

“Ensuring the Data System Used for Public Health Centers Equity and Well-Being”

Mathematica Webinar

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[Deliya Banda Wesley] I'd like to welcome you all to today's event. My name is Deliya Wesley. I'm a Senior Director for Equity here at Mathematica. Today, we're incredibly excited to host this timely discussion, Ensuring the Data Systems Used for Public Health Centers Equity and Wellbeing.

When we think about public health data and what that means to most people in country, especially in the times that we're in, we're challenged to look beyond our narrow definition of what that is and recognize what currently constitutes public health data has a lot of limitations. We need to look well beyond the traditional outbreak surveillance systems or a disease or immune organization registries to adequately capture and reflect the complexity of our communities, and to more accurately and completely characterize local populations to identify opportunities for investment. This includes data reflecting community strengths and assets to identify true community needs and to enable the effective mobilization and coordination of resources across sectors. As we all witnessed in a real time during the COVID-19 pandemic, still in it, the existing public health data systems failed to do this, and it's fractured inconsistent, and is primarily focused on disease.

In its current state, the public health data system begs an opportunity to be transformed, and that's what we're talked about today, transforming so that these data are meaningful for everyone, in particular, for those who tend to be excluded from the public health data system and for those who also are the same people who tend to be disproportionately negatively impacted in times of public health crises.

At Mathematica, our mission is to improve public wellbeing, and our vision is to shape an equitable and just world, where evidence drives decisions for global impact. And at the core of that is data, and that makes this a topic of critical importance to us. Together, with our partners across sectors, and, most importantly, the diverse communities impacted by our work, we're at a critical moment in time with an opportunity to catalyze the needed change in our public health data systems. We want to contribute to reimagining how best to collect, how to share, and how to use meaningful data, how to modernize the public health data system but to center equity and to center wellbeing in doing so. Helping to uncover what's required to achieve this change requires all of the voices and the types of voices we'll hear today at the local, at the state, and national level, and across sectors in identifying who the key actors are and who those voices are that should be shaping this change, the voices, in particular, that have been historically and systematically excluded.

Our hope is that today's discussion will start to get at some of these core issues, given the different perspectives that are represented by each of our speakers, who I'm extremely excited to introduce to you and to bring together on this same platform. For this discussion today, I'd like to welcome and introduce our five guests. I'm going to give a very brief bio, but you have access to each of the presenter's complete bios in the provided materials.

Without further ado, I'd first like to introduce our moderator for the core discussion for today. Vivian Singletary, who is the executive director of the Public Health Informatics Institute. In this role, Vivian steers the work for the Public Health Informatics Institute toward a world in which every country has the capacity to access, use, and share timely information to protect them through the health of its people. Her experience combines nearly 30 years in systems development and public health. She serves as the vice president for Digital Bridge. It's a forum of health-care experts, public health professionals, and industry partners to discuss the challenges of information sharing and incubate solutions for a nationally consistent and sustainable approach to promoting bidirectional information exchange between health care and public health. So, welcome to Vivian.

And then our panelists for today, I'd like to welcome Dawn Heisey-Grove, who is the public account analytics leader for the state and local government team of Amazon Web Services, AWS. In this role, she

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helps state and local public health agencies think creatively about how to achieve their data and analytics challenges and long-term goals. She has spent her career finding new ways to use existing or new data to support public health surveillance and research.

Before joining AWS and while at the Office of the National Coordinator for Health IT, she partnered with the Centers for Disease Control and Prevention to explore how electronic clinical quality measures can serve to generate national population estimates of hypertension. Heisey-Grove started her career as an infectious disease epidemiologist and public health informaticist at the Massachusetts Department of Public Health, where she was a leader in identifying new technological solutions automate data capture, clearly share data with clinical and local public health partners.

Our next speaker is Alastair Matheson. He is an epidemiologist at Public Health Seattle in King County in the Assessment and Policy and Development and Evaluation Unit, and he's also an affiliate instructor in the Department of Epidemiology at the University of Washington. Alastair's work includes analyzing population data to identify health needs in King County, developing visualization to make data more accessible, and linking data across sectors. Matheson has several years of experience working at the local health level on program evaluation, policy development, and public health informatics. And for our next speaker, there's a last-minute change, and Alonzo Plough from the Robert Wood Johnson Foundation cannot attend, unfortunately, today due to illness, so we have our own So O'Neil, the director of Mathematica's Health Philanthropy Portfolio, and she has graciously agreed to step in to help provide some perspective on recent philanthropy efforts in this arena, including work being done by the Foundation's Transforming Public Health Data system, which Alonzo was going to speak to. So, currently direct Mathematica's Domestic Health Philanthropy Portfolio, which is supported work for more than 50 philanthropic institutions, nonprofits, and professional associations. Thank you, So, for your willingness to step in at the last minute.

And at last, and by no means the least, I'd like to welcome panelist Artair Rogers from Shift Health Accelerator. Artair serves as an equity advisor for Shift Health Accelerator, an organization focused on community governance, equitable institutional investments, and antiracism accountability principles within the health-care sector. He is pursuing a doctoral degree in Population Health Sciences at the Harvard TH Chan School of Public Health. Roger's research interests are frameworks for antiracism, accountability for health-care organizations, health equity data frameworks, and reparations as a public health measure. Before his current work and studies, Rogers was California program director for Health Key, which is a national Nonprofit focused on addressing social determinants of health, in partnership with health systems, community-based organizations, and community members.

So, a warm welcome to all of our guests, and I'd like to welcome you all in the audience, and I'll hand it over to Vivian for some opening remarks and to get today's discussion started.

[Vivian Singletary] Deliya, thank you so much for that wonderful opening, and you said a lot of what I would have said too, so I'm not going to repeat all of that. But I do want to welcome all of our esteemed panelists. And I think we have a very important discussion today. Today, we're talking about, you know, equity within the systems that we're creating, and right now, there are tons of data modernization going on. In fact, I was just at a data modernization workshop just right before I jumped on this call, so I think this is a wonderful time to open this discussion so that we can make sure that as we modernize our public health data systems, that we are leading with equity. So without further ado, I am going to jump into it.

So, I want to open up the first question for the panel, and I'm going to start with you, So, and we'll go around. What does a transformed public health data system look like to you?.

[So O'Neil] You and Deliya touched on a little bit by saying that it would be a system that focusses on wellbeing. Even beyond prevention, it's how to be holistically healthy, and what that means is not just thinking about the data sources and the measurements and how we visualize and share data and who owns the data, it's governance and so on, it's actually a huge mindset shift, because to transform a public health data system, we need to be thinking about upstream factors, because as we all have knowledge of the discourse around social determinants of health and the influence of non-health-care factors on people

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and populations health. So, it takes a mindset shift to think, oh, yes, we need to be layering on upstream data, on housing, welfare, education, all of these things into the public health data system.

The other piece I would say about transforming public health data systems, it is not just thinking about acting at a national level and having public health systems be at the national level, but really thinking about it in terms of hyper-local data, being able to inform hyper-local action that meets the context of people within it, and, of course, with the equity framework help for, and that mean it is system has to work, the data has to work for those that have traditionally been minoritized and marginalized.

