

Transcript

Matters of Engagement podcast

Episode: "Health Policy Series: Black Communities, Medical Mistrust and COVID Response, with Alpha Abebe and Rhonda C. George"

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SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Alpha Abebe, Rhonda C. George

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 00:17

As promised, we're bringing you the rest of our discussion with Alpha Abebe and Rhonda C. George. Alpha is an Assistant Professor in the Faculty of Humanities at McMaster University, and Rhonda is a PhD candidate in Sociology at York University. They're both researchers with the Public Engagement in Health Policy Project.

Emily 00:36

So in the last episode, we explored some of the themes and issues that emerged from their interviews with leaders of Black-led organizations and initiatives about how Black communities participate - or don't participate - in formal processes of health policy engagement. In this episode, we're featuring the part of our discussion that focused on how Black communities responded to COVID, and public health response.

Jennifer 01:01

Yes, it turned out to be one of the focal points of their research, and I don't think they were really expecting that to be the case. Alpha brought us up to speed on how their interviews led them to bring engagement during COVID more to the foreground.

Alpha 01:16

We begin by asking people to tell us the longer narrative and history in terms of how they got into this work, and their engagement with Black communities and some of the advocacy work that they've been doing around health matters. And then we sort of, towards the tail end of our conversation, ask "How has COVID impacted any of this work, in any way?"

Jennifer 01:36

The research team is continuing to analyze their findings. But one thing that stood out right away is that Black communities were not in the least surprised at how things unfolded.

Alpha 01:45

[There was] a suggestion that nothing has changed in the sense that there was no big surprise, no big revelation. That it didn't open their eyes to things that they hadn't been aware of, or they were essentially... what it meant was an amplification of a lot of the dynamics and issues that they had been working to address. Many people spoke to the fact that it was very much a revelation to other people. You know, we have some really harrowing stats that show that Black communities were disproportionately impacted by COVID, you know, by a large margin in many respects, and a lot of people were surprised by that. But many of the Black health advocates and community leaders have sort of said: Obviously, like, clearly, they would be the most impacted. That writing has been on the wall for a long time. And it's a reflection of the gaps in the cracks in the system that we've been raising alarm bells around.

Emily 02:46

I remember there being so much reporting and talk on social media about the disproportionate impact of COVID on Black communities. It was shared with alarm and surprise and a sense of: we have to DO something about this. But it was all a bit vague.

Jennifer 03:04

Rhonda describes that surprise as evidence that people outside of Black communities just haven't been paying attention.

Rhonda 03:11

I think it demonstrates the ways in which across racial groups that Black communities in particular, they are experiencing health and health care and the healthcare system in different ways. And so when everybody, or the broader society, is surprised by COVID, or when they start to recognize gaps in the system and they're surprised, what we were hearing is that "we've been in a pandemic," or "we've already been on fire in regard to these issues." So it's... I think it's very interesting - and not surprising - but very interesting. Watching how surprised other people are about how our healthcare system and our broader systems are responding. And the disproportionate... the disproportionalities, when, as a community? It's kind of like, we already knew this. It's not new information. I think it just further reinforces the notion or the idea that y'all are not paying attention to us. We've been speaking, advocating for a very long time and you're not listening. I think it can... it may contribute to a lot of mistrust, a lot of negative feelings perhaps. Because, you know, this is yet another reminder that they're not paying attention, or that they may not care.

Jennifer 04:33

And with COVID, that apathy gave way to a kind of panic. Government, health care, all of our big systems... they were caught off guard and tried to quickly pivot their services and ways of thinking. And in that process, even the most basic efforts of community consultation went out the window.

Emily 04:51

But as various public health initiatives and messages started to roll out - including social distancing, masks, vaccinations - mainstream media and healthcare institutions were taken aback when some communities expressed skepticism about some of those interventions, or were non compliant.

