

## Transcript

Matters of Engagement podcast

Episode: "Critical Reflections on Public Engagement"

<https://mattersofengagement.com>

## SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Rhonda C. George, Joanna Massie, Genevieve Fuji Johnson, Alana Cattapan, Katherine (Katie) Boothe

### **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.

### **Jennifer** 00:16

It can be really valuable when people can come together to hear a range of ideas and presentations, see what work is being done and get a sense of where things are heading. Conferences are great for that.

### **Emily** 00:27

So we wanted to bring some conference vibes to the podcast, and share some recent presentations and conversations that take an unflinchingly critical look at public engagement.

### **Jennifer** 00:39

The discussions we're bringing forward in this episode are related to health policy. But we could see parallels across all areas of engagement in health care, including research and service improvement.

### **Emily** 00:50

We're going to share some of the ongoing work from team members of the Public Engagement In Health Policy Project, followed by a conversation we had with Katie Boothe and Alana Cattapan - we'll introduce them again later. They're academics deeply interested in both research about engagement, and also the work of engagement.

### **Jennifer** 01:12

You know, we should clarify something here. We describe many of our episodes as conversations. But the truth is, we do a lot of editing and rearranging. They're not actually true conversations.

### **Emily** 01:25

No, that's right. We have the advantage of being able to script and edit ourselves in every episode. And we have total control over how we sound. But this time, we're including pieces of our actual recorded discussion.

**Jennifer** 01:40

It's like those lunchtime conversations at a conference with people you really connect with. You get to think through the themes and hear how other people make connections. It's pretty cool.

**Emily** 01:51

So we really hope you enjoy listening in.

**Jennifer** 01:55

Okay, but first, we'll share the work of the panelists who gave presentations at a conference we attended back in September. It was organized by the Engagement In Health Policy Project at McMaster. The theme was reimagining public engagement in a changing world. We already shared the keynote from Jamila Michener in the last episode. The three presentations we're about to share are from researchers on that project team. And shout out to McMaster - thank you - for providing the audio.

**Emily** 02:24

Each segment is less than five minutes and so obviously doesn't cover their entire presentation. We'll put links in the show notes to everything in full. We'll briefly describe each project and the presenters will describe their findings or reflections.

**Jennifer** 02:39

First up, we will hear a short piece from a presentation by Alpha Abebe and Rhonda C. George titled “ ‘If we don't do it, who will'? An exploration of Black community agency in health policy and advocacy in Ontario”. Alpha is an Assistant Professor at McMaster University, and Rhonda is a PhD candidate at York University. You might recall our conversations with alpha and Rhonda in previous episodes, this presentation builds on that work. So if you haven't already listened to those episodes, we really recommend that you do. There's links in the show notes.

**Emily** 03:11

In this excerpt, Rhonda shares their critical reflections developed after many conversations with black leaders of black community organizations who discussed their experiences of health policy engagement...

**Jennifer** 03:22

...which included when and how they were engaging with policymakers, why they weren't if they weren't, and what those experiences looked like.

**Emily** 03:31

So here's Rhonda, sharing insights on the challenges and barriers of participating in formal engagement processes, as experienced by leaders of Black-led organizations.

**Rhonda** 03:44

So some of the challenges and barriers. So when these community members actually try to engage within, you know, formal engagement processes, there are some of the key things that occurred. So first, epistemic

invalidation. There's a way in which they would always be put in a position where they would have to prove that anti Black racism was indeed an urgent marginalizing factor and that these were pertinent issues that needed to be addressed.

**Rhonda 04:11**

And so there was a type of invalidation of their lived experience and the knowledge that they acquired about this issue and their expertise. And so many times when they would get into these spaces, they would have to start at Racism 101. This was also compounded by what we term I guess, "what about ism". And so when maybe they would win that argument, let's say, but then afterwards, it becomes "well, what about x community? What about y community?" And so that was a quite a challenge to get them to say, Hey, this is something very specific rooted in an intergenerational issue. And so we need to address this head on.