[Vivian Singletary] Thank you. I like that comment about hyper-local data. So, I'm going to take that question and toss it to you, Dawn. And give us your perspective on what a transform public health data system looks like.

[Dawn Heisey-Grove] Yeah, so I think that So's points are very good ones, and everything that's occurred leading up to this is very accurate. I'm going to take a technological approach, since I'm representing AWS, with two key points that I think we can't forget. The first is that this new modernized system is going to need to provide timely and complete access to information for the health status and wellbeing status for all members of our communities, not just the people who are captured in the digital data that we have right now; right? So, we know that not everybody has access to the health-care system, or they do not access for a variety of reasons. We know that not everybody uses digital apps in the same way.

So, whatever solutions that we use, we need to make sure that we know who's not measured in the solution and find alternative ways to measure that. I don't think I have all the answers on how we immediate to do that, but I think we have traditionally had those gap and not always measured them well. Reliance on surveys and things like that is not going to be a great solution, but there are new entities, and AWS has partners that are trying to figure out how to get, as So mentioned, some of those hyper-local pieces of data from groups that engage in community advocate and community organizations to gather that kind of information from those individuals who may not be digitally enabled to get that kind of information. So, I think that's really important that we keep that in mind. And when we do have to measure using just digital information, that we make sure we're estimating in some way who we're not measuring and that we make that very clear.

And then the second component that I think we need to keep in mind, especially if we're talking about hyper local, as So mention, is making sure that we not only this nice data that everybody can access but that all public health jurisdictions -- state, federal, county, city, and local -- have equitable access to the technologies that enable them to do this kind of analytics and use the data wisely, and if they don't, that we've provided them with the resources to do that. And it's not just the technology, but it's the people and the processes. So, can we build shared resources and shared collaboration to ensure that we have an equitable distribution of public health resources across all those jurisdictions to facilitate a comprehensive view at the state, national, and local level?

[Vivian Singletary] Thank you, Dawn, for that insight. So now I'm going to transition to Artair and toss that question to you.

[Artair Rogers] First, I just want to thank Mathematica and all the panelists for letting me join this conversation. And when I think about this question, I have to think about my positionality when I enter a conversation like this, just being completely honest, you know, with my thing, just being a black male in America, being from the rural South, and especially being particularly cognizant of harms that happen to people of color through COVID, as well as the fact that this was happening in the context of police violence against communities of color.

And so when I think about a transformed public health data system, I have to think that a transformed one would be one of humility; meaning, one that's always cognizant that even though we may have good intentions in bringing all data together using technology, that harm can occur, and are we thinking through how we mitigate harm and address harm as it occurs? So, I immediately think through data collection processes that seek to reduce harm, making sure that everyone that we extract data from or collect data

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from, that they are truly aware and understand the data uses from that data collection process, because a lot of times, that doesn't happen.

We collected a lot of data, and we can profit off of that data, but people who we glean that data from don't know how that data is being used and don't know that systems are able to profit off of that data collection, sometimes even of their pain or the disparities that they experience. Thus, I think it's important that we start thinking through how those marginalized communities can have some type of agency over the data use, as well as, potentially, ownership of the data if that calls for it. And then I guess the last thing would be making sure that the data used results in true investments within the community, particularly marginalized communities.

So, we talk about data visualizations. Are we understanding the shared objectives or the objectives of the community to make sure that data visualizations and data uses actually allow for communities to advocate for themselves, or even promote liberation for their own wellbeing, for their own community health? So, that's what I think about when I think about transform public health data infrastructure.

[Vivian Singletary] Wow, that's very insightful, Artair, and I'm sure we're going to come back and revisit this a little bit more. And so I'm going to go, last but not least, for Alastair, for you to weigh in on this critical question, what does the transform public health data system look like?

[Alastair Matheson] Yeah, some great points being made, and I'm excited to come back to some of them. I think we will be able to touch on some of them a little later. When I close my eyes and think of the perfect public health solution, when I'm sitting here at a local health environment, albeit a very well-resourced and able health environment that serves a large population, I'm picturing data flowing smoothly without friction, both within the health departments, significant enough barriers, trying to get the information across even within our own organization, but then also between other organizations, housing, other social determinants that have been pointed out, and then data flowing up and down through state and local. We rely on the state heavily for many data systems, and we receive data, but we could definitely be doing it in a more effective and more efficient way.

All of this and bringing this all together in some fancy integrated data world is really just a means to the end, and I think the end has been touched on by others before. That end is enabling more accurate, more informed decision-making that can actually improve the population health of people who have traditionally not received services that they should have or have been marginalized.

Another piece I think is super important in this great new system we're dreaming up is that access to data. And Artair touched on this a bit as well; that making data available to those who stand to benefit from it, I think, is really important, or who could benefit from it, and haven't in the past. So, that could be through data visualization. It could be through data workshops, democratized data, whatever terminology you want to put around it, whatever technique you want to put around that. I think that is a key part of whatever this transform system looks like. It's not just the black hole of data that public health departments traditionally are, it's like getting that two-way or multidirectional exchange is important as well.

[Vivian Singletary] Thank you, Alastair. We've heard a lot from the panelists here about the importance of hyper-local data, timely data for all populations, not just those included with access to health care. We talked about the importance of harm reduction, understand how the data will be used. And, Alastair, you talked about the importance of having data flow very efficiently from the state/local levels, and that is available and open to all so that we can move forward in helping our community. So, I think we're just opening up on a good discussion here, which brings me to my next question for the panel, and, Alastair, I'm going to start with you, since we ended with you.

So, at the beginning, we talked about a transform public health data system looking like one that focusses on wellbeing. How much do you think about measuring wellbeing, and tell me who gets to define wellbeing, and does this type of measure make any sense to standardize? And so that's a lot, and I'll be happy to repeat that if you need me to.

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[Alastair Matheson] Yeah, I think that word, “wellbeing,” the term is very nebulous. But we do have some definitions out there already, or some concepts around wellbeing, and public health particularly. I mean we talk about the social determinants of health as a foundation for health. But really, that is, I think, a conceptual piece of wellbeing. You have safe stable housing. You have a reliable income. Are you living in an area that has access to good schools and parks and jobs, transports, those sorts of things that we call the social determinants of health? I think you can sum that up as that is wellbeing.

If we want to get down to the more medicalized approach, we have standardized questions and definitions around things like how would you rate your health. You know, that sort of broad question that has been found to be quite predictive of health outcomes. So, people generally have a good sense of themselves in terms of how they're doing, and you can ask people questions in a standardized way to get at that.

I think a piece that we often overlook is mental health, and mental health and wellbeing are really tightly bound together, and the past few years have brought that to the fore, I think. There's been an increase on mental health, particularly pediatric mental health, but mental health of all ages. I think, again, there are -- I'm not a psychiatrist or psychologist, but there are standardized measures out there to sort of get at that from a medical sort of thing. But I would be curious to hear if there are further upstream standardizations, we can get at to measure mental health in our community. But I do think that is an important piece that shouldn't be overlooked.

[Vivian Singletary] Thank you, Alastair for that. Very appreciative. Now I'm going to jump to So. So, can you give us your input on this focus on wellbeing and how we might think about measuring it.