Alpha 05:09

As soon as COVID hit, on the ground, Black community leaders... they knew that what was coming, right? They knew they knew what was going to happen. It's not unique to Black communities - many other communities who experienced marginalization I think were in a similar position, where they could see the avalanche coming and wanted to think creatively about how to be responsive. But were kind of left out of those decision-making processes. And I think there was this sense that "we don't have time to consult, we don't have time to, to engage, and we just have to act." And then, lo and behold, you have these outcomes. And also you develop these systems that are meant to support communities. And then there's this surprise and shock that community members are not responding, are not accessing these resources, do not trust the various sort of medical responses that... including kind of, you know, the rollout of the vaccination, and all these things happen. And then it was like, "Oh no, what's going on?" Like, how do we respond to this?" And you and then you had all these follow up initiatives and funding streams that were popping up. Like, "can you come up with interesting solutions that are going to get communities to trust the medical system?" It was just all backward, a lot of this could have been avoided.

Jennifer 06:34

Yeah, it seems that perhaps a public health crisis is the exact wrong time to try and build relationships and trust with communities who have not historically been included in health policy decision making, and whose health and health care needs continued to be neglected. But this, of course, doesn't mean that Black communities didn't recognize both the real danger posed by COVID, or their own tenuous connection to mainstream health services. Alpha notes that communities did respond to COVID, but did so on their own terms.

Alpha 07:06

For me, one of the most inspiring things to really watch during this pandemic time has been all the incredible examples of mutual aid and community and grassroots support that developed - I mean, almost overnight - because many communities, including various Black communities knew right away instinctively that "okay, we are in a lot of mess. And we know that it's going to take a while before they even think to come to us. And so we're gonna have to act and act now and figure out how to support each other." And you see so many incredible grassroots initiatives that that grew out of that understanding. I think it's important to... as we talk about some of the apathy and mistrust and resistance that community members might have displayed, it's important to recognize that they were not just sort of sitting in this burning house doing nothing. Many of them were out there looking for ways to support their neighbours, to support their communities, to develop really sophisticated response systems that meant that they could weather the storm. Although they shouldn't have had to, in many respects.

Emily 08:14

Yeah, Alpha talks about these grassroots efforts developing seemingly overnight. And yes, COVID-specific responses would have had to pop up quickly. But this level of organizing could only have been possible because of how much experience Black communities have and fending for themselves and seeking creative solutions, due to a long history of neglect and mistreatment.

Alpha 08:37

I think it's really important whenever we have any kind of conversation about mistrust, or resistance, particularly some of the racialized undertones that come with those conversations, to recognize that that mistrust, that resistance, that anger... is a very logical response to a long history and a very contemporary history of being ignored, of being mistreated and of not being served in various healthcare settings. And so the only logical response, given those certain set of circumstances, historical and current lived experience, would be to be mistrustful and to be skeptical, and to look elsewhere for information and support. So I think we saw a lot of that during this time COVID.

Emily 09:19

And even as all this information came to light, first that Black communities were disproportionately affected by COVID... and that Black communities weren't so bought into public health interventions... and even acknowledging then that their mistrust of the medical system is justified... well, as Rhonda observes, these awarenesses haven't amounted to much.

Rhonda 09:49

I also think we have to think about how did our responses or non-response - including the surprise, right? - and including this scrambling that we saw the broader society do... how did that kind of exacerbate existing relations between the community and the broader medical system? And I'm thinking about the fact that we collected the data, we found out that Black people were being disproportionately affected. But then what did we actually do with that information? Besides the vaccination clinics. Which is a good thing, and which is necessary. But when we have these vaccination clinics, how does that actually address the deeper issues? So we're dealing with the acute issues, but not the broader, deeper, more long term issues.

Jennifer 10:43

Well, and like so many of our modern ills, this avoidance of dealing with deeper issues partly stems from a failure to confront or even know our country's history. And regardless of whether it's due to willful ignorance, or having convenient short-term memory, or a strategic rewriting of history, it all amounts to the same thing.

Rhonda 11:04

One of the things that really irked me that I noticed is, we were using African American History and African American narratives. So I don't know if you saw the articles of Tuskegee, and all of these discussions, and we're using that to talk about Black Canadians [fades]

Jennifer 11:21

Rhonda mentioned Tuskegee. She's referring to a 40-year long, cruel and unethical medical experiment conducted by the US Public Health Service. It was performed on African American men and caused terrible harm and suffering related to untreated syphilis. It's certainly an important part of a wider narrative of anti-Black racism in North America, but not necessarily relevant to the experiences of all Black people in Canada. We'll put some links in the shownotes for more information.

