

Transcript

Matters of Engagement podcast

Episode: "Health Policy Series: "Flipping the script" on narratives about Black communities and engagement, with Alpha Abebe and Rhonda C. George"

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SPEAKERS

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Jennifer 00:02

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

Emily 00:12

And I'm Emily Nicholas Angl.

Emily 00:16

In this episode, we continue our Health Policy series with guests Alpha Abebe and Rhonda C. George. Alpha and Rhonda are members of the Public Engagement in Health Policy team based at McMaster University, which aims to strengthen health policymaking in Canada by providing a platform for interdisciplinary scholarship, education and leadership in public engagement. Their research foregrounds Black community experiences and insights related to health policy engagement.

Jennifer 00:46

We're featuring their work over two back-to-back episodes. This episode focuses on the engagement work of Black communities. Our guests want to "flip the script," shifting away from a deficit model of understanding Black community engagement. The follow up episode features Alpha and Rhonda's research on Black community engagement during COVID, and includes discussion on why they think it's valuable for Black researchers to be doing this kind of work. For transcripts and links, please check the show notes.

Jennifer 01:19

Hey, Emily! So what do you think, how about we just jump right in? Alpha and Rhonda can do some quick introductions, and we'll carry on from there.

Emily 01:28

Yep, let's do it! Let's meet our guests.

Alpha 01:31

My name is Alpha Abebe. I'm an Assistant Professor in the Faculty of Humanities at McMaster University, and also a researcher and part of the team on the Public Engagement in Health Policy Project.

Rhonda 01:44

Hello, my name is Rhonda C. George. I am a PhD candidate in Sociology at York University. And just broadly speaking, my research focuses on race and racialization within social institutions - so within educational systems, within sporting systems, but also in healthcare systems.

Jennifer 02:02

Both Alpha and Rhonda are part of the Public Engagement in Health Policy Project. To get things started, we asked about why they thought it was important to bring a Black community focus into the project. You'll hear Alpha first, followed by Rhonda.

Alpha 02:16

One of the things that became clear to me was that, particularly with the onset of COVID, where we saw very clearly how Black communities were disproportionately affected by the pandemic in all different respects... and so given that, and given the fact that we had a pretty good sense that Black communities were not very well represented in public engagement processes, it felt important to have a Black specific focus in our project.

Rhonda 02:45

How policy engagement happens in Black communities is very different than what is expected or how policy engagement is traditionally designed. And I don't think we're having enough conversations about why it's different and what that actually looks like, or why that actually is happening.

Emily 03:04

Drawing on interviews with leaders of Black-led organizations and initiatives, Alpha and Rhonda are examining the extent to which these efforts have engaged, or been engaged by, policymakers in that process.

Jennifer 03:17

Their goal is, in part to change the way we collectively look at engagement, particularly in Black communities.

Alpha 03:24

We are kind of flipping the script to some extent, and flipping the analysis to look from the bottom up. And so in looking at community-led engagement processes and advocacy efforts, I think it makes it more clear why it's more kind of broad-reaching and holistic look at different forms of engagement and different kinds of groups.

Emily 03:49

Based on conversations we've had in the past, I think it's commonly understood that Black communities are underrepresented in public engagement processes, particularly related to health research, health care and health policy.

Jennifer 04:01

Yep. And the mainstream instinct is to lean into ideas of diversity and inclusion, and often it's not terribly nuanced or differentiated. People who are identified as not white or not middle class, end up being kind of conceptually grouped together in one category, often labeled as "hard to reach" in mainstream engagement activities.

Emily 04:24

Do you want to just say a little bit more about what we mean by "mainstream"?