[So O'Neil] Yeah, I just don't think we've gotten there yet, you know, as much as Alastair has pointed out, there are measures that folks have used, you know, in terms of measuring social determinants of health, you know, food security, housing stability, so on, and we have the social vulnerability index, the area deprivation index, these types of measures. But to be honest, I think we really need to break down and think about how those measures have been structured and constructed and for whom and by whom. And so, I really think we need to go back to the drawing board and, as Alastair mentioned, work with communities to have them define what are the dimensions of wellbeing in your community? What does that look like to you? And how do we think about developing approximate measure just to gauge where we're going, and are we close to there yet? I would say that that is my thought about how to measure wellbeing.

[Vivian Singletary] Thank, So. I want to jump to Artair and then Dawn, because I think it will be interesting to hear from the technology perspective after we talk about how we measure this a little bit. So, Artair, over to you.

[Artair Rogers] Sure. I really appreciate the point by So and Alastair. I think that standardization has its place, in that it's okay to have this goal of like how do we have standard measures that allow us to understand wellbeing. But I really appreciate So bringing out the nuance of data context and that we need to make sure that we're understanding the unique data context, even if we have a standardized measure. So, I think, like, the area deprivation index was one measure that was thrown out. And it's great to have some type of standardization of, like, how we're measuring that. But the data context of that measure could look different in each community. And I think it would be really helpful if we start to pay attention to the data context of these standardized measures if we're creating them.

And I think another reason behind that is that even the way we talk about social determinants of health could change from now to five years from now, or even ten years from now. And sometimes we can get stuck in the same measure without considering how has social determinants of health changed. What measures should be incorporated under that umbrella, because, you know, the way we're measuring it five years ago just doesn't make sense anymore. And that's why we have to have those pull ups with the community to really understand what is the data context of the measure that we're seeking to measure to understand wellbeing and public health, and in a broader sense.

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[Vivian Singletary] Great. Thank you, Artair, for that data context form. Dawn, I'm going to shift over to you so you can weigh in on this.

[Dawn Heisey-Grove] Okay. I mean, I do appreciate what everybody said. I think I heard we need to get community engagement, which I completely agree with. I think the sense of wellbeing is definitely going to vary depending on your community, your cultural background, where there has been harm, as Artair mentioned. I think, you know I'm a technologist, a public health informaticist. I love standards when they're appropriate. I worry that if we focus too much on standards in this, as everybody has mentioned, there's a lot of shifting going on in this environment, and it takes years to get standards in place.

So, I think coming up with standardized ways to ask questions so you can monitor trends over time is important but focusing on building out standards to capture this information may not be the pathway we want to go to. I think about how we can get sentiment analysis and generally use machine learning and natural language processing and other technological advances that are super simple, if you get to your data scientists, but also that you can apply easily in the cloud with new technologies, on large amounts of data to kind of explore these concepts with the right community engagement, with the right protections on data and data privacy; right? All of that can be done without focusing all of our attention on trying to standardize nuances that may not be important in three years, as our guess, our assessment of what we need to be measuring changes.

I also liked Alastair's point about making sure that we capture the different kinds of buckets of wellbeing; right? It's mental. It's physical. It's emotional. And, you know, the ability to build out standards for all that, I think, is just going to vary over time, and I think we just need to think how do we take the data and get good enough measurements instead of perfect ones.

[Vivian Singletary] Thank you for that, Dawn. This is such a fascinating discussion. So, Dawn, I want to stay with you for a little while and give you a couple of questions to help us and give your perspective on. So, tell me what types of non-traditional data are or could be used for public health, and what does that look like?

[Dawn Heisey-Grove] Yeah, so, you know, I was thinking about this question as I was preparing for this session, and I could go through a laundry list of non-traditional data sources. I think that there are many people listening to this session and on our panel who are probably a lot smarter than me on that. But I think if you are thinking about buckets of data, we're thinking about administrative data from other government sources. I think folks mentioned WIC services, food provisions, child welfare, family services, all of those things that government collects that can give us an insight into the health and wellbeing status of the populations that we're trying to measure.

I think environmental data, like influence of climate change, we're talking about weather, we're talking about other environmental factors, walkability in a community, access to green spaces, air and water quality, all those things that impact health and wellbeing, policy data, because we know that local and state and other jurisdictional regulations can really influence how people are able to live in their homes and travel to different locations. So, I think that's another key component that we haven't really tapped into, are those local city and county policies. And then leveraging and accessing clinical data in new and novel ways is also very important.

So, when you think about those big buckets, I think it's also important -- and one other one I want to mention is integrating and leveraging community-based organizations, and I'm not talking about necessarily just capital C, capital B, capital O, CBOs but like all community organizations, because that gives a sense of what other services and ways to engage our community are there. Those groups, obviously, don't have a lot of technological advances, and so we'll need to figure out how to engage them and how to help them without producing burden.

But I think that whatever information system that we build, or a new modernized health information system, needs to make sure that it's flexible to adapt to new data that may be identified in a year or three

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years. I mean, there's so many new data sources that we started filling in for COVID, just as an example, we didn't anticipate any of those. I mean, some folks may have. But if we build a system that just is focusing on what we know now, it won't be extensible and it won't be flexible or scalable for the next new thing that we need to adapt to. And so rather than -- so, I mean, thinking about the data and how we access it now is important, but also making sure that we build a system that's flexible for the future is even more important in my opinion.

[Vivian Singletary] Yeah, I agree with you, flexibility is key. I have the notion that as long as there is disease, as long as technology, we'll constantly be retooling, and we have to be flexible. So, let me ask you -- go ahead, Dawn.

[Dawn Heisey-Grove] I was just going to say, making sure that the system is easily adaptable, I mean, that's critical. So, the concept of not building this huge monstrous system but actually building small micro services to kind of link things together and make it easy to change out pieces and parts as new technology or new things are changing, I think, is critical. Sorry.

[Vivian Singletary] No, I think that's a real little important key point here. So, let me ask you one more question before I move on to one of our next panelists. What needs to change in the data governance landscape to allow for better use of non-traditional data to inform public health?

[Dawn Heisey-Grove] Yeah, so very informatics kind of focused approach here. I think, from a high level, we need to start embracing a yes mindset and not a, no, I can't share anything kind of mind set. That's not the technological person speaking. That's more of a we really still need to very much respect individual privacy and data security, and I'm not suggesting that at all. But I do think that we have a tendency, everyone who owns data and uses data, to say, this is mine, and I will only let you use the data if you pass, like, these five fire walls that I've built up, right? And I think that's the wrong way to think about it.

If we start sharing data, and really sharing data across organizations and across entities and governments and things like that, in a safe and secure way, which is totally doable -- my favorite way to think about this is through a federated analytics model, where each owner maintains their data, and they hold it secure, and then you have a shared kind of governance approach with privacy-preserving record linkage so you could still get that hyper local kind of analytics that So was mentioning, I think that's the mindset that we need to think about. Everybody maintains their own control of their data.

We're not talking about some massive, centralized kind of hub. What we're talking about is a common shared governance model that folks agree to that says yes more often than it says no, but respects each data owner, each agency providing those data, their right to say, yes, we'll share it, or, no, we don't. And if you do that, then everybody has more power and access to control, like to get better sense of what's happening within their communities, their hyper-local arenas.

