sharing/using health data? So it is, again, the Public Advisory Council is a bit involved in that and helped us shape that. But it's reaching out to a broader group to get those whose ambitions requirements identified. So what we did is a review of the literature of all sorts of other focus groups, deliberations, surveys, and things that have been done with the public about expectations and desires around health data use. Then we categorized them into things around governance, things around sharing, that sort of thing. And I think we found something like 40 or 45 of them, and this group now has expanded that list to something like 85 essential ingredients. So there's lots of commonality and agreement, but there's also lots of places where people really… there isn't, obviously, just one voice and one view, and it's a complex space, there's not… you can't boil this down to having three rules.

Jennifer 11:39

Okay, so you can tell they're really focused on process and working things through slowly and iteratively, which is why the conversation turned to deliberation as one of their modes of engagement. The complexity of the issues and decisions that HDRN is grappling with calls for this kind of in depth and nuanced approach to involving the public.

Emily 11:59

Right, so let's not go off on too much of a tangent here… but maybe some further context is helpful. The health and health care data that Kim has been referring to so far, the kind collected by the various data centers, it's known as administrative health data. It's the data that's been de-identified so that any one data point can't be traced back to a person that reflects aggregate information. Like hospital admissions over a particular time period, or the number of treatments and tests for a particular condition, stuff like that.

Jennifer 12:34

And it's collected by government funded organizations like provincial health care systems, research institutes, universities, funded research projects. But of course, the health data space is rapidly changing in terms of where data can be collected. It's not just government funded organizations - think of tech companies with their apps and devices.

Kim 12:56

So there's so many more things that we call data now, so many more on different ways to collect data, so many things that could inform health that we haven't necessarily traditionally thought of as health care data. So it's… this is not just about the services you receive in the system. It might be your grocery shopping patterns, or your Fitbit monitoring information - all sorts of other things that could influence health and well-being as well.

Jennifer 13:22

Yeah, this might be where for, most people, their ears will perk up. There's a lot of concern right now about the privacy and use of that kind of personal data.

Kim 13:32

There's also been obviously enormous change in technical capabilities, computers and their ability to store data to process it, to do all sorts of additional new kinds of analysis, and so on. So this space that we're working in is complex, changing quickly and then made more complicated by things like Cambridge Analytica and high profile cases where people see that their data are being used in ways that they don't want, or they don't expect. And so we feel that the deliberation approach is really important, because that can get at areas where people disagree, and more importantly, areas where you really need to make values based or normative decisions about policy. There's not an empirical model we could create or information that we could collect that we can derive the right answer to something. This is really how we use data, how we collect data, how we share it, how we tell stories from data. Those are really fundamentally at some point about values, principles, ethics. I guess the thinking around this is that where you're in those spaces, you really need to have public involvement. Because it's not for politicians or people who happen to be in power to make all of the normative values-based decisions that we need to make around this.

Emily 14:55

Yeah, so these points are all compelling reasons why the public should be invited to get into these sorts of policymaking spaces. But I'm always kind of skeptical. Often there's talk of robust engagement. But in the end, it's just some kind of survey or maybe a discussion among volunteers that doesn't really go anywhere.

Jennifer 15:17

And for Kim engagement shouldn't be a hollow exercise that just looks good on paper but doesn't yield substance. So deliberation may be the approach that gets them closer to the guidance they're looking for. Plus, I think it seemed to be more in the spirit of democratic participation than typical patient engagement activities, including patient partnership.

Emily 15:38

Yep, we chatted a bit about different models of engagement, usually represented by a spectrum or a ladder, indicating different levels of patient or public contribution, and sometimes showing where decision-making power lives. For Kim, deliberation sits at the far end of the spectrum, where there's a high degree of participant empowerment.

Kim 15:59

And in my mind, when we're deliberating in the health data space, a deliberation is really about trying to be way at that right hand side of the spectrum or the top of the ladder. It's about saying: your advice, your policy opinions are going to actually feed into decisions about how we're going to run data systems. So it's not informing, for sure, it's not consulting. Okay. So then the next question is, what does that mean? Who's involved? What's the deliberation?

Jennifer 16:30

Yes, good questions!