Rhonda 11:49

And we're using that to talk about Black Canadians, who are very diverse group and do not necessarily share all of the history that African Americans have, right? And so do we even have, you know, an understanding or data about what medical mistrust looks like in a Black Canadian context, in our diverse communities? Why it's there, why it happens, what are the roots of it? And as Alpha was saying earlier, may actually be rooted in a medical neglect that is happening contemporarily. So I kind of feel like...we have this great opportunity to address something and I feel like yet again, we're going to miss it.

Emily 12:40

In Canada, we think we're better than our southern neighbours. And we tend to blame it on their influence when bad things happen here. And it's not just these sorts of specific historical events, or things like gun violence, that we as Canadians like to point to. It's also the influence of ideologies that threaten our identity as an equity minded multicultural society.

Rhonda 13:05

I think we're not very good at talking about race in Canada. At all. We don't have a good understanding of our history here and the history of Black communities here. But then we also... anything bad that happens in Canada around race, we say that it's influenced by the US. Or American ideas are coming here. Or whatever it is. And I feel like we haven't grappled with the issue of race and the ways in which anti Blackness and racism were at the foundations of the formation of this country. And I think until we do that, it's going to keep hitting us in the face. We're going to have to...we're going to keep seeing these disparities, we're going to keep seeing these problems. We like to believe that we are multicultural and we're all friends and we share samosas and patties and we all love each other, right? But, it's deeper than that. There are communities that are really experiencing a Canada that is different from the narrative. And we're not ready to grapple with that. And so it keeps happening over and over and over again.

Jennifer 14:18

In broader Canadian society, there's a vacuum of knowledge, understanding, and even acknowledgement of Black communities' experiences. And we often conflate and confuse different Black communities' histories, whether here or in the US. And so in broader society, I think some people are genuinely shocked when we hear about anti Black violence and mistreatment, like the murder of George Floyd. It kicks us into a flurry of allyship, alliances and support. And it's a pattern. A wave that rises and inevitably recedes. Alpha notes: this isn't lost on Black community leaders.

Alpha 14:57

One of the community leaders that we were speaking to was saying that up until George Floyd, he wasn't even working off the side of his desk. He didn't have a desk. He literally didn't even have a desk. But at least this little bit of an injection of attention and kind of focus has afforded their particular organization and network with some resources. So now he at least, you know, has a desk! Not a physical desk necessarily, but you know, has some more capacity, some more resources that they could put to capacity building. And talked about it as a bit of a... almost like a frantic effort to do as much as possible, to take advantage of this moment, with the full knowledge and understanding that it is a fleeting moment. Hopefully there's a way to sustain it and to use this opportunity to build the infrastructure necessary so that we are not back in the position that we were in before that pandemic. That we are better resourced and better able to advocate for our communities, that we establish certain initiatives that will have a sustainable impact. But I don't think anybody is nurturing this idea that this attention and focus will stay at the level that that it is.

Emily 16:10

This fleeting moment that Alpha mentioned, where there's been an increase in funding and support for Black communities that wasn't there before? Well, we can try and trace this to a number of things. Perhaps we can attribute some of it to a kind of shocked response to current events, especially the murder of George Floyd and several other high-profile police involved murders of Black women and men. But we can also imagine the panic of government and public health, to discover that the long-standing neglect of racialized communities, including Black communities, has left a gaping hole in terms of how effective a widespread pandemic response can be.

Alpha 16:49

The unfortunate truth that many of us were... you know... it was not lost to many of us and to many people working in the community, that a lot of the attention and focus had to do with the fact that this was a public health issue, right? That the health of Black communities was intimately connected to the health of the broader public in a way that many did not have to really reckon with prior to the pandemic. And so that came with more attention and more care and more focus. So yeah, I think people are understanding that this is not going to last, but are working to take advantage of this moment as much as possible to mobilize and to build up those resources.