And to Artair and Alastair's point, we can better engage the communities to understand how they would interpret those data and what kinds of questions they want to ask of those data, because they have better access to all of the information about their community and that whole of community kind of approach if you take that more federated model and move away from putting in a central place and you have to jump through 10,000 hoops to get to it.

[Vivian Singletary] Thank you.

[So O'Neil] I'd like to talk a little bit on some of Dawn's comments.

[Vivian Singletary] Sure.

[So O'Neil] If that's okay.

[Vivian Singletary] Sure. Yeah, jump in.

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[So O'Neil] Hopefully it's not too disruptive. My dog has stopped barking. So, I mean, I think that this is a really interesting point that Dawn is saying about federated data. I know that a lot of philanthropy has been think about how to leverage existing data to be able to layer on each other, to do those analytics and so on. I do also want to bring in -- and this has been talked around the water cooler and beyond for quite a few years, is big data, unstructured data, that is here. And we've seen it through COVID, where it's not very burdensome for folks to collect, where you can do analytics to do contact tracing, to do other types of public health -- feed public health data to inform spread, and so on, of disease, but also could be leveraged for wellbeing as we're talking here.

And I think that, ultimately, too, I like the idea of being able to engage with communities that Dawn was talking about. But one of my mantras has been that data is owned by the person who gives it, and, you know, how do you start thinking -- and this is one of the questions I see in the chat, how do you start thinking about people's rights to their own data? That it's no longer an extractive process of taking data from people and going somewhere with it, and then never seeing it again, but having it come back to them and work for them because they own that data, ultimately. Not us, not the registries industry, not the people who collect the survey data, not the Medicaid or the Medicare claims folks, processing folks, not insurance, so on, if we're talking about the more traditional sources, of course. But I think that, like, that that's something that came to mind, Dawn, as you were speaking.

[Vivian Singletary] Yeah, I think that's incredibly important. Go ahead, Dawn.

[Dawn Heisey-Grove] Sorry, Vivian. I was just agreeing with you. And the thing that I think is most important is, when you start thinking about people owning those data; right, if you have a fed rated model or something like that, where they're exploring the data to answer their own specific question, they're going to be able to tell the story back to their community and the people who matter the most to them in a way that I think nobody else could, and I think that's how we make changes. When we're think about this environment of mis- and disinformation and how it's so hard to get public health messages across, I think making sure and empowering individuals to get access to data to tell that story in a way that is most impactful to their community members is critical.

[Vivian Singletary] Yeah, I agree. And I love this conversation and where it's going, because now I want to turn to Artair. And it takes me back to one of the comments that he made on the earlier question. Just as you were talking, Dawn, about from a technology standpoint, it is very possible to bring data together in a way that we can analyze it, use it for new insights, et cetera, but now we come back to this point that both so, you know, is talking about, and Artair, it's about ownership of data.

And back to, Artair, specifically for you, how do we operationalize this notion about not causing harm by going through and using data in different ways? You know, I think most people go in with good intentions in terms of their use of data. But to your point, they may not understand the harm that it could cause, so can you weigh in on that for us, Artair?

[Artair Rogers] Yeah. I'm hoping I don't get on too much of a soapbox about this. And I will say that I don't have all of the answers to this, and so I appreciate this being done in a space where we can dialogue about it. But I definitely believe that it's really important for us to start by naming harm. Like, we oftentimes look to produce an equity-oriented solution and want people to engage in that solution without recognizing that there are some historical harms that happen there. And that calls for some type of truth to be to be stated so we can start doing some type of feeling process so people can engage in new transformed systems.

So, I think one thing that we have to be very conscious about is just mapping out where bias may happen in both the data generation pieces, but also when we start talking about machine learning and algorithms, also in the model building and implementation side of that. So, when we think about the data generation pieces, you know, a lot of times data comes to us in a historical biased way. So, are we able to really start to articulate what are some of the biases that come from the data that we're hoping to use? There may be

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representation bias that comes in. How many people are samples within a particular study or within a survey? How we measure could create bias as well.

And then, you know, that's just data generation, but we also have to look at, like, when we start doing model building, the testing of that model, how is that model learning? What is the model learning bias that comes with it? It's just really important to start mapping out where bias may happen throughout all aspects.

I think it's also important for us to think about who interacts with that data and start really naming positionality. So, a lot of times, the people who are marginalized, you know, they have no interaction with that data. There's no one from those communities who is able to be in those rooms. So, it's important for people who have the privilege of being able to interact with data to really start even looking at their team and saying what is the overall positionality of the team, and these are our strengths, these are our weaknesses when it comes to looking at how data is used, how it's interpreted, how it's presented. And that should be public basis. So, when people are able to use that data, they're able to say, hey, here are some of the gaps that may come up. Here's how we may need to interact with this team, or even ask the team questions about how the data was used, because the people who are experiencing the disparity may be able to ask a different question or may be able to see different things than the people who are able to engage with the data. There was a question in the chat. I don't know if it's okay, Vivian, for me to kind of read that.

[Vivian Singletary] Yeah, of course. Go right ahead.

[Artair Rogers] But I think when we don't do that, we can create interventions that don't necessarily meet the need of the community, and so I think that creates harm. I think that was the question, was like, how can the use of health and wellbeing data be used to create harm? So, if we're creating interventions based on data that ignores the data context, it doesn't really bring the community into any type of governance of how the data is used, we could create interventions that are not helpful to the community.

We also have to be mindful that the people who have privileges and in generating data, who's able to participate in model building and the implementation of those models, if they're not coming from the community, we have to recognize that data is a commodity within this environment. And so, the commodification of data itself allows us to – we could be participating in the extensive racial wealth gap that's present within our society today.

So, I look at, we talk about social determinants of health a lot, and I think it's great that we've been talking about social determinants of health. The fact that there's been an increase in the number of social determinants of health interventions, which has led to a rise in a lot of social determinants of health technology. Not saying that social determinants of health technology is bad on the forefront. But if we're thinking about the fact that the theory of change or the premises that if we start connecting people to resources to address those social determinants of health-care gaps, then why are we not seeing that level of investment in community-based organizations? Why are we not seeing that level of investment in especially community-based organization or social service organizations that are led by these marginalized groups?

So, we are collecting data on groups or expanded marginalization. Groups who are not from those communities are able to benefit greatly, particularly financially, and then we see that, hey, there's not that much investment going back into the community. So, we have to be mindful of, like, how our use of data, how we're collecting data, and who has the privilege of stewarding that data can benefit, while others, even people that we're hoping to help, don't benefit as much. I know that that answer went way longer than probably should have, but that what happens when I'm talking about harm.

[Vivian Singletary] Yeah, I think that is incredibly insightful, and it's an important discussion for us to have, because, like I said, we all go in -- I have a very positive thought about people using data. I don't think most people use it for harm, but it can go into that direction. And you started to touch upon this concept of uses of data. Some people that may be profiting from data, you know, from others that it's their

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information but they don't have access to it. They don't know what's going on with it, and they don't know other people are using and profiting on it. So how might we think about this whole concept of restorative justice, and, you know, as we seek to create transform public data health infrastructure? Maybe you can tell us a little bit about that.