Kim 16:32

Deliberation is a very particular kind of model of engagement. The way we have done these is that you actually convene people over four days. So it's two different weekends, two days, two weekends apart. So you spend quite a lot of time with a group of people, it's usually 25 to 30 people. And you tried to get as diverse a group in the room as possible. And with the intent that this is very much participant-driven. At the end of it, we want policy advice from this group, but it's in their language. So the facilitation is quite different from facilitation of other kinds of things. You're not trying to drive people to consensus, what we were really trying to do is get as wide a set of opinions on the table as possible. And then you have large group discussions that tried to say, we're a diverse group with varied opinions, values, attitudes, beliefs. We are not ever going to be anything other than that, especially in a country like Canada. We're not going to come to agreement on lots of things. But we do want to find ways of living together. So given that we have this diversity, what are the rules of data use, that would allow us to live together comfortably? And that's the kind of policy advice you try to draw out.

Emily 17:52

I bet the discussions were fascinating.

Jennifer 17:55

Yeah, but I also bet it was a bit messy. I mean, even for straightforward meetings it's hard to take accurate and complete notes. So for this sort of deep dialogue that goes on for days, how do they record it and synthesize it and make meaning from it? And who's actually listening?

Emily 18:14

Yeah, these are questions I have with pretty much all engagement activities. In this case, their deliberations are meant to inform policy. And Kim said that she wouldn't undertake something like this without an actual policy person involved. She used the term policy receptor, someone who's actually interested in the output of the deliberations.

Kim 18:36

…. the experience that I have you do a deliberation when you have a policy receptor. So it is when you very explicitly have somebody who's interested in hearing the results of the deliberation you're going to do with the public. And that's partly because you do want to have influence on policy. But it also reflects respect for the people's time that they're going to be putting into the whole process and wanting to be able to assure them that it is time well spent, not just as an academic exercise. They're not just, you know, for the fun of meeting a really interesting group of people who might not meet otherwise. But really to try to inform policies. So then we develop the questions with our policy receptors as much as possible so that we're addressing things that are actually of concern to them, or interest to them at the time. And then we also invite them to participate and observe the deliberation itself.

Jennifer 19:31

Yeah, that's pretty cool. Kim said for the sessions they ran, the policy receptors were there for the entire time. I imagine it was useful to hear the discussions firsthand.

Kim 19:41

I think one of the things I consistently hear back is how impressed they are with the depth, the level and just the kind of conversation that actually happens in that space, things that we're able to do in those four days.

Jennifer 19:59

…and speaking of conversations, we asked what the group actually talked about.

Kim 20:03

The kinds of questions we were talking about are things like: is it okay to combine multiple, multiple different sets of data? And when do we start getting worried about the ability to call those de-identified or non-personal data? So we're talking about cases where researchers might be linking data from 14 different data providers, which they are de-identified. They don't have names on them, they don't even have full birthdays, they certainly don't have, you know, highly detailed geographic information. But when you link so many different things together, pretty clearly you're getting a high dimensional view of somebody. And so there are concerns and there are, in our deliberations, we were concerned specifically from people in smaller areas and rural communities where that kind of mosaic effect might be far more identifiable than in an urban area. So that's one question. Another question might be, what about linking private sector and public sector data? How do we feel about that? What about commercial entities having access to your data from healthcare systems? So they are up the chain kinds of questions, but they have very practical kind of things that information and policies that go with them. And what comes out of the deliberation is a set of policy recommendations. Like the public had a lot to say about the kinds of governance that they would be comfortable with. Like, don't put all the data in one location because that creates a target for attacks and feels less secure than it might be if data were kept separate until they were needed to put together for a research project. Make sure you understand who the researchers are, what their intent are. Have a trusted third party involved. There was a lot of… a fair bit of reticence about leaving everything to government, for example. So it's those kinds of recommendations that you could actually then pick up and put into policy.

Jennifer 22:04

That's a lot. It would need a highly skilled facilitator to guide the group without inadvertently directing the discussion in a particular way.

Emily 22:13

Yeah. And they'd have to not take comments only at face value, and perhaps push the group to dig deeper.

Jennifer 22:21

I think patience is key. And active listening. It's really a very different approach to what we're used to.