Jennifer 17:30

So we can't assume that recent attention to the health and health care of Black communities is because of a sudden appreciation of the historical or current needs of underserved communities. We've heard in this episode, and in the previous one, that Black communities have been ringing alarm bells... forever. It's just that now that broader society is impacted, it's suddenly important to pay attention. So if this is indeed a fleeting moment, well, it's a time to act as strategically as possible, as it will all inevitably die down when things return to normal. Which in itself poses another kind of threat.

Rhonda 18:09

One of the things I always think about - and this came up in our work - is this notion of back to normal. Like back to normal for whom? Because for certain communities, normal was awful, right? If people want change, and not just like these symbolic forms of change, but substantive, sustained, real... "I'm listening to you," "Here's the

issue, us as a community have identified it, what are you going to do?" Right? So when I keep hearing this the slogan of like, "back to normal, this and this and that," it's like, there isn't even a sliver or a consideration that maybe normal wasn't good enough and we need to do something else. And that in of itself, I'm also thinking about.... it's a very subtle form of dismissiveness, or just obliviousness. How does that further contribute to feelings of not being heard, you know, not being important, so on and so forth?

Emily 19:17

So initially, Black communities were left out of the policymaking and planning. But as public health strategies started to roll out, and the response from Black communities wasn't as hoped, well, the public and community engagement engine sparked to life and started to reach out to Black communities. As Alpha describes, it was a double-edged sword.

Alpha 19:39

Many of the folks we spoke to definitely talked to the double-edged sword of awareness and engagement, where people were very interested in like, "Oh, you do Black health right? Okay. Let's so let's figure this out together." And so it definitely, I think it cut both ways. There was an assumption that they... I mean, the level of engagement that some of these policymakers and health systems leaders were expecting of these Black community leaders, you would expect that they were these well-resourced institutions. But they're grassroots initiatives or mid-sized community organizations that are incredibly, in my opinion, criminally under resourced, given the level of work that they're doing on the ground. But there was this desire and an urgency around engaging them and getting them to offload a lot of that the work in terms of responding to this crisis. So yes, I think that engagement definitely spiked, and it's good, it's good, it's important that... we need these people at the table, we need them, really providing some direction and leadership in terms of how to respond to this work. But they also need to be resourced, and in a position to do this in a way that doesn't completely burn out the individuals and the organizations and networks themselves.

Jennifer 21:03

So I just want to give a plug here for the episode that came out just before this one. We spoke with Alpha and Rhonda at length about engagement from Black communities' perspectives. Definitely worth a listen for a more robust discussion on what Alpha just described. Okay, back to this conversation: Rhonda shared her thoughts on engagement and power sharing.

Rhonda 21:23

And I think one of the things too, is that there also has to be power sharing in that process. Because often when they were engaged, it was whatever institutions or entities coming to the table already with something designed or planned. And then they want the Black partner to further legitimize it, rather than engaging and building something together that is rooted in what the community actually wants and needs. And so there's this tension between the community needs these things, and we need to engage. But we don't have any real power. This isn't a real co-design. This isn't a true partnership. And so there's also these negotiations that have to be made. And so I think in these processes, yes, while engagement can go up, we have to think about the kind of engagement that is happening and is it just ticking a box? Or is it actually respectful and interested and one that

is trying to be community led rather than top down still, or like give a veneer of partnership when it isn't true partnership?

Emily 22:35

Well, and harkening again, back to the previous conversation, mainstream engagement doesn't serve Black communities well, and so they continue to figure out creative, strategic and productive ways to get things done. And that doesn't mean never engaging. But it's taking a different shape.

Alpha 22:53

And I think one of the things I was struck by in our conversations, and I've seen sort of on the ground as well, is that Black community leaders are really beginning to - not beginning - but are really setting the terms of their engagement a lot more forcefully and in a more kind of direct way. And I think we've learned a lot from some of you know, I think Indigenous leaders, communicators have really taken a lead on this thinking of the development of like the OCAP principles that govern the ways in which researchers can, you know, engage in research [fades]

Emily 23:29

So OCAP stands for Ownership, Control, Access, and Possession. It's a set of principles that outlines First Nations jurisdiction over information about their communities and community members.