**Rhonda 04:49**

There was also chronic and inconsistent underfunding. And so even if they were able to acquire funds for the kinds of systemic changes that were needed. And because this is an intergenerational systemic problem that touches on, you know, many different many of the social determinants of health, rather, the funding they would get would be for six months, one year, one and a half years, two years. And so as soon as they start to kind of get a little momentum, the funding runs out. And then they need to go back to step one and make the case again, and then sometimes they don't get that funding. And so it just dies. Right? And so it's like that cyclical, never being able to get ahead.

**Rhonda 05:32**

There's also again, as I said earlier, the issue of capacity, but also having to reverse-engineer the social determinants of health and structural problems. So again, these issues around Black community and health are grounded and intersect with so many different things, whether it be socio economic status, whether it be education, whether it be no employment, precarity, there's so many intersecting factors. And so the kinds of work that they're expected to do, and so little time with transient ad hoc funding, they often did not have the capacity to do it. Because often they were doing this work off the side of the desk, sometimes in a volunteer capacity, they're not receiving salaries doing this type of work. And so this is in addition to, you know, their day job, whatever that may be, in addition to childcare, and whatever other challenges they may be facing in their life.

**Rhonda 06:28**

And then lastly, symbolic anti racism was something that came up a lot. Just to quickly define it: this is a policy approach that gestures towards, you know, progress, rather than actually doing the work of systemic change. And so often this was evidenced through, you know, tokenistic inclusion - one of our participants called it fluffy conversations. And often this, this approach was often quite unsafe, because it was almost the getting your hopes up, and then having them dashed, realizing that this is just, you know, a photo opp.

**Rhonda 07:01**

So what we recognized in this work so far, is that there's a tension existing within this space of the futility or the perceived futility of the work that they're doing. But then also juxtaposing that with hope. There's also this

question and this existential question, it's an age old question of, should we be trying to hold the system accountable? Or should we be self determining? Or in other words, have the freedom to do the work as we want to do it.

**Jennifer** 07:37

Next up is a presentation on deliberation as a method of citizen engagement.

**Emily** 07:41

We actually did an episode on deliberation not long ago,

**Jennifer** 07:44

We did! With Kim McGrail. But this project covers some different ground. Joanna Massie is a PhD student in political science at McMaster. Her presentation was called "Engaging deliberately: Exploring deliberation in two Canadian health systems".

**Emily** 07:56

And basically what she found was that the reasons for choosing deliberation as a way to engage the public were not only different in the two health systems, but neither were aligned with some of the commonly understood ideals of deliberation.

**Jennifer** 08:15

Right, so what are those ideals?

**Emily** 08:17

Well, that was part of Joanna's presentation. She describes the ideals and then looks at the gaps between theory and practice.

**Joanna** 08:29

The theory goes that deliberation is an opportunity for free and equal citizens justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, but with the aim of reaching conclusions that are binding in the present on all citizens, but open to challenges in the future.

**Joanna** 08:51

There's a couple of things I want to draw out here. Firstly, that there's an element of learning. That citizens have an opportunity to learn about, to consider and discuss, and to reach conclusions that they deem to be in the public interest. There's also this piece about reaching conclusions that are binding. It's usually used in a way to inform policy, although not exclusively, although generally it's about informing policy.

**Joanna** 09:23

There's also been a growing use of deliberation in the last 30 years or so, what the OECD has called deliberative wave. These processes in real terms look like participatory budgeting citizens, juries, deliberative polls, and

deliberative mini publics. It's particularly useful in complex systems where there are conflicting public values, high levels of controversy, a need to combine experts in real world knowledge and low trust in government.

**Joanna** 09:57

And it's for these reasons that I actually think it's particular good in healthcare. It focuses on informed decision making. There's an emphasis on equitable participation. And it's binding or in theory, it should be binding. Although there's a rich, descriptive literature about the methods and internal dynamics of these processes, there remains relatively little literature on why these processes are chosen in the policymaking system. So my research questions are why policymakers choose deliberation as a method of engagement. And to what extent do policymakers actually consider these values of deliberation when they're making decisions to use deliberation and policy process?

**Joanna** 10:48

So I use two cases. One in Nova Scotia and one in Algoma, Ontario. Both loosely use this definition of deliberation. One had community roundtable discussions and one had a citizen's [muffled] panel - a deliberative mini public by another name. So, in both cases, organizers articulated that their decision making processes were not actually directly related to the goals that we've in the literature understand deliberation to be.