Kim 22:29

Deliberation isn't the only answer. It is, I think, an important source of getting a conversation among people. So this is really not about asking for a bunch of individuals, opinions, and then putting it together and making a conclusion. It's really, really fundamentally about getting those diverse individuals to talk to each other, to hear different perspectives, perhaps to change their minds in some ways, but really much more to accommodate how those different perspectives can be fit together into a policy that will be acceptable to everybody, or at least to most people. The other important thing is that we always work to find where the agreement starts to disperse. People will say things like: we want data to be used for research - and you can get people to vote on that. And everybody genuinely says yes. I mean, that's like a fundamental thing we see in the literature, people want their data to be used. But it's always, always, always context specific. As long as these protections are in place, as long as these other things are happening. And then you can push forward. And you get to the point in talking about private sector access to data, and you can see that the agreement starts to fall apart. So the other thing we provide back to policymakers is the vote. Not because we're trying to take qualitative information and make it quantitative, but it's important for policymakers to see where there's a large agreement and where that starts to fall apart. And then we always provide rationale, as well. So we ask people when they vote that they have reasons behind the voting, and the reasons become part of the conversation to help move things forward.

Emily 24:06

Okay, so we have a sense of deliberation as an activity. But wow. I mean, it raises all kinds of interesting questions. Kind of the same ones that affect patient engagement as we usually know it, but this is on a whole other scale.

Jennifer 24:24

Yeah, and in fact the idea of scale has so many dimensions. I mean, in this case, we're talking about a pan-Canadian initiative that potentially impacts everyone who lives here. So as soon as you get a bunch of people in a room, no matter how they've been selected or recruited, I think there will always be gaps in representation.

Emily 24:44

And there will be critique about whether certain people are maybe too knowledgeable are familiar. And so are they the right people to be deliberating? I mean, how do you even begin to sort these things out?

Jennifer 24:56

Well, on the matter of people becoming too knowledgeable – it'ss that age old question of whether people have a lay perspective or are considered experts. And it's definitely a concern that Kim shares. And you know, even if you assemble people who aren't experts, well, they may not stay that way. The deliberation process is a bit like a jury process and a trial. The longer it goes on, the more the participants learn, the more expert they themselves become. So in a way, the deliberation process turns people into experts.

Emily 25:29

Okay, well, let's go back to your point about representation for a minute. The topic has taken up a few of our episodes. And usually we're talking about the impossibility of perfect numeric representation. And so it's kind of a bad thing, or maybe a shortcoming. But Kim has another perspective.

Kim 25:47

So on representation, probably the most important thing I would say first is we are not interested in statistical representation of a population. So we would never - I would never - engage in a deliberation where we're trying to recreate the demography of Canada in the room. And part of the reason for that is, how would you ever do that? It's way too complex of a country for that. But the other reason is, if we're really interested in understanding diversity and addressing equity, you have to, in some sense, almost over-choose for people who will have views that are not on the average, that are different in one way or another.

Jennifer 26:30

Yeah, it's well established that from a health equity perspective, you might need to prioritize or amplify the views of certain groups or communities, which might also mean de-emphasizing group diversity, per se. And instead speak to community groups separately.

Kim 26:45

it might be you go to a community and have the community self-organize and have a deliberation amongst that group or a focus group or whatever it might be. Or you go to seniors homes, and you do see… you go to where people are, and bring voices in that way. It's always… I don't want to call it a trade-off necessarily, but it's a different consideration. So putting heterogeneous people in a room creates a different conversation and a useful conversation. Having community or population focused deliberations or conversations might be more homogeneous. It has its own advantages and brings its own fruitful nature as well. To me, this is part of the interesting complexity is that there is not ever going to be a single answer where we, you know, the right way to do engagement is to have this kind of group or that kind of group. I think it has to be an ongoing process.

Jennifer 27:45

You know, we could really hear it in this conversation just how complex it all is, to think about engagement at the scale. Sure, there's the logistics, and tactics, and so on. But it's also complex conceptually. It just seems insufficient to use ideas from patient engagement and simply expand on them. Instead, it might be more appropriate to think about how we engage in democracy more broadly. And work it out from there.