Jennifer 04:28

Oh, sure. Yeah, we do use that word a lot in this episode, and I guess it's a bit of a shorthand. Many organizational decision-making spaces are indeed predominantly occupied by people who identify as white. But that's not exactly what we're referring to. Mainstream here, the way we're using it refers more to the cultural perspective that seems to dominate these spaces, which is sometimes referred to as liberalism or maybe liberal multiculturalism. People are welcomed, and there's a friendly and open invitation to participate. But there's virtually no acknowledgement of historical or current oppression or disadvantage. It's essentially Canadian culture, which tends towards inclusion but without the messiness of history and context.

Emily 05:17

We asked about these notions of diversity and inclusion that use labels like "hard to reach". Here's Rhonda:

Rhonda 05:25

I personally am not a fan of grouping everybody together as vulnerable communities, marginalized communities... what's another one...? Visible minorities. Because I think people of African descent have a very distinct history. And within even within the African diaspora, we're thinking about people in Canada - we have people from the Caribbean, English speaking Caribbean, French, Spanish, Dutch speaking Caribbean, people from South America, people who are Black Canadians who have been here since the 1700s. We have people from the continent, East, West, North, South, Central, different languages, different religions. And so the Black community is so diverse in and of itself, that to group us with all these other communities that have different histories, different concerns, different experiences - it just doesn't make sense. But I also feel that, within the Canadian context, we're quite uncomfortable talking about race and talking about our historical context and our historical contributions to marginalizing some of these communities, that I think it's very Canadian to just lump everybody non-white together.

Jennifer 06:38

Rhonda is pointing out that, of course, Black communities have distinct and diverse needs. But as Alpha explains, in terms of advocacy, while Black communities don't tend to fare well when grouped with other communities, even if there is an overlap of needs.

Alpha 06:53

I think historically, we have the data that we need to understand that when initiatives and efforts and policy directives, resources have come together under the banner of marginalized, visible minorities, vulnerable

communities... Black people generally have historically been underserved within that grouping. Sometimes grossly underserved, and underrepresented in those efforts. So there's a track record there. We know this. You start to see the ugly legacy of anti-Black racism, rearing its head and creating barriers, even when Black communities are supposedly part of the target and these efforts. So we we've seen this before, right? I also don't want to discount the value of solidarity across experiences, identity groups. And I think, even in the conversations that we've been having, so far with our own project, some of these Black leaders, or many of them... I think all of them probably... spoke to the strategic value in aligning their efforts and advocacy efforts with the efforts of other groups who are experiencing these barriers. And they do that thoughtfully and with skill and savvy. And so there's room for that. And there's important... there's definitely a level of importance that should be afforded... and space that should be afforded... to that work.

Emily 08:20

So working together with other groups can have its place, especially when done strategically. But as Alpha points out, there can be a limit to how much solidarity can achieve. Especially when underlying needs of Black communities are not prioritized.

Alpha 08:36

Just let's be honest about our history. I think 1) we have to recognize that there has been a resistance to creating supports and spaces for Black communities specifically, and we need to unpack that resistance and understand why that makes us so uncomfortable as a first step. And 2) recognize that many times when we do do that kind of grouping, Black people are just not served. And that's why you see so many of these really great grassroots efforts that pop up within Black communities to support their own communities. Because these other equity focused initiatives or other kinds of initiatives are not serving their communities well. So it's great that we see those grassroots efforts, but we have to recognize that it's in response often to the gaps in the system.

Jennifer 09:32

The gaps that Alpha is talking about are felt in very real and tangible ways by people in Black communities. But the stories and the testimonials of that lived experience don't seem to easily translate directly into action. Rhonda shed some light on why collecting data is so important.

Rhonda 09:51

I can speak for myself as a researcher: you may know things instinctively, you may know things anecdotally, but it actually being documented, recorded? That data gap does exist. And so that does not give us a good foundation to sometimes do the work, ask the questions, think about policies, figure out where gaps are. And so I'm always questioning: we're always trying to act, but what data are we using to act upon? How are we making these decisions? Who are we speaking to? The people who are in the decision-making seats, do they have the capacity and the knowledge and the training? And do they have the data to even be informing their decision-making processes or their policies? And so I think taking stock is definitely a first step in getting some of this important work done, because there is a lot of work being done on the ground. But certain people know it and others don't.