**Joanna** 11:26

In Nova Scotia organizers developed a roundtable model based on the advice of their team to essentially mitigate the opportunities for disgruntled citizens to hijack the conversations, and to maximize the opportunity for productive conversation. They also wanted to redevelop this relationship with citizens that's been worn down as a result of regional policy changes. In Algoma, it was very much about this novelty about doing something different, engaging citizens who wouldn't normally participate, and to host activities that could be a unifying factor among the members of the health team.

**Joanna** 12:03

My point here is really just to highlight the we can talk about the theories of engagement or theories of deliberation, and the goals that we want to see. Actually, when it comes down to practice. It's not that those goals are not valuable. But ultimately, this gap between theory and reality is sometimes quite, quite large.

**Jennifer** 12:34

Our last presentation is by Genevieve Fuji Johnson, a professor at Simon Fraser. Her talk is titled "The Epistemic Injustices of Public Engagement: When nothing is done to meet the demands of Nothing about Us without Us!"

**Emily** 12:50

It's based on her collaboration with Kerry Porth, who is a sex worker rights activist, educator, and writer. Their work looks at the governance of sex work in Canadian and US cities. And in this talk, Dr. Johnson discusses how ongoing stigma has led to sex worker activists and organizations being left out of various forms of civic engagement, particularly in policy areas, which affect them directly.

**Jennifer 13:16**

Right. And the part we're sharing here is a theoretical framing of that exclusion, along with some lessons learned. Here's Dr. Johnson.

**Genevieve 13:28**

What I want to talk to you about today are forms of injustice that can play out in public engagement. And I want to call attention to these injustices. One is ontological. And another type of injustice is epistemic. So that researchers and practitioners of public engagement can minimize the risks of these transpiring, when members of the public come together to deliberate on matters of shared concern.

**Genevieve 14:02**

I think that those who are most likely to experience these forms of injustice are already marginalized, excluded and or oppressed. Ideally, forums of public engagement accord with principles of inclusion, equality, mutuality, and reason sharing, all toward reaching an agreement with which participants can basically agree. So that's the ideal, but because these forums take place within an unjust social context, they run the risk of not only replicating and justices but also of reinforcing them.

**Genevieve 14:49**

So the lessons that maybe we can think about in the context of today's discussions, I think are threefold. So forums of public engagement can be sites where injustices occur, especially against racialized, stigmatized, and or otherwise minoritized peoples. So peoples with, for example, precarious migration status, access to precarious housing, ability differences, neurodiversity, and so on.

**Genevieve 15:30**

The second lesson is that social ontologies matter in terms of how we treat people and how they are treated generally, but also more specifically in the context of public engagement and collective deliberation. So they matter in other words, in terms of realizing the normative principles central to the ideal of deliberative democracy.

**Genevieve 15:52**

Finally, the third lesson is that forms of epistemic injustice can be both obvious and not so obvious. And so this is really important. And I think it's the not so obvious that's worth dwelling on - particularly those who have the privilege of not experiencing the not so obvious forms of exclusion, marginalization, etc, etc. So, these epistemic injustice is can take the shape of outright exclusion from forms of public engagement, but they can also take the shape very sort of subtle discrediting or gaslighting of participants, dismissing their knowledge or ignoring them, while privileging are preferentially treating other participants who lack actually the relevant knowledge and relying on often debunked evidence or ideologically driven arguments. So lots of lessons to learn and build on as we continue to develop forms of public engagement.

**Jennifer 17:08**

It was such a pleasure to hear those talks in person, especially after hearing Dr. Michener's keynote. The conference overall had a strong critical through-line. And the talks were so varied.

**Emily** 17:20

Yep. And like all good conferences, there was so much to talk about. So we wanted to debrief afterwards and to hear more from researchers who think about and study public engagement. So we hosted a small group conversation...

**Jennifer** 17:36

a very small group...

**Emily** 17:37

And of course, we recorded it.

**Jennifer** 17:39

It was you and me. And Katie Boothe...

**Emily** 17:43

...conference organizer and previous guest...

**Jennifer** 17:46

and a new friend of the podcast, Alana Cattapan. Do you have her profile handy?