Emily 28:11

Yeah, well, it's a question on Kim's mind for sure. And the question she raises really highlight the difference between patient engagement and public engagement at a pan Canadian level.

Kim 28:23

I'm just going to admit that this is part of why I hesitate so much with some of the language I'm using. Because I work very much in the health data space. But it is really difficult for me to separate this completely from basic conversations about what we want out of society, and what does democracy actually mean in practice? And just always this space that I think is kind of contained. But when you start talking about public engagement, it becomes this much, much bigger conversation about the relationship between people and governments and so on. So it's really hard to kind of keep your hands… I find it hard to keep your hands around the topic area, in a very interesting way. But it kind of involves all of these other things.

Jennifer 29:12

So obviously, Kim and her team are not the only ones thinking about these issues. Kim referred to other kinds of public advisories, like one in Paris.

Kim 29:21

I'm quite attracted by some of the more recent developments like in Paris, where they've set up a Citizens' Assembly to advise the city government to Paris. And they have given that Citizens' Assembly two kinds of power. One is that they can provide recommendations directly to the political layer, the actual municipal governor. So they're not working through staff, their recommendations go directly to politicians. They also have the authority to call for deeper public engagement. So if there's an issue that comes along, and instead of giving advice directly to governors, they can say, Look, you need to go and talk to the public more broadly. You need a survey or you need to more engagement. So that kind of dual role I find compelling - though I don't know that we know how effective these things are yet.

Jennifer 30:17

This was an interesting example. But let's save our comments on this until a bit later in the episode. It's less about deliberation exactly and more about the potential role of the public in governance more broadly.

Emily 30:30

Okay, so before we wrap that up, we wanted to ask a couple of lingering questions.

Jennifer 30:36

Yeah, one was kind of about representation, but also about this idea of replicability. Regardless of the tactics or the format of any proceedings, the people assembled in a deliberation are always going to represent a particular place and moment in time. Another group with different people, maybe even convened at the exact same time, would probably deliver different outcomes, no matter how consistent you tried to be.

Emily 31:02

So it raises some interesting and maybe confounding questions. If you know you're going to get a set of outcomes that's particular only to the group you've gathered, well, what do you do with that?

Kim 31:14

Should you do the same deliberation multiple times? And the question that always that comes back from the theorists around this is what would you do with that if you've got different answers? And you have to understand that when you're doing a deliberation, you've picked 30 people, there's a character to the conversation that goes in a particular direction. And of course, you're going to get at least slightly different… you're not going to get the exact same policy recommendations if you ran a deliberation twice. And I don't think we should apologize for that. That's reality.

Jennifer 31:46

Yeah, fair. Okay, so I had one more thought as well. You know, the term "wisdom of the crowd"? It's a theory that assumes large crowds are collectively smarter than individual experts. And I think the same is sometimes said about patients or people with lived experience that they collectively know better than experts. But the thing is, I don't actually think crowds are usually all that wise. We've seen crowds do and say terrible things. And popular views can easily land on the wrong side of history.

Emily 32:18

Yes, we mentioned this to Kim. She's also cautious, but thinks the crowd can be managed.

Kim 32:24

The wisdom of the crowd thing I would be careful about though, because think about if we had done a deliberation about equity, some aspect of equity, three years ago. And we did it again now. I'm guessing you would get a different answer. Because of the experience of the pandemic, because of some of the conversations that have happened since then. The crowd itself can change and the wisdom of the crowd itself can evolve over time. In fact, we hope that that's what… I mean, if we think about that arc of history and progress, and so on, that's what we hope is going to happen. So I think that part's fine. You do have to manage that a bit, in the sense that a deliberation is not then a recipe for action. It is an input into policy decisions.

Jennifer 33:17

So I guess one way to look at it is that the crowd gives a kind of temperature read of what the public thinks and wants, which is different, of course, from subject matter expertise. And Kim's clear on that distinction, and offered some insights on why she thinks it's important to have both.