Alpha 10:57

I think there is this tension between the need for more data and more research and also not using that data gap as an excuse not to respond to issues on the ground. And so I think part of it is also what, as Rhonda was alluding to, some communities... that information exists. But in what form and who's listening? And which forms of knowledge and data are validated and considered legitimate and which ones are not? Do we have to wait until "X Policy House" or X University" conducts a 10-year longitudinal study before we know that "Community X" needs a health center? Maybe not, right? And so I think it's this balance between continuing the fight to collect more data and get more of these important issues documented, but also not using it as an excuse for inaction. Especially in light of just the decades and decades of tireless work and advocacy, and research of different kinds that Black communities and other communities have led.

Emily 12:11

Yep. So this sounds very familiar. We know this is the case in other spheres, like when researching issues and mental health, disability, poverty, the list goes on... It seems there's always another study to commission, which often creates barriers to action. Rhonda connects this to questions of trust.

Rhonda 12:31

I think one of the biggest questions that we need to ask is: do we trust communities to know what they need? And to make those decisions for themselves? Right? Data is important. But if these communities are living these things, and speaking out about these things, and creating interventions in their own communities, why do we think that there's only one way to move forward - which is the top-down, policy engagement, that kind of thing? So I think at the root of that is we need to question what does it mean for these communities to not necessarily... Their own knowledge and their own ways of doing things or their own ways of knowing - why is it or how is it that we devalue that?

Alpha 13:17

The point that you raised or the example you raised about sickle cell ... [fades]

Jennifer 13:24

In this part of the conversation, I had referred to an interview we had with Biba Tinga. She's the President and Executive Director of the Sickle Cell Disease Association of Canada. Biba spoke about the lack of action and support for health issues that disproportionately impact Black communities - and sickle cell disease is one of them - and her need to not only advocate, but contend with resistance.

Alpha 13:46

...for us, Black-identified people doing this kind of work both within and outside of academia...that's not surprising in the least and it wouldn't be surprising to I would say everybody that we've spoken to so far in our project work. We see this day in and day out. We know that people... the body language... there's a discomfort, and sometimes apathy, which often points to a long history of racism. And people are not prepared to create space for issues that affect Black communities in particular. They're not prepared to, they don't feel comfortable with it, they find other language to guise their discomfort. Sometimes they're not even aware of the source of that discomfort. And I think the sickle cell example, which has come through in some of our work as well, is such

a poignant example, right? Because you see that it's not always about numbers, right? It's got some... there's something else there. That's the common denominator.

Jennifer 14:45

In a few of our interviews, there's been a lot of careful wording about how we talk about that "common denominator," which in many cases is code for racism.

Emily 14:55

I've noted this too. Particularly as Canadians, which Rhonda referred to earlier, we're more comfortable talking about lack of services or lack of funding, lack of access - but we rarely get down to the race-related systemic causes.

Jennifer 15:11

So here, I was curious to know how this careful language is addressed within Black communities. How was racism named and discussed, when it's so rarely talked about out loud in mainstream engagement spaces.

Alpha 15:24

But to your point about how Black communities are describing this? I would say that Black community leaders are very clear and articulate about these experiences and very certainly - within intra community conversations - very clear about naming the issues for what they are: racism, structural racism, whatever they that might be. Sometimes there's a level of... there's a dance that you have to play when you're outside of the community, and advocating for and drawing attention to these issues. Many of us have a long history of trying to ring the alarm bells around these issues, and very quickly being shut out being labeled the angry Black person, being met with resistance, and people who are not prepared to acknowledge issues for what they are. A lot of gaslighting. And so sometimes you have to couch it in other language to be able to just have a conversation about those barriers. I think we're at an interesting place. You know, as a society, post-George Floyd, where that space to have more explicit conversations about anti Black racism is expanding. It's an interesting time to be asking these questions and thinking about these questions, because I think people are, for better or for worse, whether they want to or not, are a little bit more primed for these conversations. But I would certainly say from the perspective of Black communities, this is old news in a lot of respects.