Alpha 23:42

... and I see a lot of that beginning to... that sort of spirit of taking the reins. I see that happening with various Black communities as well, where they're recognizing and really pushing back against some of what Rhonda just described in terms of engagement on someone else's terms, engagement in ways that is not equitable, and saying no if necessary, when those terms are not favourable for Black communities.

Rhonda 24:14

I think it's very important for us to make space for Black people to speak for themselves. And to define the parameters... I would say the parameters of the discourses that are taking place in society. Because what I've noticed with COVID, and with all of these health issues, it's other people who are not in the community who are deciding what is important, what is a priority. What does medical mistrust look like? They are defining what that means, and the conversations they're having looked nothing like the conversations that the actual community are having.

Jennifer 24:54

So this is one of the major focal points of public engagement, patient engagement, whatever engagement. There's an understanding that there are many conversations happening that people who make decisions either ignore or don't get to hear or maybe don't even know are happening. So the solution is to set up formal engagement processes, which bring in a variety of people to sort of embody different perspectives....

Emily 25:19

So like... diversity!

Jennifer 25:21

Yes, like diversity [laughs]. We've chipped away at the problems with this approach in a number of episodes. But what we haven't talked about much are alternatives or other ways of addressing this disconnect.

Emily 25:33

Right. So we're quite familiar with the idea of lived experience when it comes to patient advisors or patient partners. But we haven't talked as much about the value of researchers sharing a common background with the community in which they're conducting their work.

Jennifer 25:49

Okay, so I want to just back up a second and acknowledge that neither of us are members of a Black community. Emily, you're white...

Emily 25:57

Correct, primarily of British descent.

Jennifer 26:00

And I have a mixed background. I'm Norwegian and Chinese. So from our joint perspective, when we talk about the experiences of Black communities, we're obviously not talking from personal identity or experience. We're outsiders. So for us, these episodes about engagement in Black communities? Well, it's important that they're rooted in community perspectives.

Emily 26:23

Right. And so Alpha and Rhonda's work helps us to bridge that gap. And so with that context, we asked them about being Black researchers themselves, researching issues in Black communities. And what that lens brings to the work.

Rhonda 26:37

I just think, as a researcher, lived experience matters. I think there are, again... the Black community is very diverse, but depending on the section of the Black community that you are part of, there are linguistic, cultural, just social norms. There's ways that even just culturally, I'm thinking about that we communicate just with sounds and just facial expressions. There's just a way of knowing and a way of being that is distinct. And I don't think that's something that you can teach in a methodology course in grad school. And so I think there... as much as research, we like to think of research as this super objective, you know, straight-laced thing, lived experience can actually enrich the work. Because there are things that you understand just by the way somebody sometimes says something to you. Or the way that they respond. Or maybe even like the little sounds that they may make. You have a deeper understanding of what that means that other people may miss. So I think it is very, very valuable for Black researchers to be doing this work, to also be supported in doing this work. And also to be funded to do this work. Because until we get the real narratives from Black people about what it is that they're experiencing, in all of its intersecting and complex ways, we're going to keep trying to impose other people's ways of seeing the world onto them.

Emily 28:22

Having that shared experience or identity is not just about having a heightened awareness to cultural or linguistic nuances, or perhaps building trust more quickly. As Alpha describes, it's also about reorienting or even redefining the nature of the relationship between academia and Black communities.

Alpha 28:40

I think historically, Black people's lived experiences, along with many other communities has been seen - and there's a sort of a colonial legacy here - has been seen as data and like data points, but not seen as a legitimate kind of framework and theoretical framework and rigour in the way that Rhonda was just describing. And so there's been a very extractive relationship between the academy and Black experiences. You get to address that in a way that, you know, that's more, there's a more sort of systematic and integrated way in which you can engage with and learn from Black experiences as data... but also as an analytical framework and theoretical framework when you are yourself a Black researcher. I had a lot of moments like that. I don't know about you, Rhonda. But in our conversations with this research, where you sort of have these moments where lots has been said without anything being said. Or you were able to kind of get right into a conversation in a way that you recognize wouldn't have been possible if there was not this shared understanding and also a certain level of trust. Sometimes as a Black person in these spaces, it can be tedious and you have your moments where you're just like, well why, why do we have to start here? So you definitely have those moments. And I think that's why it's so important to have spaces where you can debrief and have support and have people to understand that. And so it's been great working with Rhonda on this, because we can, you know, sort of debrief and just be like... "listen," and then she says, "Yes, I know." And then we find a way together. And so that's an important maybe survival tactic that accompanies this work. I think we just need more of us here. And as Rhonda said, it needs to be validated and supported both in terms of the platforms that are provided for this work, as well as the actual resources.