Kim 33:33

If we have ongoing public involvement, it's about holding people to account for the way that we want our society and some of these public, big public decisions to be run. So on the question of expertise, again, this is something we talk about a lot in our research group, and very, very explicitly describe to participants in deliberations that we are not trying to make them into mini experts. It is not subject matter expertise that we're looking for. And in fact, if something could be settled with subject matter expertise, it's probably not a great

question for deliberation. Right? So you wouldn't take a question to the public about "should we use x technology or y technology" to pursue something because that clearly is a question that somebody with… someone who knows something about those technologies should be able to answer if we've got the right principles from the public about what it is we're trying to achieve. So is this a replacement for expertise? Absolutely not. If we're plugging the public involvement in to the values-based decisions that we make on a day to day basis about what to prioritize, and how to do things - so then that gets to the 'what is the expertise that the deliberation or other public participants bring?' And that is, frankly, that expertise of being a person in society, a community member with multiple identities, multiple engagements and involvements, and a whole history of being in those spaces and understanding your own experience. But hopefully having some empathy for other people's experiences, too.

Emily 35:24
Okay, so let's bring this full circle. We opened with some thoughts about the nature of engagement when we're not really talking about patients or communities, but rather, the public. And in this case, the whole public. In Canada anyway. That distinction is important, because we're now moving away from local or targeted issues affecting stakeholders, and instead talking about much broader ethical and value space questions that affects society, and how we might all agree to live together.

Jennifer 35:54
Sure, but I also don't think we can just leave it at that. Should we think of society as just a bunch of individuals living beside each other and making agreements? I mean, I guess that's one way to look at it. But if health equity is a priority, then we have to also account for the fact that not everyone experiences health and health care equally. And even well-intentioned efforts to serve the public often leaves certain groups and communities out in the cold or worse off. So yeah, we can talk about all the people in Canada. But I also don't think we can leave it to the wisdom of the crowd to determine how to best serve everyone.

Emily 36:32
No, that's right. And I think that's one of the things that Kim and others grapple with - the complexity of trying to capture and reflect the values of a population, while also trying to bring to light the conditions and experiences of particular communities from a health equity perspective.

Kim 36:49
We haven't generally thought about the use of large datasets as being something that needed to have patient or community involvement. Because what is the community, if I'm doing a study of the entire country or an entire province? It's not like I'm working with a defined geographic community or a defined population or community. So what does it mean to have community involvement in that? And I think that that has been to our detriment, because what we've missed in all of this is the ability for the public, and patients, to help inform what really matters, what things that should be priorities for research. It's impaired our ability to pick the outcomes that matter to people. And I think most importantly, it has led to stories being told about communities without their involvement, and it's been done in damaging ways.

Jennifer 37:56

Hi Emily

Emily 37:57

Hi Jen

Jennifer 37:59

Hey so we should be clear that even though we talked mostly about deliberation with Kim, it's not the only approach HDRN uses to engage and inform the public.

Emily 38:09

Right, this was just something we haven't talked about before as it hasn't crossed our paths much.

Jennifer 38:14

Yes but even after this conversation I feel I've gotten only a glimpse of something much larger and more varied. With Kim we talked about one kind of approach that was specific to HDRN's needs. But deliberation isn't just one thing. The term 'deliberative' is used in all kinds of ways.

Emily 38:31

Yep. There are more formal sorts of councils, like Citizen Juries which meet to deliberate on key decisions at city or state levels. There are also deliberative methods and approaches that kind of fall into more of a qualitative research category. And sometimes the word is just used to describe an in-depth discussion or dialogue. It can be sort of a catch-all term and each time you have to really look closely to see what they mean.

Jennifer 38:57

Well, it was interesting hearing about the experience at HDRN. I can see how it's a good way to uncover a diversity of ideas and views - not just to develop a list, but to reveal motives, rationales, beliefs - the reasoning behind peoples' desires and preferences.

Emily 39:14

Yep. But there were some aspects we didn't get to, like recruitment and selection. We decided not to go deep into logistics in the conversation, but I do find myself curious about how people were selected. And in the end, it's so interconnected with not only questions of representation, but also outcomes. Or maybe more specifically, the legitimacy of outcomes.

Jennifer 39:37

Hmm, yeah. So say more about what you mean by that?

