**Data Access in Public Health**

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**Sasha Tretyakova (ST):** Welcome to Ideas for Practice, a podcast of the Region V Public Health Training Center. As one of 10 public health training centers across the country, the Region V Public Health Training Center seeks to strengthen the skills of the current and future public health workforce in order to improve population health outcomes. We hope that this podcast will share insights and spark ideas among those working in public health practice. Thank you for tuning in to our episode. Today we're going to be talking all about data equity in public health. I'm your host, Sasha Tretyakova. In this episode, we will gain insight on the role of data equity in public health, explore barriers to equitable data practices, and provide strategies for ensuring inclusivity and fairness in data collection, analysis, and application.

Our guests today are Janie O'Donnell and Maris Brummel from the Kent County Health Department, which is in Grand Rapids, Michigan. Janie is a Public Health Program Supervisor in the Center for Community Health Strategy, where she works to advance health equity, develop better community engagement practices, and strengthen the linkages between academic and public health practice. Maris is a Public Health Epidemiologist. She facilitates the community health needs assessment process and provides data support to Kent County Health Department teams and community partners. Welcome to the podcast. Janie and Maris. I am so excited to be speaking with you today.

**Janine O'Donnell (JO):** Thanks so much for having us.

**ST:** All right, can you start by telling us a little about yourself and about your work? We'll start with you, Janie, and then go to Maris.

**JO:** So thank you. I think you covered a lot of my background currently in that introduction, but I can share some information. I've been working in the field of public health for close to a decade. I started with my master's in public health at Brown, and while I was there, I focused on health disparities and infectious disease, and that kind of common thread has really been throughout my entire career. My first few jobs out of grad school were focused on substance use disorders, and then in 2018 I began working at the Kent County Health Department where now as you mentioned, I do a lot of work in the health equity space and then I'm also manage our academic health department which hosts interns three different times a year, and we also work with clinical providers as well. So sometimes we have nursing students or medical residents on site which is really fantastic.

**Maris Brummel (MB):** So I've been at the health department since 2019. Prior to that I worked for Grand Valley State University doing research for the Johnson Center for Philanthropy. At the Kent County Health Department, we do a community health needs assessment every three years, which is my main role there. So I've been there for the past two cycles along with Janie, and we work closely together on it.

**MB:** So, yeah, I've been at the health department for about six years, but I was born and raised in the Grand Rapids area, so I just feel very connected to the community here and very passionate about public health.

**ST:** Thank you both for kind of talking about your backgrounds a little bit. So our first question to hop right in to our data equity conversation is how would you define data equity and why is it important in public health? Maris, we can start off with you and then pop over to Janie.

**MB:** So data equity, the way we've been defining it and thinking about it, is really the whole process of collecting data, analyzing data, and then using data in ways that promote fairness and inclusion and really just being purposeful about data collection and use and making sure that it's representative of communities, that you are hearing from people that aren't always represented in data. Data equity is really both a process and an outcome of having equitable data. It's really necessary to achieving health equity because the data that you collect really drives the actions that you take. So, if certain groups or certain populations aren't reflected in your data, then the challenges that they're facing won't be reflected in any of the public health improvement efforts or policy development or any of that.

**JO:** This is Janie, just to, I guess, underscore the fact that so much data decision-making in public health is made on the available data. So if you have critical gaps in information that you're working with, that can be really problematic, and you may end up funneling resources in a way that is actually away from the folks who need it the most. And in some ways you may unintentionally create harms to those communities, which is obviously antithetical to public health. So it's very important that when you're making data-based decisions that you have data that is robust and representative of the communities that you serve.

**ST:** It really sounds like data equity is quite critical in this field. What would you say are some common barriers or challenges to achieving data equity in public health? Janie, if you want to kick us off this time.