Jennifer 16:58

Alpha mentioned George Floyd. Actually, she said, "post-George Floyd", and she's referring to the past two years or so where it seems that there has been more room to have explicit conversations about anti Black racism. We just want to take a minute here to remind everyone who George Floyd is. George Floyd was a Black man and was murdered by a white police officer during an arrest in Minneapolis Minnesota about two years ago. The assault of Mr. Floyd and his death were recorded on video and posted online and became a flashpoint for protest and outrage.

Emily 17:32

It was one of several cases that got the public's attention, to acknowledge what Black communities have been experiencing and reporting all along about anti-Black racism in policing.

Jennifer 17:43

Right. Old news for Black communities, and a moment of reckoning for others. And even as there does seem to be some openings for more dialogue, Rhonda reminds us to look deeper, beyond symbolic gestures.

Rhonda 17:56

In the North American context in particular, we're very obsessed with symbols of progress, right? Or like symbolic anti racism. Like "look at how great we are, we're talking to the Black people," right? But we don't actually do anything substantive, measurable, in order to facilitate change. And so I'm just thinking about how deeply entrenched that anti Blackness is, that it is normal to do that dance, it is normal to have to align yourself and make those compromises. And are we thinking about or even questioning the psychological cost and the extra labor that goes into having to use these strategies just to be heard? Or to be counted or to be seen as equal to somebody else, or equally deserving to.... just good care, good health care.

Jennifer 18:49

Now, this makes me wonder if one of those symbols of progress is the heightened interest now in pushing for diversity and engagement practices. We've talked about this in other episodes, that focusing on diversity can be seen as sufficient and perhaps can be used as a way to excuse inaction. Rhonda doesn't speculate about intentions, but certainly sees how things play out.

Rhonda 19:11

And I mean, you can't necessarily judge people's intentions. But I do have some experience in the research realm of engaging in some of these partnerships. And often, again, if we don't deal with the root of the problem, which is anti-Blackness, then that also means that we're not dealing with the power dynamics that are present. And so what often happens is you get invited in for a partnership, but you don't really have any power. You don't really have any decision-making power. And so often, you're brought in to tick a box to be like "See, we're not racist, we're nice, right?" But you in that project don't actually have any room to do what you do, or to share what you know, or to ask different questions. Usually the research or the work is already set out for you. And they just want you to fit into what is already being done. And so my experience has been that true co-design and true partnership and true power-sharing does not actually happen. And so it becomes, again, another dance of like, "how do I reduce harm to myself and the community I'm trying to serve", rather than "this could be a great opportunity to move things forward". In many ways, some of these partnerships, they're doomed to fail from the beginning, because from their inception, they're designed by people who don't have the lived experience and didn't consult those who do have it.

Emily 20:49

We do often touch on the theme of how mainstream engagement activities aim for improved diversity. But there's a bit of an unresolved tension here. We say that more diversity means better representation. But at the same time, we insist people are only representing themselves and don't speak for others. It's hard to reconcile. Alpha points out that these tensions also show up differently, divided along racial lines.