[Artair Rogers] Yeah. I think, you know, restorative justice includes the truth telling that I talked about. There's also the reconciliation piece that comes from it as well. And I think we have to be really honest that COVID did not just reveal disparities that were new, like these disparities have existed far too long. And if we're not really using data -- and, again, there are some people who use data in kind of like a predatory type of way, and I don't think that public health, in general, is using data in that way. I think we have to be very mindful that even if we're well intentioned, that we can still create harm because we're in systems that have historically created harm, and so that's why we have to be mindful of it.

And so restorative justice, in my opinion, really forces or focuses on liberation. And for that to happen, I think that we have to, again, name harm, but also look at ways that the community is able to have agency to say what they need. And looking at how do we use data to provide communities with what they say that they need, recognize that communities have the power and have the ability to be able to address disparities that are present, or at least to be able to name those disparities that are present, and even for are provide solutions on how those disparities can be fixed. So, if we can come together and allow the community to use data to address things in the way that they see fit, I think we're moving more towards a restorative justice type of approach, because we're naming the harm, so we're also shifting power to the people who need the power, because they've been deprived of that power for so long.

[Vivian Singletary] Thank you, Artair. Very, very, insightful. I want to go to you, Alastair. I have some good questions for you here. So, you're working in the Seattle/King County area. Can you share with us the specific problems that you're solving as it relates to this equity-based data, this equity-focused system, and how are you going about addressing them, and what specific data are you working on? Can you give us some insights to that?

[Alastair Matheson] Yeah, sure. I think I'm going to talk about, like, the nitty-gritty day-to-day stuff I do, and then I'm going to take it up a level and think about the bigger picture. So, on a day-to-day level, you know, what I do is think about how to ingest all these different data sources that we get from all around the place in an efficient way, to process them more efficiently, and I think a lot of times linking them altogether. So, we have here in King County, what we call integrated data hub. So, this is the centralized behemoth model that we have, and that is bringing together the behavioral health data, management data, Medicaid claims data, booking data, health care for homeless network data, all these different sources that we generate and/or use within the county, from across public health and our communities, and human services side. We're looking at adding in public housing data, which we already link to Medicaid and other sources, trying to get that in there as well. We're starting to think about the integrated data, and we started to use it for many planning purposes, programmatic and policy purposes.

Just this morning, we were talking about thinking about how we can use this data serve for folks experiencing homelessness in the area, which is a big problem in the King County area. Housing prices are through the roof. We have a huge crisis in housing affordability, and there are a lot of people who experience homelessness. So, part of what we're trying to do is use the data to really be able to data serve. So, that's sort of the day-to-day, like how do we make this happen, how do we put in place data governance structures to make sure we're using it appropriately, how are we protecting the data, those sorts of things.

On the bigger picture side of things, one thing I'm excited that we're going to start working on is some work with AISP, that Actionable Intelligence and Social Policy. And now that we've built this integrated data hub, we recognize it's very internally focused. But that the data belong to others, and are generated by other, and so we're going to embark on a process to figure out how we can engage with communities - - whatever definition we're going to use for that, I'm not entirely sure yet -- how we can engage with community in governance and use of this resource.

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So, it's all the points that we've done before, all the speakers done before, we're actually going to try and figure this out. I'm not saying we're going to guarantee it. In the back of my mind, we have this fear we're going to go out and say, hey, we've putting all this data together and people are going to flip out, and it's going to be a negative process. We're hoping to not do that. We're hoping to talk through the potential benefits of having a data, bringing it together, but also get input on how we can better manage it, better use it, make it available to help the community. You know, that's why we're doing this. So, I'm excited for that work. Let me think.

So, just some other points, I think one think public health is really good at is pointing out problems, and so I'm going to point out the number one. So, we're able to get together and say, look, there's the problem over there, with this population over here. And we may even point to the structural issues. Red lining has led to the segregation, which has led to this, and even public health, I think we're getting better at doing that. But it's not always within our ability to control the solution. So, I just think we need to acknowledge in public health that we don't want to always be the ones to point out problems. We need to be engaged and find solutions, so we can actually do that.

One last thing I'll talk about, and another reason I love working at King County and sort of in this health department area is -- so like many places, we have declared racism as a public health crisis. This didn't just come from a small part of the county. It actually came from leadership, from the executive office. So it's a truly organizational-wide attitude now around recognizing racism as a public health crisis, and that now infuses a lot of the work we do, how we think about the work we do. And equity has all been very essential in the work we do, but now it's really taken on new levels, specifically as it relates to racism.

So, I think that, you know, those early days as to how [inaudible] work, but I'm starting to see that now, even down to how we even collect race/ethnicity. And one of the things you need to do when you collect data is figure out how key things just causing demographic profiles when you're putting people together. This system says they're an Asian female, and over here the system says that it's a black Caribbean transgender man. How are we going to reconcile these things? Well, this system has the ability to put multiple levels of gender diversity to say this system binary construction.

So, I think that is an area I also started thinking about, how to improve our data collection system to make sure they select the people that are in there, and that they're selected in a way that the people who are in there might surprise themselves. It's a very common story to see, you know, white as the default option when there's nothing else provided, and things like that, which drive me crazy, and so we work with the departments to try and improve them. So, there's another piece, and I'll stop there and see if you have any thoughts.

[Vivian Singletary] Yeah, that's great. And I think you started to get at some of my next questions, which are, what are some of the innovative data collection methods, especially for specific communities, like you were talking about, trying to reconcile these things? Where should standards for public health data be established, and are policies needed to provide guidance? So, you used a specific example of racism/ethnicity. Do we need standards for these things, you know, and do we need policies to guide how we develop these standards?

[Alastair Matheson] I'll go to the innovative part first, because one cool thing that some colleagues of mine have done is we have an initiative here [inaudible] for kids and that is really a huge program that aims at improving health and wellbeing of children and young adults. And it's probably that we do a survey -- yes, we do lots of surveys -- of our community, of caregivers in our community, because we don't really have a lot of information on kids from birth and teen years. There's a gap where we don't really collect information on that age group, so we built a survey to generate a lot of quantitative numbers.

But the next step we did was to take those numbers out to specific communities, and we held community cafes and we generated data placemats. We made placemats and said, hey, these are the numbers, and this is number specifically for the community, the Marley Group, whichever one it was, the transgender LGBT community, and say, do these numbers resonate with you? And so, there was a focused qualitative

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data collection piece that came with that. We're still trying to figure out how to best represent those two quantitative, qualitative data collections. We put them out on our website and things like that.

But I think that one way we should be thinking about contextualizing all this quantitative data that we get is to go out and ask people, does this resonate with you? Why not? Why would we see this number or what would you expect it to be? So that's one, the innovative data collection we did. Are these the standards? Yeah, it would make my life a lot easier if these were the standards. But those standards have to be not just imposed from one part, so they have to be reflective of the community that we're trying to serve, but also probably, honestly, just within the national picture, because CDC is always going to – and federal/state level are always going to want to stock up data. But at the local level, that doesn't always work.