**Emily** 17:51

Yes, I do. So Alana is Canada Research Chair in the Politics of Reproduction, and an assistant professor in the Department of Political Science at the University of Waterloo. She studies gendered inclusion in policymaking, identifying links between the state, the commercialization of the body, and reproductive labor. And she also directs the Politics of Reproduction research group at the University of Waterloo.

**Jennifer** 18:22

Yep, great to have her with us. So yes, a small group. But mighty, we put together some of the more interesting moments so you could listen in.

**Emily** 18:31

And just to orient you to our voices, Alana speaks first:

**Alana** 18:36

"I'm an assistant professor in the Department of Political Science at the University of Waterloo and I hold the Canada Research...."

**Emily** 18:41

Then us. Then Katie joins in, talking about representativeness:

**Katie 18:46**

"...question of representativeness is sometimes a little uncomfortable, like, they don't want to be seen as representative..."

**Jennifer 18:57**

Here's Alana starting us off, outlining some of her key takeaways from the morning sessions.

**Alana 19:03**

I'm really interested in the division between what we think of as academic research about public engagement and the work of public engagement. And I think Dr. Michener did a really good job of talking about the work of public engagement. That is our responsibility as community engaged or social justice oriented scholars - not every social justice oriented Scholar does this kind of work, but many do - so I think that that was a really important thing. Listening to community, making sure the ideas come from community. On the live drawing that was there, the graphic art that was happening at the same time, I thought the most important thing I saw was that communities know what they need. And so thinking about community engagement, as led by community, inspired by community and responding to community need is what really resonated for me, I think. At least in the keynote, but also in the panel.

**Emily 19:58**

I'll pick up on kind of what you're saying there. One thing that... the term epistemic injustice came up a lot and these ideas about which sorts of knowledge are sort of real, or can be used. And a theme I thought was really interesting, or something that was relevant in each situation really felt like this idea of how do we... when is something legitimately able to be used as knowledge? And I'll particularly use the policy context here to then be translated into policy - and who decides that and which stage of the process does that happen?

**Jennifer 20:30**

I was saying to Emily earlier that the term "policy elites" was something I hadn't really thought of before as an expression. And so now I'm thinking of kind of public elites, or patient elites, and policy elites talking to each other. And that's kind of how it's been. And it's very, I think... this came up actually, that's kind of the easy thing. It's the simple way, it's like, everyone's available, they're all socialized to collaborate and talk to each other. And it all feels like it's this very engaged kind of process. And meanwhile, there are people literally dying, screaming for resources, putting out fires, you know, organizing at the grassroots level, who are just like, not at the table. And so, anyway, that's what's resonating for me, and all of these, you know, different communities that were discussed or represented this morning and thinking about the work that they're doing as an organized group, and how, not only is it policy elites getting in the way, but it's public elites who have been doing this kind of engagement, who then talk about, oh, we need to get, you know, a diverse group of people, that's going to fix it. And so it's the cherry picked people who kind of blend into those elite engagement spaces who are involved and invited.

**Alana 21:48**

Dr. Michener really raised that and talking about sort of be who becomes the idealized subject of the representative. But on the sort of flip side of that, I think about one of the communities that I've worked with who experience just a lot of marginality, homelessness and potential drug use, many have like recently had a baby, there's just a lot going on. And some of those people are involved in our work. But many can't be like. Just don't have the time, even if we gave them every resource we have, you know, if we paid support, which we tried to do, there's just not an interest in like... there are other pressing needs in people's lives. And so finding a balance in that, I think it's important because it has to be in some cases somebody who's a little further along, or somebody who has more capacity, who isn't somebody who is fighting every day, and was able to participate. Although sometimes we hear from people who say "I have to do this, because I am fighting for my life every day".

**Emily 22:46**

And that's something that's come up definitely in our discussions previously around this idea of representation, too, which is, you know, who is it, then, that represents a community? And is it better to have, you know, this, the advocacy model, where there was someone who clearly represented a group, and this is who spoke for them. And that's been very much - especially in the sort of patient-oriented research and collaborative model - sort of push against this idea of advocacy. And it was not supposed to be someone who belonged to something or had an agenda. But at the same time, then, you end up with people who don't actually have any responsibility to a group or sense of being connected to that group who are then coming and often being taken as representative. If there are people in a community or in a population that couldn't be at the table because of their own needs... but then the person who inevitably can fit that mold, but isn't technically represented about them becomes the voice?....It just becomes very tricky,

**Alana 23:46**

This is such a political science conversation, because the question is like, how representative is representative enough?