Alpha 21:17

There are particular groups of people, primarily racialized groups, who are expected to, for better or worse... or who are seen as representatives of their community... in ways that non racialized people [are], right? If you're a white person, you're a white person. You're not a representative of the white community, because what the heck does that even mean, right. But if you are a Black person at the table, regardless of whether or not you're connected to a larger network, you are seen, you are expected to be able to, speak for and respond to wider community needs and interests. So I think at a high level, that's definitely something that resonates and we hear about. And then coming back to some of Emily's points earlier about whether or not there is a level of harm that even with good intentions might be perpetuated? I think, absolutely. Many Black people generally, but particularly Black advocates, leaders, community workers, are extremely tired. They are doing critical work, filling the gaps of failed systems, often on shoestring or no budgets. Dealing with also their own life challenges and living in Black bodies in a world that's not kind to Black people. And so when they are engaged or tapped for these kind of engagement processes, many of the people that we spoke to talked about the fact that they looked upon these engagement processes with a lot of suspicion, which is informed by past experience. They find these spaces often to be quite draining, and sometimes toxic, sometimes racist spaces, where they often don't have a lot of power and voice and influence. But many of them spoke to the fact that they felt that they still had to say yes. We had one respondent who said, "If not me, then who? Someone's going to have to be there." For me, that's very harmful, right? That you're not only creating these systems that are not effective, but you're pulling people away from the work that is actually effective and advocacy efforts that are actually moving the needle for them.

Jennifer 23:26

This is an example of how mainstream engagement can actually cause harm. It can drain resources from communities when their attention is better served elsewhere. And harm is also caused in this whole deficit framing as well. For example, when we talk about people being hard to reach, we locate the blame or problem within the community. Alpha wants to change the narrative.

Alpha 23:47

On that point, I think something that I want to make sure comes out in our conversation is the whole framing of our project. And the reason why, for us, it was important to start from looking at communities who were already on the ground working, responding to these issues, and engaging policymakers through various efforts is to really challenge this sort of deficit framing and model with which we often look at Black communities. And where we often see... I think we've come to a place in many of these conversations where we recognize that, "hey, there's a gap here in representation, we need to be engaging Black communities more. Black representation is not there, we need to be doing that." But sometimes even in framing it as a gap, we sort of feed into this rhetoric and discourse that suggests that the community is actually... the problem is the community, that Black people continue [to] sort of embody the sort of social problem which we see mirrored in so many different domains in society.

Emily 24:49

This is the "flipping the script" that Alpha mentioned right off the top. Black communities are engaging, just not in the way mainstream culture has defined or made space for.

Alpha 24:59

For us, it was important to show that Black community leaders, many of them, are... they're not sitting around waiting to be invited to a panel on health issues. They're out there, literally doing the work. And often what they're doing is they're doing the work, they are making their voices heard, they're finding ways to intervene in really impactful ways and shifting policies in impactful ways. And still attending these formal processes because they are playing the long game, right? And understand that it's still important to be at those tables, and hope that eventually things will get better and are trying to sort of do it all. That's important, I think, to this conversation and to our understanding of these issues. So to really recognize that yes, there are these gaps in these challenges. But it's not reflective of apathy at the community level, and that these communities often have a very acute understanding of how change happens and where change doesn't happen, and are making calculations about where to participate with a broader kind of agenda in mind.

Emily 26:14

I suspect that part of the problem is that when we think about doing engagement, we're only looking in one direction - top down, or from the inside looking out. Alpha has a challenge for people working in this space.

Alpha 26:30

I would really love to challenge the community of practitioners and scholars and thinkers who are looking at patient and public engagement, to look at their definitions of engagement more closely. And to shift their gaze and look at what's happening in the... again, sort of activism advocacy space... that might look like community level agitation, protest.... these things that we label in these ways and put them in a particular box and sometimes look down on those efforts, or look at them with suspicion. And most often don't afford them the sort of legitimacy that we would other formal processes of engagement. Nicer processes, cleaner processes, more institutionalized processes. But when you actually look at the genealogy of social change, policy change in different domains, including the health policy domain, particularly as it relates to marginalized racialized and Black communities in particular - the big needles, when they've been moved, have often been as a result of this sort of agitation, advocacy, activism, right from the outset. And so for me, we're missing the action to some to some extent, right? Like, we need to understand that this is a form of engagement, of community-led policy engagement. It's not always comfortable. It's often not on the agenda and not convenient. But it's grounded. It's responsive to community needs and realities. And it's community-led. And, and so I think we need to take that work seriously. The conversation, if it's going to continue to circle around how do we tweak this existing model? I think we've missed the boat, and will continue to miss the boat.