Emily 39:41

Yeah, well, I think it's just it's easier to grasp something like voting. Majority rules. Or, say, 60% of the people preferred option X. When things are tangible in this way, it's clear how the process leads to the outcomes. They're likely to be just seen as more legitimate. Because deliberation is a more complex process and probably

quite opaque to anyone not involved, well, I do wonder how much confidence the general public would have in findings that have had to be interpreted, where the process doesn't map so directly to the results.

Jennifer 40:16

Yeah, I know what you mean. Kim said that they're not aiming for statistical representation, which is reasonable. But then how do you account for those whose voices aren't included? And regarding outcomes: well, I mean, you can leave a deliberation with a whole bunch of divergent views, and it will give a sense of people's interests and concerns. But it's only those particular people. There is full acknowledgement that outcomes aren't expected to be the same across groups. That's the nature of the method. And I agree with Kim, that there's no need to apologize for that. But yeah, all of these complexities raise questions about whether deliberative processes are any more or less on the far end of the spectrum than other kinds of group-based engagement activities.

Emily 41:04

Yeah, I'm not sure we're getting to power-sharing with deliberations. But I can see how the experience is more participant-directed, and therefore perhaps more empowering. They spend a lot of time turning things over and discussing the ins and outs, looking at all the perspectives and hearing each other out. Even though it's facilitated, and it's likely not everyone will be completely satisfied with how things turn out, I think people at least feel more in control of the messaging than, say, a typical co-design exercise. And I mean, again, it's the process itself and how people feel about it. That's a key aspect of these deliberations. It's not just the outcome or the final decision.

Jennifer 41:44

It's definitely a more sophisticated endeavour. Like you said, more in depth and lengthy. And I think the potential for deliberation to actually generate useful insights is much higher than some other forms of engagement. But you know, of course, this doesn't let it off the hook. Many of the same critiques apply, including some of our open questions about recruitment and selection.

Emily 42:06

Yeah. And we also have to remember that there's not a straight line between deliberation and policy decision making. It's a dotted line, along with all the other dotted lines. Like politics and economics, science and technology itself. People can want certain things but it may not even be possible.

Jennifer 42:25

Well, and one last thing on this point, Kim mentioned they're actually aiming to capture where agreement falls apart. And some of those things just aren't going to be irreconcilable. And ultimately, policymakers have to make decisions which will leave some people disappointed.

Emily 42:42

Yeah, it sounds a lot like life in general!

Jennifer 42:45

Yeah, I know. Anyway, can we return briefly to the Paris example? Can you just read out quickly how it's put together?

Emily 42:53

Yeah, okay. Okay, here it is: So the Assembly has 100 Parisians, minimum age is 16. For a one year term, renewable for six months. They randomly selected 5000 people from the electoral lists, which have about 1.3 million people. And those people were asked if they were interested. And then they had another random draw for the final 100. Okay… "members carry out a citizen watch to take the pulse of public opinion. They evaluate public policies, interview elected officials, agents and outside experts, issue proposals for wishes and deliberations on the priority subjects defined and submitted to the Council of Paris."

Jennifer 43:41

Yeah okay. So it seems like a group that might actually have some influence. They can order evaluations and seek public input where they think it's warranted. And I think for Kim, what's captured her interest is that it's a citizen group that persists beyond any particular issue or moment in time. The duration of membership in the group seems to be long enough maybe to build some cohesion, but short enough to hopefully represent current society.

Emily 44:07

Yet, it's an interesting model for sure. Even though this is more about the role of the public and governance more broadly, they do refer directly to making proposals for deliberations. So there's some crossover there. Anyway, Kim mentioned that it's not yet known how effective these models are. So something to keep an eye on.

Jennifer 44:29

I think, I mean, do we end all of our episodes saying that? I'm having a bit of deja vu? I mean, what do we mean by effective? And how do we know whether one approach is better or worse than another? No, I'm also still a bit stuck on the wisdom of the crowd. I also just don't know [fades]

Emily 44:47

Okay, let's close off there. Thanks to Kim McGrail of HDRN for participating in this episode. Don't forget to check the show notes for links and a transcript.

Jennifer 45:17

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. This series is supported by the Public Engagement in Health Policy Project, which promotes research, critical reflection and dialogue about engagement issues that have a health and health policy focus. Learn more about this Future of Canada project at engagementinhealthpolicy.ca