So, here in King County, we have a large African population, so it's no good to just have “Black” as an option. We really need to drill down and say, you know, even specific to Malawi, Ethiopia, other East African countries. We have a large Ukrainian population in which we might want to differentiate Russians and other Eastern Europeans. Other parts of the country do not care about that nuance, but that's really important for us. Whatever standards exist, I think has to work at the local level, but then also be able to apply at the national level. Yes, I am all in favor of standards.

[Vivian Singletary] Thank you, Alastair; very insightful. I think we have time maybe for another one or two questions before we get ready to transition into Q&A. I want to toss out this question here. And this one I think is leaning towards you Dawn. We talk a lot about security and privacy, but every time we open a newspaper, we see data leaks. How can we build trust in the public health community when we see these things happening? What are things that we need to consider, from the public health perspective, to make sure that we are securing data in a way that is to a high standard in securing people's privacy?

[Dawn Heisey-Grove] I'm just going to start with saying there are smarter people in my organization than me on data security and privacy, so I'll just do my best to channel them. I think it comes back to, I mean, first and foremost, training and just ensuring that we're all following the right policies in terms of setting up our infrastructure and leveraging the best practices that we know exist. If you follow those, then those data breaches, you're not going to hit those on the front-page news if you follow the best practices and you keep that secure.

I think somebody, earlier in the segment, mentioned making sure that folk understand when and how data are going to be used, and if there are risks about data privacy being breached, then I think they need to be aware of that, if it's something that is like that. I think public health does a good job at trying to make sure that when we release aggregate data, we don't release it at an identifiable level. But that starts getting into that mental area, where are we releasing it so that it's actually usable and interpretable and meaningful to people, or are we breaking that trust? So I think there has to be a balance there, which is, again, as I think everybody at this point has mentioned at least several times, there has to be a conversation with community members who know best about their communities, how the data can be used, how the data can be shared in a way that is respectful, maintains privacy as much as possible, because the more we release data, the more easily it becomes to reidentify those data, so there will be tradeoffs, I think, going forward.

[Vivian Singletary] Yeah, thank you for that. We know that it's tough. You know, I've always heard that systems are only as good as the people that are using them, because it's the people that are oftentimes the leak, and not intentionally, so very good points here, Dawn.

Before we wrap up here and go to Q&A, I want to go to So. I want to ask you a question about funding in the space of modernizing systems. We're talking about this equity focus here. Can you tell us, from the world of philanthropic funds, who is supporting this work, and how long do you think funding will continue to support this massive data transformation that we need to go through, and particularly with a focus on equity?

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[So O'Neil] Yeah, thanks for that question, Vivian. I would say that a lot of folks have been involved in thinking about data tangentially or directly, public health data, and informing the public health data system. It is not one organization premise to be able to do this. I mean RWJF has been very involved in speaking with government agencies and communities and kind of trying to be the bridge and the facilitator of thinking about what a transformed public health data system might look like.

And then you have other funders, like Rockefeller, that are very much putting their bet on data and data science as one of the key tools to answering social good and for being able to forward and advance social good. Then you have Bloomberg who has committed data to public health and so on as well. And so you have a bunch of big players in the philanthropic field being committed to this. How long will it take? How long will this investment continue? I hope that the revelations of the inequities and the reckoning that we've all had to save means that there will be investment until we get it right, which I hope it is in the near future. But I don't know how long it will be. But at least for the next decade is what I would say.

You know, data is so integral to information, and it's integral to power, and we need to shift power in this country from where it is now to those that really have not had it and have not been heard, because they're the one that know the most about themselves.

[Vivian Singletary] I agree, So. Thank you so much. I'm going to give each panelist a final word before we transition to Q&A. So, I'm going to start with you, Artair, your final word on this panel, what do you want to leave the audience with?

[Artair Rogers] Oh, first, I just want to say I really appreciate all of the comments from my fellow panelists. I feel like I was taking notes on what you all were saying because I was learning from you all as well. Yeah, I just think that thing that I want to stress is that making sure that we understand that even well-intentioned data uses can unintentionally create harm and making sure that we are bringing the right people in or shifting power, as So was saying just a moment ago, to the people who know themselves the best to reduce that harm, or even, hopefully, to eliminate that harm. So, I just want to make sure that we're stressing the importance of mapping harm, but also bringing people in who are from those marginalized groups who can -- who are best equipped to tackle that harm and create more liberatory data systems.

[Vivian Singletary] Thank you, Artair, for your final words. I'm going to go to you, Alastair. What do you want to leave with the audience today about this important topic?

[Alastair Matheson] I think it's great that we're having these conversations. It's really easy to get focused on a technical solution or a particular legal agreement or legal requirement or some sort of really nitty-gritty kind of thing. But it's really important that we keep stepping back, think about what equity means in the sense of data, and how we can operationalize that, how we can turn that into action in the systems that we are working with, that are great. At this point, that means getting the right people to have that conversation. So, yeah, I think it's great that we continue this conversation.

[Vivian Singletary] I appreciate that, Alastair. It's very important, having the conversation. I'm going to turn to Dawn and then to So to finish us off. Final words, Dawn.

[Dawn Heisey-Grove] All right. So, I appreciate everybody's perspective, and I somewhat feel guilty for turning it to the technological piece. But I think there's two technical pieces that kind of blend with what everybody else has been talking about from a technological perspective. We need to make sure that we develop not only a system that can capture data to allow us to understand equity and wellbeing throughout our community, but also enable non-technologically enabled public health agency, staff, entities to do that work themselves. We can't hear their voices if they don't have access to this data, so we need to make sure that we're building a structure that is equitable for public health staff.

And then the second piece, which goes back to the conversations we were having about machine learning and making sure that those are bias free or as bias free as we can make them, we need to be

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measuring everybody, not just the people who are in the health-care system or the community system or the governments right now. So, I think that's the other key piece we cannot forget.

[Vivian Singletary] Thank you, Dawn, for that measuring everybody. And, So, you get the final word.

[So O'Neil] This is a lot to have the final word with such an esteemed panel, as you were saying, and really appreciate everyone's participation. I am blown away by the different perspectives and the knowledge, and the knowledge that we're all trying to row in the same direction here, which is very powerful and in and of itself.

I think the last thing that I would say is that to create this vision of what a transformed public health system requires many people to talk, and I think philanthropy has a large role from facilitating those conversations, between the technology folks, between the governments and the governance and the communities, and I think that there is an opportunity here for us together, along with philanthropy, to move forward with that conversation, and what does it look like, what does it mean [inaudible].

And the other thing I would say, too – sorry -- is that data, as we think about it, is not -- I think we need to expand our definition of data as well, especially as we start to tackle systemic and root causes of inequity. And so, our traditional data of, like, little units and little zeros and ones may not work as measures for us, data, to inform whether or not we're truly making those systemic and broader changes.

[Vivian Singletary] All right. Thank you so much, So. That's very insightful. I love the way that each one of you gave your insight, and I just want to thank you for allowing me to be your moderator and to get such great insight and answers to these difficult questions and topics that we're all trying to tackle as we go through and transform our information system. So, without further ado, I'm going to turn it back over to Deliya, who is going to step us through the Q&A session. Thank you, Deliya.