**Katie 23:51**

And that's a big thorny question. And one that in previous research that I've done with mostly patient advisors, the question of representativeness is sometimes a little uncomfortable, like they're, they don't want to be seen as representing a community and when, you know, because they don't feel authorized to be doing that representation. And so, like, I think there's a couple questions. First of all, what are the situations where individual lived experience is going to help meet the goals of the public engagement, have that particular element of public engagement? And when do you really need to hear community voice and have something that, you know, in some way represents a set of experiences or a collective experience? And then, so first you discern when these two things might be most important, and then you have to figure out how to achieve them.

**Katie 25:05**

And something that really stuck out for me from Dr. Michener's talk - and I think also Alpha and Rhonda mentioned it - is the necessity of long term relationships with community organizations. I think that's so important. It's one that has come up in other aspects of my job. Not the research part of my job, but the service

roles that I do in my department. Like, if you want to be involved in the community, it's not, it's not a one off thing. And it might not be clear at the beginning what the outcome is going to be, or you know, how the relationship is going to be, is going to evolve, or what the researcher academic "expert" is going to end up getting out of it. Right, it's probably more important that their contribution to the group be clear if the goal is to create relationships that will, you know, perhaps down the road, allow for that person to be trusted to hear a representative voice or carry that to other spheres.

**Alana 26:30**

So I'm of the view that I don't think that it's generally possible for a graduate student in a one or two year program to do meaningful community engage work, unless they're already part of that community, or unless a project exists for someone can bring them in. I think to put, you know, community organizations on that timeline is unreasonable. Although sometimes community engaged work moves so fast. But the opposite of academic work, but it's sort of opposite of what we're trying to do with grad students - which is teach them often, you know, how to build a research project, develop a question, develop all the methodologies that they want to do to carry forward in their life. That might not be what the community needs at that time, or whatever, whoever we're talking about - the people who are seeking out the research. But it's certainly possible within the Canadian funding model to do this in some ways with graduate students. And I'm thinking particularly of SSHRC partnership engage program, which is a one year funding project that involves one researcher in one community organization. And in those cases, the case where I've worked, that it was the community that came to me with a question. Like, we need research on this, can we go do this, let's go get money, we got the money, we did the thing. A grad student was involved pretty much from the beginning. But it didn't align with her timeline. And she did it as a research assistant on the side. So we could have done it, it would have been possible. It wasn't really possible in COVID. But it could have been possible. There are ways that this could happen. But it would have to be very ideal circumstances.

**Jennifer 27:58**

How did they... how did they know to find you have to ask to see if you were interested in their research question?

**Alana 28:03**

I'm walking around all the time, just I feel like with a sign on my back being like, "this woman will do whatever you need". So in that case, I had a student who had started an organization that serves people with HIV and AIDS and Saskatoon. She took one look at me and was like, let's do this. And so we did that with the research assistant at the home, helping us design this project who somebody who has just been working in HIV and AIDS stuff in Saskatoon for a long time. So that really came together but didn't even follow the timelines.

**Jennifer 28:35**

So it was just serendipity that you're interests and her needs kind of came together to at least formulate, like a discussion point, of whether you could do something.

**Alana 28:44**

Yeah, in that case, she just like, came up to me after class was like we will be working together,

**Jennifer 28:50**

I see.

**Alana 28:51**

But in other cases, you know, I've been brought into projects where community has approached another academic who might not know what... quite how to design a project or speak to policymakers. But my general policy with these things are that I will... I serve at the interest of the community. So I'm not typically consulting, it usually comes the other way. And they already have a question, or already have something in mind.

**Katie 29:16**

And if I can just jump in here. I think that that speaks to the kind of researcher that Alana is and that availability to the community is not necessarily the norm. And it's also not necessarily rewarded.

**Alana 29:37**

I'm in a very privileged position with my Chair now, especially, to be able to make these kinds of decisions that I don't think is true of a lot of people.