Jennifer 30:49

Hi, Emily.

Emily 30:50

Hey, Jen.

Jennifer 30:52

So our topic is ostensibly health policy engagement and Black communities. But really, at the heart of it, we're talking about the work of Black communities to address their health and healthcare needs. Now, in that light, from the perspective of Black communities, the diversity efforts we see in mainstream engagement spaces just really don't cut it.

Emily 31:13

Yeah, exactly. I mean, I think what I heard, and this is really a culmination of both our conversations with Alpha and Ronda, was the importance of increasing the number of Black researchers and research teams, prioritizing

Black community needs and interest, and improving funding and support for Black Community Health Initiative, especially those that are Black led.

Jennifer 31:36

I think anyone listening to these episodes, at least I hope so, will know that anti Black racism impacts the health and well-being of Black communities. But what I really hope comes across is that anti Black racism shows up in a multitude of ways that goes unexamined by broader society. From how we describe Black communities as being hard to reach, to how we disregard or penalize activism and protest, to how we expect Black community leaders to participate in formal processes of engagement while devaluing the work they've already been doing. We talk about diversity. But what's actually needed is a true and honest reckoning with historical and current racism in Canada.

Emily 32:20

Yeah, we haven't shed our colonial legacy, we're now just more polite about it. And we've made it more systemic - these formal processes of engagement are increasingly integrated into health systems ... and they seem to have become the only legitimate ways to hear from the public. While protest and activism are not. This essentially establishes formal engagement as a kind of gatekeeper to legitimacy. For strategic reasons, it makes sense that people will feel compelled to participate.

Jennifer 32:52

This idea of legitimacy extends well beyond engagement processes to legitimacy of knowledge, of experience, of expertise - all the things we've talked about before, particularly about patient engagement. A lot of people see patient engagement as acknowledgement of essentially the legitimacy of patient perspectives. But we know this is a problematic or at least incomplete view. The way engagement is practiced often not only reinforces the status quo, but rationalizes it. And it's often on the backs of people who are there with sincere intentions of making a positive impact.

Emily 33:29

Right, so we can see the immense challenge that Black communities are up against. There are significant health disparities and inequities related to access to good health care, which are further entrenched by underfunding and lack of resources. So with that set of realities, communities are essentially picking up the slack and doing the work themselves.

Jennifer 33:51

And underlying all of this, the cause really, is systemic anti-Black racism. But the broader society often refuses to even name it, or even see it. We've developed very sophisticated ways to disguise it even to ourselves. In a previous episode, Nav Persaud called it "anti-racist pantomime". And we're very good at that. We want to feel good about ourselves, which requires that we craft a story and even alternate history that better fits our narratives about Canadian values. And for Black communities, and many others who experienced this pantomime, this must seem like an impenetrable wall.

Emily 34:35

Well, to bring it back to Alpha and Rhonda's research... Based on their interviews with leaders of Black led organizations, they're calling for a different framing of how Black communities are engaged in the work of informing and changing health policy. And this requires us, as a broader society, to discard the idea that only formal engagement processes are legitimate ways of contributing to change. And no, we don't need another study! As Alpha said, historically, positive change for Black communities has come from their own hard work at pushing for change, not from participating in these formal processes.

Jennifer 35:13

Yeah, bottom line... we need to acknowledge this work as legitimate and trust Black communities to know what they need. Which, if that's all going to stick, will require us to confront our ongoing history of anti-Black racism in Canada and to understand it as part of our colonial legacy.

Emily 35:33

Thanks to Alpha Abebe and Rhonda C George for participating in this episode.

Jennifer 35:44

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 35:58

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