**JO:** Sure. There are a number of different barriers, and I'll start with ones that I think are maybe a little bit easier to address and then end with some that are large systemic challenges that can be pretty difficult to overcome. But the first is not asking the right questions. So you may ask race ethnicity questions, let's say in a survey, but if you don't ask someone, if they identify as a refugee, immigrant, New American, for example, you've suddenly missed out on capturing a huge part their identity and experience. This is something that impacts their ability to access healthcare, navigate different systems. And, I gave the example of refugee, immigrant, New American, but this applies to obviously different groups or other groups as well. So members of the LGBTQ+ community, veterans, returning citizens, or formerly incarcerated individuals. There are so many facets to a person's experience, and more often than not, with sort of basic survey questions, you're not capturing some really important information. So that's something that can be a relatively easy fix. It's just adding an additional bank of questions.

**JO:** The next thing is if you rely on traditional convenience sampling, and what I mean when I say that is a lot of surveys, because it's cost effective, rely on a method of distributing the survey where you're sending it through your networks, and you may ask those networks to send it through theirs but it really is just kind of the most convenient way to push the survey out to folks. But what we have seen time and time again is that often that sample is going to be overrepresentative of white, highly educated females specifically. So it's really important when you are thinking through how you push out that survey that you're cognizant of ways that you may want to change your surveying approach because if you're not getting a significant number of responses from different populations, you're therefore not able to disaggregate that information and really look at the issues through that lens.

The next thing that is true for everyone, no matter what area of public health you're coming from, is funding. So there are often funding restrictions, ways you cannot spend funding, that may make it challenging to have a really flexible process when it comes to collecting data. The next thing, too, that often goes hand in hand with this is the pace of large systems. So this could be local government, health systems, academia. A lot of these large institutions have really complicated contracting processes that can take quite a long time to navigate through. And in a little while, we'll be describing the approach we took to improve data equity. And while others may like this approach, those two points I just raised about funding and the pace of different institutions, those are pretty significant barriers for folks and may impact your ability to replicate this exactly. So again, as we kind of move through, try to think through how could I tweak something so that it would work in my institution. Maybe I can't do this exactly, but what are the ways that this could translate well in the work that I do.

And then last but not least, a huge barrier is mistrust in systems, whether it is, like I said, local government, academia, health systems. Understandably, we can appreciate why someone may not want to disclose, like if they are a refugee, immigrant, New American. Even if they themselves have a green card or citizenship status, if they're living in a mixed status household, that can be really scary. And certainly some of the other groups that I listed previously, there are very real reasons that they may not want to share that information, especially with a group that they're not familiar with.

**MB:** Yeah, this is Maris. I would just add to that. So I think mistrust is a big one. But how you're communicating with potential participants about the data collection method, whether that's surveys or focus groups, how you're communicating about what happens with the data that you're collecting, and just making sure that you're being transparent. If you're not transparent or if you're only giving limited information, or if you're giving information in a way that doesn't resonate with community members or they're not understanding the information you're giving, that can be a huge barrier as well. And community partnerships are really essential for that. So I think in public health we rely a lot on community partnerships. And if you don't have strong partnerships or you don't have the right partnerships, that can be a barrier to data equity as well.

**ST:** Thank you both for illuminating so many different barriers or challenges that exist. I feel like there are some that public health or people in public health haven't even thought of. So definitely good to go over. Can you share a specific example of one of these barriers or challenges that you faced and how you were able to actually overcome it? Maris, if you want to start us off.

**MB:** Yeah. So, I just kind of talked about community engagement and partnerships potentially being a barrier. We definitely experienced this with our community health needs assessment. So just for a little bit of context on that, we do it every three years here in Kent County, and we collect data through a variety of different methods, a variety of different sources. And ultimately we want to understand what the health status is of our population and what the health of our community looks like. And then we're also, we want to hear directly from residents of Kent County about what the biggest health concerns are, what their biggest health-related needs are, for them, their family, their community. And we take all of that data and analyze it and then prioritize the most pressing health issues that are then addressed by health department, hospital systems, community partners, through a community health improvement plan.