Alpha 28:24

And so I think a lot of it is thinking about and understanding and creating space for the ways in which communities are already doing this work. And how do we listen, when they do make their voices heard? Like we have some of the people that we were speaking to who said - because we asked in our in our interviews - we said, "Okay, we have these people who are interested from a technical perspective in refining these public, these formal processes of public engagement. What recommendations do you have?" And a good number of them responded to say, "We don't really have many recommendations for you. Our recommendations are that when we come, just listen. When we come to you, have a listening ear." And so "don't call us we'll call you" is a

sort of refrain that we've heard from many of our respondents. And I think that speaks to the fact that they have found other ways to engage. But they're often... they have to do that with such resistance. And so I think starting to remove some of those barriers and that resistance would go a long way in shifting just these dynamics.

Alpha 29:26

We heard a lot of fatigue from people who are saying like, "Listen, at this point, especially sort of post-George Floyd - if you're bringing us to the table and we have to start with Racism 101, we're not interested."

Jennifer 29:40

We did an episode not long ago featuring Nav Persaud. He's the Canada Research Chair in Health Justice and a physician at St. Michael's Hospital in Toronto. He was strongly critiquing diversity as a tactic when it's used as some kind of equity intervention. And he was also critiquing engagement in general. And that also happened to be the episode where we were asked by our funder at the time to include a patient partner reflection. So we did.

Emily 30:06

Yep. And as it turns out, the patient partner didn't agree with Nav at all. And as a non-white person herself, thought that diversity was something quite important.

Jennifer 30:16

Well, it certainly made for an interesting episode. We asked if they had listened to it, and what they thought.

Alpha 30:23

I actually liked that... the way that episode sort of played out, because I think it highlights, it highlights that tension, right? And it shows the limits of representation. And it shows that that person - or any person - should not necessarily have the respons[ibility]... like, they don't have the responsibility to necessarily carry the.... they were not an elected official of racialized communities, right? They have their own experience, right? Their own politics, their own personal politic, their own ideological kind of worldview, and their own set of interests, right? And so to expect as an individual that they, especially divorced of any other larger kind of network, should necessarily align themselves with a broader agenda? I think it's a lot to ask. And it shows the limits of these processes of engagement. So I think that it's good that there was that tension, that kind of came to the surface. And absolutely, it's something that surfaced... even I mean, certainly I hear it across... it's very much an alive conversation and surfaced even in the conversations that we've been having within this project. And we've had some really interesting conversations about what happens to people as they become, as you said, sort of socialized and institutionalized. Also the self-selecting process, right? Like who gets invited and re invited to these tables because of how well they play the game, if you want to call it that? Or how well they just fit into the institutional agenda and change process.

Alpha 31:56

I think one of the more interesting conversations that we have we've been having within our project is sort of - again, going back to the savvy of these communities, recognizing that we need all of these things that we need

people inside institutions who understand those systems and are working within those systems, and are internal advocates. And I think that that patient representative was talking about the small incremental changes and the importance of those... and I think she's right. Those changes are important. But we also need the people on the outside who are pushing the envelope, who are holding people accountable, and that sometimes... definitely within communities, those tensions arise. You have charges of being a sellout or just tensions around around that agenda. So it does come up. But I think in really important moments and opportunities, you see people aligning and coming together for a common cause, understanding that there are those shared interests there.

Emily 33:00

Alpha's highlighting the importance of having both insiders and outsiders working toward change in different ways. Rhonda had additional observations that patients can come into engagement spaces with potentially competing interests and identities.