**Katie 29:44**

Yeah, I mean, just on the break, I was talking to another another researcher who does, you know, intensely community involved research. It's essential to the kind of research that they do. I'll quote them without identifying them. But they were told, you know, pre tenure, oh, you know, all this participatory research community engagement that you do is just the cherry on top, but like, do everything else. I mean, that person is a superstar in all aspects of their work. And so they did everything else, plus the so called cherry on top. But when Dr. Michener was talking about, like the texts at 8 pm, and, you know, are you going to the community meeting? Or are you going to go home and have dinner with your family tonight? I think it really emphasizes the fact that the type of work is not necessarily sustainable if there is not some sort of institutional support.

**Katie 31:03**

That means things like real actual recognition in the ways that matter for academics, which is recognition on par with peer reviewed research contributions. It means the amount of funding given and the timelines for funding. You know, how much longer do you need if you want to train community members to do the research with you, to conduct interviews, to help you facilitate focus groups. And so I think there is more talk in the university about recognizing the importance of community engagement and community engaged research. But it's not a rhetorical problem. It's a practical problem. And I think the practicalities of that... we've not yet seen enough change.

**Jennifer 32:18**

We had an interview with another researcher - Lori Ross - a few weeks ago, several episodes ago - she was expressing these exact frustrations with institutional constraints around doing community engaged research.

And I think she... not to put words in her mouth, maybe I'll just say it this way: I came away from several conversations feeling like frustrated academics wonder to themselves, "is this even a place where we can do the kind of work that we want to do?" So it makes me wonder... can you imagine an alternate universe where there is an entirely different structure set up for this kind of research for communities, where there's even like a clearinghouse where you match researchers with community and it's not in the academic institution.

**Alana 33:03**

But you could do it in the academic institution. Like where, as part of the work I'm currently doing, I keep having conversations about how can we create a list of available researchers in my field on reproduction for community? Like saying what our capacity is, do we have grad students right now, and what are the skills? Do they need us? What do they need us for? How can we create projects with them, and use grant money to do it. There's all kinds of ways we could be doing this so much better. And there are... like Indigenous scholars in particular have been leading the way and fighting for changes to tenure standards. To recognize the length of time it takes to do work, build relationships, go through research ethics, all of that - when you're engaged in community based projects, especially for Indigenous scholars, who are also getting research approval from communities that they're either a part of, or not part of.

**Alana 33:51**

And so there are fights that other people have been engaged in to make this happen so much better within the context of the university. And I was very fortunate to be at the University of Saskatchewan, where many of my Indigenous colleagues were doing that work. But you know, there's also significant constraints, I think about the Social Sciences and Humanities Research Council's requirements for collaborators, that you can't pay somebody who's a collaborator on your grant unless they're doing very specific work. So if they are somebody who is experiencing precarity, but is also bringing so much to your project, you can't recognize them in a formal way that they can put on their CV, that they can take forward and also pay them. It's troublesome.

**Emily 34:32**

...and Lori's... this discussion we had with Lori, very much the same problem. While she talked also, like the whole sort of premise of it was once you do then hire them on or start paying them, the connection to the institution itself and what that means and the layers of that what it means for the peers. It was just, she did a very reflective, interesting... where they where they have these sorts of discussions openly during then the process and kind of in the discussion we had with her the conclusions around it feeling like to do to meet the ideals of - it was peer led research in this case - was not possible within the institution. To meet the ideals that had been laid out for that research. And I think that's the other part that I often come up against is: it would be one thing if we wanted to sort of do good work and help and have these things. But when we set up ideals of like, equal power, and like sharing, and partnerships, and authenticity, and all of these words... I just really think it does set up people for harm, or at least being let down. Because by the structures that are there, we have to follow certain sets of rules, which then end up tokenizing to an extent, if the person has been promised partnership or empowerment. Or that we will be collaborating together in this co-design, when the whole structure actually doesn't work that way. And so I genuinely also think it's about having more realism in what we describe as actually going on.

**Alana 36:09**

You two are the clearinghouse. Like, I feel like you have all the knowledge about the concerns...

**Emily 36:14**

... we just talk to a lot of intelligent people, that's the good thing about our job [fades]....