So when we are collecting community health needs assessment or CHNA data, engaging community members is a huge part of that because we want to hear directly from them. And previously, we really struggled with engaging community members who had lived experiences with health challenges or kind of who were closest to those issues and could speak to those issues from personal experience. So we're trying to engage partners, but a lot of the planning meetings that we had were being held during daytime hours. People were attending on behalf of the organizations they worked for. So we were getting a lot of collaborative input. However, we noticed that we were missing a lot of key sectors and also community members. They just weren't able to attend daytime meetings and volunteer their time to participate in planning for CHNA data collection.

So in 2022, a group called the Health Equity Council formed. And this is a group of residents and community-based organizations who represent different populations of Kent County. And we recognize that this group is already meeting. They had evening meetings so community members could attend outside of traditional 9-to-5 hours. Community members were compensated for attending meetings, so they're paid for their expertise and their involvement. And so we aligned community health needs assessment efforts with the work of the Health Equity Council, so we didn't have to create a new group of residents to get input from. And because this group had been established for a few years, there's a lot of just intentional relationship building invested in that, which is huge for trust.

**MB:** So, working with the Health Equity Council, we talked with them about different ways to improve the CHNA surveying process and what were the best ways that we could connect with their communities and hear directly from them, and different ways that we could get people from these diverse communities to participate in the survey and contribute their voice to the needs assessment. And we heard a lot of different things about, different communities face different barriers, and that community leaders were really in the best position to address these barriers because they were so different.

So for the 2023 community health needs assessment, we partnered with different community-based organizations serving populations that we really wanted to hear from that had been underrepresented in past needs assessment data. And we worked with them, we provided a stipend for them to do the work of engaging residents in their communities in the process, communicating what the survey was, why it was important, what would happen with the data and how it would be used. And we really relied on those partners to collect surveys, but more importantly, collect that data from communities that we had been missing before.

So we were able then to take that CHNA survey data and disaggregate it by those different communities, different demographic variables, and provide that disaggregated data back to those community partners so that they had specific data on their communities. And because the community should own that data, so we provided that data back to them, but then we were also able to use that data in the overall county's needs assessment and really make sure that the needs and voices from those groups were represented.

**ST:** It is really inspiring to hear that you were able to conquer this sort of barrier/challenge that you faced with CHNA. Kind of building off of that, could you share examples of strategies or frameworks that have been effective in promoting data equity in your organization or community? And how do you know if a strategy or framework is effective?

**JO:** This is Janie. I'll start. Something that I want to plug right away is the KConnect Community Compensation model. And this is something that we will link to the podcast. You can also Google it. But KConnect is an entity in Kent County that aims to ensure all children have a clear path to economic prosperity through quality education, family and community support. They are a collective impact agency. And I would say that they excel at partnerships. And something they did early on was develop this compensation model to communicate with all of the partners they have in their collective impact model, kind of what their expectation was around compensating, especially residents. So if you're calling people in, you're asking them to share their lived experience, you should be compensating them. And they set a standard for what that looks like. And that's something that we routinely use for our focus groups and other types of data collection methods.

Now, I will say the method that Maris described earlier, where we compensated key partners, that was a little different. That exact compensation amount was not reflected in their compensation model.

**JO:** So you do have to be flexible, but it gives kind of a baseline, especially for those one-offs, if you're asking them to attend a singular meeting or participate in a focus group, we found that to be really helpful. So I think that's a great resource for people to use. But for the flexible compensation that Maris mentioned earlier for our community health needs assessment partners, I want to describe that now because that was really effective for us. So she mentioned that we use the Health Equity Council meetings to promote the CHNA. We talked about it really early. That was very important. I would say even more important than that was the fact that we'd been working with them for quite a long time.

At the point that the CHNA launched, we had built trust. They knew that they could rely on us to first be transparent about what we were doing, circle back with them about information. They knew it would be an iterative process where they would be able to give feedback throughout. So that was very critical in getting them to agree to push the survey out into their communities. And what we did was we compensated 12 different community partners that represented gaps in our data. So populations that have historically been un or underrepresented in data, and we gave those partners $2,000 for a five-week survey period. So the survey that we produced was done in partnership with community, with community-based organizations. We had them come and review the survey tool.