Rhonda 33:14

I've seen this in data sets before - patients have competing interests. So while they may see that there are racial dynamics, or racial power dynamics, in their care or what is happening, they also are facing life and death situations. And so sometimes, from what I've seen in the research is they often have to choose. They have to choose to go along with whatever the narrative is, because they're made to feel that this is the only way that they can live or get treatment. There's also the fear of upsetting or offending the clinicians and the medical team that is working with you. It's like, "if I say what I really think about how this is going, is that going to affect my care?" And so when we're thinking about patient engagement, a patient may not understand the research process, they may not feel that it's as confidential as they're saying it is. And so in many ways... I'm not saying that they're not telling the truth... I'm just saying there are competing interests there and there are fears there that may alter or shape how much they say about the racial dynamics that are present in their care.

Jennifer 34:42

Hey, Emily,

Emily 34:43

Hey, Jen.

Jennifer 34:45

Well, we covered a lot of ground with Alpha and Rhonda and have decided to pause here, but we'll carry on in the next episode.

Emily 34:51

Yep. Great! How about we go over some of what we just heard before wrapping up?

Jennifer 34:57

Yeah, okay. Good idea. So I'll start. So... irrefutably there are significant health and health care gaps for Black communities. And mainstream healthcare kind of knows this. And its main response is to, I guess, on occasion, talk about diversity and inclusion. Maybe even reach out to Black communities and ask members or leaders to

participate in... I don't know... discussions, roundtables, whatever's going on at the moment. Alpha called them formalized processes. Awareness of those gaps, the health and health care gaps, they're higher now, as is scrutiny and visibility of how mainstream healthcare responds to that awareness. I imagine that invitations to Black community leaders to participate in certain conversations, well, they've increased as a result.

Emily 35:48

Right. And in the meantime, Black communities have been fighting their own fires. Based on a very long history of broken commitments and neglect, they're rightfully leery of formalized processes, but feel that they can't say no to participation. So they're exhausted. Doing the work to patch up the broken system while also performing the role that mainstream healthcare has assigned to them. Dancing the dance, as Alpha mentioned.

Jennifer 36:15

So at the heart of all of this is racism. Systemic and individual, both overt and hidden just below the surface, couched in Canadian politeness and liberalism. Both Alpha and Rhonda talked about the limits of our usual engagement processes. People who are individually recruited may in fact not be connected with a larger network that speaks for wider community needs and interests. Now, this is certainly the baseline assumption that the engagement enterprise strives for.... but it's actually not an assumption always afforded to people from racialized communities.

Emily 36:51

Especially in a health or healthcare context, individuals may feel that they have to pick which of their many lived experiences to foreground. Is it their experiences as a patient? In this case, as a member of a Black community? As someone with a particular language or cultural background? It's not only about thinking "what am I actually here for?" but also recognizing that there are potential risks and serious repercussions when foregrounding one identity over another.

Jennifer 37:23

We see a lot of well-intentioned efforts in mainstream spaces to contend with or respond to all of the things we just discussed. And there's actually a rather simple answer, which is not doing more engagement! As Alpha and Rhonda's research has illustrated, Black community leaders know what needs to be done, what data needs to be collected, where efforts should be directed. What they need is funding and resources - not yet more dialogue and studies they didn't ask for.

Emily 37:57

Okay, so that's a good place to pause. We'll pick up this conversation again in the next episode, where we carry on with Alpha and Rhonda about Black communities' response to COVID, and why they think it's valuable for Black researchers to be doing this kind of work.

Jennifer 38:14

Here's Rhonda with some final thoughts:

Rhonda 38:16

Black communities want to be and should be defining their own issues and their own needs. It shouldn't be other people coming in and telling them what they should need or how they should do things. Everybody has a finite amount of time and resources and we cannot put so much energy into just being whole people. But also having to educate and teach and find money for this and work on this off the side of my desk and do this and do that. We need to grapple with our inability to legitimize the knowledge and the skills and the values that Black communities are bringing to the table.

Emily 39:06

Big thanks to Alpha Abebe and Rhonda C. George of the Public Engagement in Health Policy Project, for participating in this episode.

Jennifer 39:20

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

Jennifer 39:34

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