**Jennifer 36:24**

And we did a great couple of episodes with Alpha and Rhonda. And that was really pivotal for me to hear more about, you know, from a.. it was still from an academic standpoint, but for them as Black researchers talking about issues of concern to Black communities broadly. It made me start to think about like these, again, the elite policymakers, elite researchers, elite public members - it all vibrates at a very different level than the community stuff: all the community efforts and initiatives and things like that. And it creates tension in me thinking about what do we care to talk about ongoing? You know what I mean? Because it's like this divide that... I mean, you guys must feel it in this kind of insurmountable way. But from where we sit, like you said, as the sort of clearinghouse or something, but we hear this this kaleidoscope of views... and part of me thinks, I wonder if some of this just needs to be burned down?

**Alana 37:26**

I think that there's injustice in funding research that never reaches anybody or makes a change in the world. And so how can we capture the funding on offer, the supports on offer, the resources of the university, the considerable resources and prestige of the university and repurpose it. I keep thinking in this conversation too, about the language of evidence based policymaking that's extremely prominent in the Canadian government. And like, of course, we should make decisions based on evidence, no one is suggesting otherwise. But that is always it seems - not always, often - two things at once. One is that there is sort of quantitative or qualitative evidence that comes through peer reviewed academic research, or from some other sort of seemingly like legitimated space - somewhere that is seen as like a respected research place - but also has to be accompanied by stories, right? Stories or narratives of people have to occur in tandem with that research in order to make evidence based policy change. And so I think of us facilitating, but getting both of those things across at once. Making them happen together, I guess, for policymakers? I don't know...

**Emily 38:36**

Can you clarify when you say we need stories? Because it's only makes it palatable for politicians? We've had this discussion before, like, you need to hear real people saying their story because it sells it or it legitimizes it or...

**Alana 38:53**

Both. Everybody is likely to be more engaged, moved, supportive of something when they hear somebody's real experience. I think we are, that's a part of humanity, that when you hear somebody's really experience it's more moving and memorable. But that is not always sufficient to make policy change, that you need the... stats are often... emerge often when my students are reading or writing op eds, or what have you. But other kinds of evidence, but supported through academic institutions or, you know, a think tank - that has to sort of sit alongside.

**Emily** 39:29

Sorry, no, I was gonna say I was just interested. Some of the stuff we looked at around representation... like what are we asking those stories to do is something that's kind of come up. Is it to move someone like a piece of art kind of does or is it to represent something? Or like a prototypical patient? So I'm sort of curious...

**Alana** 39:46

"Prototypical patient" such an interesting question too, because that comes up...

**Emily** 39:49

...the patient voice...

**Alana** 39:50

So often when I'm writing a report from research that might include narratives, might also include sort of research that I've done. I will often get the question whether I can provide with the executive summary, an example of someone's story that would be representative of everybody. And my answer to that is like, Absolutely not. Here's a link to a newspaper story of someone who has done a journalistic intervention.

**Jennifer** 40:17

Is there anything anybody feels like... concluding... did this feel like a good discussion? Would you like to say anything more to just get it out there?

**Alana** 40:25

It sort of felt cathartic. I have a lot of complaints, and also wonderful things to say about my experiences in community engaged research, which increasingly is a bigger and bigger part of my research agenda, because I find it to be the most rewarding and also the most pressing.

**Jennifer** 40:40

It's a nice forum, I suppose, to think out loud, and to talk to people who get the sphere that you're talking about. And it occurs to me to ask: do you not have forums where these conversations... where there's a critical look at the community engaged piece, and the researchers role in it? I mean, I assume there is but do you

**Katie** 41:01

Is there?! Invite me!

**Alana** 41:07

..... that's a community of people that I engage with about my work. But because each of our areas and communities is so specialized, you're trying to build your knowledge and capacity of your methodology, work with your community, also the specific area you're working in... so in my case, generally reproduction... all of those things. Can you get to more conferences? You know, can you have more workshops? So I'm very excited to be here today to be able to have these conversations, but it's not. It's like, just it's another area...

**Jennifer 41:35**

...it's more subject matter...