[Deliya Banda Wesley] Thank you, Vivian, and thank you to our panelists. This has been a really, really rich discussion, and the good thing is it's not over yet. You can say a final word, Vivian, but there's more to come, and I think it's important that some of that comes from you as well, and so wanted to give you an opportunity to participate in the Q&A.

So, thank you to everyone who has been submitting questions. We've been monitoring chat, and there are a lot of questions to get through, so we'll do our best to get through as many as we can in the time that is remaining. And so, I'll just go ahead and jump right in. And I will pitch that some of these are very specifically for certain panel members, but I will invite each of you all to chime in when the response -- if you have a response. Please feel free.

So, there are a few technology-specific questions that I can start with. First live question received is that, big data and machine learning are often mentioned as a step forward in improving health equity; however, algorithms and big data often present the structural inequities of the world and are not bias free. Can the panelists say more about how we can move past these issues? I know, Artair, you started to touch on these in some of your earlier responses. I'll give you first right of refusal there. And, Vivian, if you want to chime in on that one as well. So, can you please say more about how we can get past these issues of AI and bias.

[Artair Rogers] Yeah, I really appreciate the question. I think I'm thinking about bias, particularly between measurement bias in particular and deployment bias, and I can start off, first, with deployment bias. So, when we any through algorithms and machine-based learning, a lot of times there's some type of product or something that we're trying to get at using that. I think a lot of times machine-based learning and algorithms in the health care concept is being used for risk assessment purposes.

And so, I think as we think through the final product, it's really important to think through what type of harm that a risk assessment could do, so thinking through what are the ways that a risk assessment can be helpful from a clinical perspective or whatnot, but also, I think, are there some unintended consequences that can come from the use of a risk assessment. Again, I think everyone has talked about

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the need to pull community into that process to have that type of dialogue. But I think recognizing what the end product could do could be something that -- you know, one way to mitigate harm.

Another thing is just looking at the data that goes into machine-based learning or into an algorithm, and I think really understanding the measures that we're bringing into those processes, do they accurately measure whatever we're looking to measure accurately across all the subgroups that may be involved in that? So, you know, the way that we measure a particular notion for a general population may be bias or can present some type of disparities for different racial ethnic groups, or groups based on gender or sex not at birth. So, it's helpful to be mindful of not only just the way that a measure construct looks across the entire population but also the substance within that population as well and seeing if there is a way to address it.

And I just think it's really important to understand if what we're trying to measure, if it's just oversimplifying something that is a little bit more complex. And I think that goes into root causes. So, if we are using machine-based learnings or algorithms to just stay at the surface level instead of looking at little bit deeper, is that measure continuing to perpetuate or is that machine-based learning continuing to perpetuate something that is at the service level and we're looking to invest and pour all of our money into that, that really hinders us doing some of that root-cause analysis work. So those are three ways that I think that we could really address some of the biases that may come up in machine-based learning and algorithms.

[Deliya Banda Wesley] Thanks, Artair.

[Vivian Singletary] I can jump in on here.

[Alastair Matheson] Go ahead, Vivian.

[Vivian Singletary] Oh, Alastair, you want to go?

[Alastair Matheson] No, you go ahead. I'll go after you.

[Vivian Singletary] Okay. When I think about -- you know, I'm an engineer at heart and I love AI, but it's definitely not without bias. And there's a couple of things that come to mind when I think about algorithms and bias. The first thing that's critically important is that any type of AI has some type of governance structure associated with it, because we need to make sure that we understand the things that we are trying to program this system to do, and we need to make sure that we have enough diversity and insight when this governance committee to bring things to bring things to the surface that may not be detected if there is no diversity there.

The other thing that quickly comes to mind for me is test data. Often time, test data for AI algorithms tend to not have diverse datasets; meaning, people of color are not included, you know, different types of circumstances. It's kind of a fairly narrow use case that is often used to test AI. So, I think we have to broaden how we think about bringing data for testing, and I think we need that governance committee to give that oversight to make sure that we're doing our due diligence so that when we're putting out new technology, that we are addressing as many of those issues and mitigating them up front before we reach the final product.

[Deliya Banda Wesley] Thanks, Vivian. Alastair. It sounds like you had a response too.

[Alastair Matheson] Yeah, I was looking to build on that. I mean, I think, first of all, people throw out machine learning, algorithms, and there's a lot of mystique around it, and, really, it's just like linear regression. There's really a lot of likes, actually, quite simple stuff behind it, and people just grab buzz words. So, you can also key apart that and recognize it's a fairly simple process that's happening across it. It's not some electronic neural network that deciding our fate. And partly because of all the points that have been made, I think there's a true moral and ethical imperative that whenever you are introducing any

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algorithm derived solutions for targeting resources, allocating resources, there's needs to be [inaudible] to evaluate. Is working as intended? Who is harmed? And then is there unintended consequences?

I think we saw a lot during the pandemic of people throwing out models of predictions, and huge decisions being made on these model estimates that no one went back, necessarily, and said, oh, we got this really wrong, how can we better next time [inaudible]? We just made more models to predict outcomes. So I think there is a key need to connect part of that governance to evaluating [inaudible] through assess [inaudible].

[Deliya Banda Wesley] Thank, Alastair. I'll keep moving. And I think this actually goes to ewe, Alastair, speaking specifically about technical assistance. So, what kinds of technical assistance services would be most valuable in helping health departments and the user communities to achieve increased equity in data systems.

[Alastair Matheson] Yeah, so for this one, again, I'm going back to [inaudible], his example, and [inaudible] said it's a real commitment to not just contracting with the usual suspects, the bigger organizations, the ones who are used to dealing with the county with a lot of bureaucratic processes and the requirements, and to really try and reach CBOs, community organizations, that haven't traditionally been reached. And so, part of that was allocating money to provide technical assistance to smaller community groups or people from groups we haven't worked with to help them navigate both the application process but also the data process, because we ask people to demonstrate the need using this data that we have collected. And so, there was a lot of work and resources committed to helping those community groups. At least know this stuff exists and how to use it and how to put it into a plan. And I think that's really essential. I think we really did change the way that we typically run a contract, and I think we're looking to build on that beyond just the [inaudible].

[Deliya Banda Wesley] Dawn, can you add to that in terms of technical assistance?

[Dawn Heisey-Grove] I want to take a flip side on that and not just about collecting data to address equity but also equitable system of -- equitable technological resources for all the public health agencies that want to use it. So, you know, I think creating open source and low-code solutions that anybody can pick up and play and use, I think, is going to be important. Again, assuming they can ensure data privacy and security and appropriate interpretation of the data are important.

For example, one of the things that we're building right now with a public health lab is the ability to low code web-based interface that allows other public health labs who don't have genomic sequencing capabilities to upload their samples so she can run them for them and run them through her analytics platform. So, as we build out new solutions, creating open source, repeatable, shareable technology that can be easily plugged into anybody else's hot environment or wherever so that they can play that and use those systems, I think, will ensure that kind of equitable use.

I also think we need to educate our public health staff on the art of the possible in the cloud. I think we don't know what we don't know; right? I'm not saying everybody has to become cloud experts, but I do think understanding how data can be secure and easily used in the cloud and much less expensive than if they were trying to do it on premises is something I think is really important as we move forward, make sure that basic level of understanding is there.