So it wasn't as though we just brought them a finished product and said, please promote this. They were actually involved all along the way, vetting questions. They would say, hey, in my community, this would be interpreted this way, or I think a better way to phrase it would be like this. And that was invaluable for us. It also allowed us to really refine our tool. So we had a version of this survey in 2020, and we reduced it significantly in size for 2023, which we knew was going to be really effective and helpful in getting more survey responses. So what we did was we compensated those 12 partners $2,000 each, and we said, however you want to promote this survey in whatever way that works best in your community, go forth and do that. So if you want to use the $2,000 to compensate folks for taking the survey, you certainly can. You can use it to pay staff. There was no rural rules around how they use the dollars. It was just in whatever way was most supportive to them.

So what we heard was there were folks that did door-to-door surveying. So they actually did kind of one-on-one interviews with people. A lot of times that was connected to either literacy or language barriers. We did have the survey available in six languages online. It was available in English and Spanish. And then there were paper versions of the survey in four additional languages. But even so, just because you have a survey in a certain language, it doesn't mean that that's suddenly accessible to everybody who speaks that language. It still is often really helpful to have somebody walk them through it. One of, I would say the most interesting partnerships that we had, it was really exciting, was they're called the Literacy Center of West Michigan, but they do a lot of work with English as a second language learner.

So they have classrooms where they work with parents of a lot of children in Kent County, and they use the survey as a teaching tool in their classrooms.

**JO:** And they actually walked every learner through the entire survey. They explained the importance of the survey, why it was so significant to have their voice reflected in the data. And we heard just rave reviews. People said they really appreciated the ability to share their voice. They liked that the survey was actually something that would be used. So often in the classroom setting, they're using practice forms or things that will not actually then be used in any substantial way. So we heard that that was really helpful. Beyond the kind of one-on-one surveying, we also had people that did email blasts that promoted the survey at different events they had.

So if they had a food pantry event, they might have a postcard with the URL code on it. And so by not telling them, by not being prescriptive, I think that really helped because they able to promote the survey in a way that made the most sense for them and their communities. I mentioned the unique URLs earlier and I want to describe that a little bit more. So what we did was for each of those funded partners, we created a unique survey link that tied directly to that partner. So when they were doing the one-on-one survey, they would, they could either scan the URL on postcards that we provided them with, or they could go online, and there was a dropdown menu where they could select their organization's name.

And the reason that was really important was we were then able to connect a response to their organization. And after the survey closed, we had told them, if you get at least 50 responses, we will disaggregate and provide the data back to you. We were pretty flexible with what the data looked like. So for example, one of the agencies that we worked with serves those in Kent County who have a disability. And we said, do you want just your survey responses connected to the surveys you promoted, or do you want survey responses for everyone in Kent County who identifies as having a disability? And ultimately they said, we want the entire county's data. They also shared that because their agency is relatively small, they really don't have the capacity to create and then administer a survey of this scale. So they took their disaggregated data and used it for strategic planning for a lot of things that they would have liked to do, just they didn't have the time or capacity to do themselves. But this gave a vehicle through which they were able to then have some very specific programming in response to the survey data, which was amazing.

And we heard similar things from other people. Our partners used disaggregated data for grant writing. It's a lot more compelling to say instead of in the same of Michigan xyz, they could actually say in Kent County among our specific population, this is what we're seeing when it comes to food security or housing or whatever the topic may be. So we got some really great feedback there. We know of many partners who have already used that data in grant writing. But just to add a last few points on this framework, I think it's not enough just to provide the data back to people. It's also checking in with them to understand, Is this in a usable format? Are you able to pull from this and do grant writing or do you need some additional support? So kind of checking in on data literacy, which is going to vary by agency, and saying if you need more support, we're able to walk with you and figure out what that looks like.

**JO:** Asking them if you need one-pagers that incorporate infographics and that's most helpful and you don't have the capacity to do that, we can take a look at it.