**Emily 41:36**

One thing I hear from a lot of researchers that I work with or consult with is that there's not a lot of space because you have to focus so much on selling what you're doing, because you're writing grants for it, or you're trying to support it, or you're trying to... so that critical element is certainly not... it's not almost feasible, to then also have the time to do that... like so much of the effort.... and I particularly hear this from patient oriented research, because they...

**Alana 42:01**

You're not going to get this in the social sciences. You said million dollar budgets. We don't have that. We don't get postdocs anymore.

**Emily 42:08**

But and if you are talking about it, you're certainly not talking about it and like, "why shouldn't we be doing this? Like, what is wrong with what we're doing here?" It's like, no, that doesn't usually I just mean...

**Alana 42:20**

There are definitely things wrong with what we're doing!

**Emily 42:22**

No, there are! I just mean, you don't... because so much of your time has to be spent applying for the grant or doing the things to promote it or supporting it. Having that as well, I'm assuming in the limited time... of human beings.

**Jennifer 42:35**

I think where we experienced this too is in this patient engagement sphere, where patients feel like they finally have a voice to bring into spaces and they're finally being invited in.... There's not a lot of critical reflection, they're just busy doing the work. And we sometimes get criticized... critiqued. We hear the rumbles of like, "well, what are those two complaining out?" They feel partly grateful for the opportunities of being heard and for having budgets for being paid sometimes to facilitate engaged patient-type things. So I wonder if there's a parallel to some extent, with social scientists, or even health researchers, who are feeling that there is at least some support or community building for this kind of work? And so maybe there's... I guess I'll ask: do you feel somewhat self censored? Or do you feel like you can't really complain out loud about it in any real way?

**Alana 43:41**

I don't know, I would complain about it to you. But there's not a lot of people - in our discipline at least - who are doing this kind of work. And so my complaints about... and also, if you have access to health research money, which I do, and which I think is funding this conference... that's a lot more money than.... I don't know, is it?

**Katie** 44:00

It's an internal grant.

**Alana** 44:04

There's not a lot of money in the social sciences and humanities. And so when you're complaining about your grant that you're on, that does have many postdocs, research administrators - it is not perhaps... I don't try this, but I imagine it wouldn't be well heard.... but my colleagues are fighting for \$50,000 grants in the social sciences and humanities. And so there are people with whom I think I have these conversations, certainly with my health colleagues, but maybe not my home.

**Katie** 44:30

The most helpful and generative opportunities I've ever had to talk about this stuff is with the research team that I work with here. We've been meeting pretty much every two weeks since the very beginning of the pandemic, and those like... aside from I'm very proud of the work that the team is producing... but a lot of the payoff for me has been going to these meetings and talking through these ideas with with researchers like Julia who have a distinguished career doing this. With, you know, people who are closer to my stage and newer to the space and then with a just absolutely brilliant set of students, both graduate and undergraduate. And that has given me so many new ideas about the kind of work that I want to do and new ideas about the questions I want to ask that, yeah, I wish everybody had a team like this.

**Alana** 45:39

Thinking about this idea of complaint too, and, and like not talking about my colleagues in part because of money or because like, you know, I have like a lot of students... they might not have a lot of students because I can fund more with the health cash.... It's also a fundamental project of community engaged research disrupts the idea of university profs as knowledge holders, as the sort of prestigious, important people who have knowledge. And there are a lot of professors certainly - they're very invested in that, right? And having a prestigious role as a knowledge keeper of society. And to say, No, you hold one kind of knowledge that is often useless and sometimes good. But you need to talk to a whole lot of other people - I think could really contest how people feel about their role in the university. And so for me, you know, I, again, think of my role as redistributive, and I don't feel about it that way. But I think many people might. And that might really challenge their identity. They've probably think what I do is not legitimate forms of knowledge, because what they do is very legitimate.

**Emily** 46:06

We've come full circle to legitimacy, Katie!

**Alana** 46:44

We answered the first question, that's the theme! [fades]

**Emily** 46:53

Thanks to the team at the Public Engagement in Health Policy Project at McMaster, who put on the conference, provided the audio and allowed us to host and record our conversation. The voices you heard in this episode include Rhonda C George, Joanna Massie, Genevieve Fuji Johnson, Katie Boothe, and Alana Cattapan. Please check the show notes for links and for more information.

**Jennifer** 47:22

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