[Deliya Banda Wesley] Thank you, Dawn. There are so many questions here, I wish we had time to get to all of them. But I do want to address this, because it's come up in several of the responses, in terms of having that community participation or engaging community members or individuals with lived experience in these efforts, so in data collection efforts. And there are a couple of questions in regard to what does that actually look like, and can you provide sort of practical examples of what it looks like to engage community member, both for individuals with lived experience in these data collection efforts? Artair I'm going to look at you on this one.

[Artair Rogers] sure.

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[Deliya Banda Wesley] And, so, perhaps you have examples for us.

[Artair Rogers] Yeah, I think that in my work, what I've seen first is, especially engaging community members, folks with lived experience, it's important to show that their decision-making is going to be reflected. So, I remember working on a housing project in particular, where we really started to implement weighted voting. So, we were bringing in community-based organizations, social lived experience, health-care system, all to the table to really address a particular issue. And we wanted community members, both the lived experience, to understand that they would be driving, yeah, just how we moved forward.

And what we started to understand was that, because these individuals had not been given power before, that it was really important not to just say that you have power but to really show that. So, we focused on some things that people may think is simple, like bringing people into a room when we're thinking about governance, and really focus on shared language, which means that folks coming from institutional powers really have to check how they're using acronyms and certain language, and we had to model the importance of, hey, can you clarify, like, what the acronym meant to allow community-based or community members and folks with lived experience, and others, to be able to raise their hands and say, hey, we don't understand what that means. You need to use that in common everyday language. And soon, people in this shared environment started to understand, like, hey, I can't come in with the same jargon that I'm used to presenting in a meeting that I'm in in the office.

The second thing was really thinking about shared outcome. So, creating dialogue between these different groups, but allowing community members to hear all the perspectives but also be able to have power to direct which way this initiative moved, and so I mentioned before, we brought in weighed voting, where, whenever we made a decision, oftentimes the community member or the person with the lived experience vote was worth, like, I think it was around three times as much as an institutional partner's vote.

So, community members, even though they were less than bringing the community-based organizations, and even the health-care systems combined, their voice actually was worth more, and you saw the validation and participated in the activity in seeing that their vote was worth more, that really began to drive, like, hey, the initiative is being directed by communities when we think about investments and the data that we collect is directed by communities. So, those are some things that I've seen where it can be effective in allowing community to dictate how things move forward when it comes to data collection, and just governance overall.

[Vivian Singletary] So, I appreciate that response. So, I just want to tug on something that Artair said, and it relates to another question, and then I'm come back to you. I think there's a tightrope that we walk here between going to the community, involving the community, and also burdening the community; right? So, could you touch on how you balance that community burnout and capacity with the significant need to involve the communities, either in data collection, analysis or feedback, or interpretation. How do we get at achieving that balance?

[Artair Rogers] Yeah, I think in that community initiative, in general, we kind of just had an open rule that, like, community members could float in and out, understanding that if we're bringing in the folks who are most marginalized, you know, we can't hold this group to the same understanding that, like, hey, they can make every meeting or that there is not a live circumstance that can get in way of their participation. So we were very flexible on the fact that, hey, you can float in, you can float out. Your expertise, your lived expertise is extremely valuable.

We had to really think through when we scheduled the meetings. I know that sounds like something simple. But we were taking into consideration that there may need to be stipend provided for daycare. We always made sure that there was a meal; that you could take food away from the meal, that that was just a norm. But that we, as people who are coming from institutions, if we were really serious about this, that we cannot expect people to meet in the window where we are in normal business operating hours, so we adjusted that.

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And then the folks who were doing the community engagement also had to be willing to do prep meetings, to go over materials to make sure that all the questions were answered before we got into the meeting so community members or folks with lived experience felt very prepared to engage with the discussions that we were talking about. So, we wanted to make sure that all folks with lived experience came in with their expertise ready to go, and that they were on the same playing field, and sometimes even a little bit more prepared than some of the institutional partners that we partnered with.

[Deliya Banda Wesley] Thanks, Artair. So, Vivian, it looks like one of you were preparing to respond to that as well.

[Vivian Singletary] Yeah. I just wanted to say thank you, Artair, for such a detailed answer. And I think one of the key things that Artair said, just in short, is establishing trust, and that is critical, and I think that's something that many of our public health agencies can start to work on now, is, like, going out and building those relationships and building that trust with a community-based organization, because it's not like you can just show up and all of a sudden, they're going to want to work with you very closely and trust you and believe what it is that you say. So, building those noble relationships is critical.

[So O'Neil] And I just want to build on that too, Artair. I have this other mantra that I sometimes get made fun of for as well, and that is that communities should decide for themselves what is burden and what they consider burden, and we should not be defining that for them. They should be telling us what they want to be involved in and how they want to be involved.

And I think the other piece here is trust and credibility, that you all have touched upon in terms of engaging with communities. That's like the first thing is, you know, as an institution, we don't have a lived experience or understand, potentially, the total reality of a community, and so we need to engage with community-based organizations or community leaders that do understand that, and then work with them to decide what data sources are credible and, first of all, what the problem looks like for them. What are the facts of the problem generating those research questions or those questions that need to be answered, thinking about what data sources are credible and feasible for answering those questions with the community, whether it be a community advisory committee or, you know, open listening sessions, and so on. Those are some tools that have been used.

In terms of data collection, we have engaged with community members to do the actual data collection, because we understand there's trust in providing and giving over your data. And then in the end, I think, Alastair mentioned data placemats and data walks have been used as potential tools to engage communities and make information digestible and relevant for them to tell us what actions can be made or how the data should be interpreted and what it really means, and not put our lens on what we think the data really means.

[Deliya Banda Wesley] Thank you, So. All right, mindful of time, three minutes, so many questions to get through. But I will end, I think, with this one important one that came in that says, "This group is working to reimagine public health data to address disparities, but no one from minority-serving organizations is at the time, is this not just more of the same? Will the panel please weigh in on how this is different." What are we doing different? Vivian, you're nodding, so I will start with you.

[Vivian Singletary] If I heard you right because you went out on the last piece, so the committee is not a diverse committee is what I'm hearing. Is that what you basically said? And I think it's -- yeah, it's time for that committee to look at who they might be able to partner with to bring them in so that they have more protective and diversity around the table. So, I would say, yes, it's a little bit of the same. You know, having diversity at the table through that lived experience is absolutely important, but also being prepared to ask the right questions amongst the committee members that are there. So, it sounds like there's already a recognition, like, hey, something may not be right, and we need to go out and seek something different. So, I think that just asking those questions is pushing you in the right direction already.

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[Deliya Banda Wesley] Thank you, Vivian, and thank you to the panelists. Unfortunately, we are at time, so you actually do get the last word, Vivian. And I want to thank you all for joining us for this great discussion. An extra special thank you to our panelists and moderator for today, and for everyone behind the scenes at Mathematica who made it possible to convene this session.

Just a quick reminder, the recording of today's event will be available in the next 24 hours, and you can access it using the same link you used to join the live event today. So, with that, I will wish you all a great rest of your day and thank you again for joining us.