And last but not least, frequently checking in on the process and evaluating the process as you go is really the best strategy to understanding if it's going well. So the best laid plans, you can do everything on the front end to try to create a smooth process, to try to make an accessible, inclusive approach. And then there may be things that don't quite go to plan. And it's really important to check in with partners. So we were meeting with them once a week for that five-week period. And what I did was I just pulled the data down and I said, your agency specifically has this many responses. This is kind of where you fall. So you're either on the top end of number of responses or you're closer to the bottom. And that wasn't obviously to discourage anybody, but just to let them know, this is how many surveys other folks have managed to get. Can I support you?

At minimum, we wanted to ensure they did get that 50 response number and then anything beyond that was obviously we were very grateful for. And we had, I think our highest response rate was close to 300. So we had one agency collect 300 responses, which was just amazing to see, especially given kind of that tight timeframe. So those are some of the approaches that we took that had really positive impacts. We saw a significant shift in the representation of responses in Kent County. So we saw a move away from Caucasian, highly educated females to... And maybe Maris can speak to this actually. But we saw more responses from the folks that we were looking to hear from. So Maris, I will not steal your thunder because she is the epi, but we are really pleased with how things worked out.

**MB:** I guess to add some context into what Janie just said, because I think that's really important, is in past CHNA surveys, this is a common thing in needs assessments and especially in local public health. But the majority of your respondents, for us, it was like 80% of the respondents were white, female, bachelor's degree or higher. And we know that that's not what Kent County's population looks like. So after that community-led surveying approach that we took, there's a lot more people of color participating, more males, more younger adults. So it just, our sample looked closer to the Kent County population than previous surveys did, but then we also collected a lot of data and had enough data to disaggregate for groups such as immigrants, refugees, veterans, people with disabilities, LGBTQ adults. So all of those strategies really helped us increase responses and just get better data, more data for those communities.

**ST:** That was such an interesting case study. It's great how you all were able to work with the diversity of Kent County as you were looking at all of this data. Public health professionals often work with diverse populations. How can organizations ensure that data collection methods are both equitable and inclusive?

**MB:** So this is Maris. I think there's a number of different things that public health agencies, public health professionals can do.

**MB:** I think a lot of it really comes back to community engagement and authentic, meaningful community engagement. So engaging partners early on in the process, not just having it be a transactional relationship where you only go to them when it comes time to collect data. So you want to engage them early, involve them in the creation of your survey instruments or of your focus group questions, and really get their buyin on the entire data process because this will just help them feel more invested in it. They're exposed to the reason why you're collecting this data and why it's important and what it means for their community. Like, why should their community care about the data that you want to collect? So early engagement is really important.

Compensating partners. So not asking community partners to always take on unpaid labor. You want to pay them for the expertise that they're contributing into your research cycle or your data collection cycle. And then you also want to compensate them for the work that you're doing. So if you're asking them to distribute surveys to residents, then pay them for that work. Just being reflective of your past data collection efforts and identifying data gaps, looking at it and asking yourself, Who is represented in this data? Who's missing from this data? And community partners can be a really important voice for that too, to say, we serve this population and we don't see them represented in this needs assessment. So then going back and trying to figure out how you can hear from them, how you can collect data and hear their voice.

And then creating survey tools in different languages. Most often survey tools, at least in Kent County, are translated into English and Spanish because those are the two most common languages. And translation is expensive and we often in public health are working with limited resources. So we want to be mindful and cost efficient when it comes to translation. So really looking at, is this going to be beneficial when it comes to data equity if we translate this survey into two different languages? If you're doing a random sample, probably not, because residents that are randomly selected, the chances that they speak a language other than English and Spanish is probably pretty slim. But if you're working with partners who are serving populations that speak these other languages and you have that relationship and you know that that partner can collect responses, then absolutely it's worth it to invest in translation so that they're filling out a survey in the language that they speak. So that can be an important tool to use too.

And also being mindful of the survey that you're creating and making sure it's not too lengthy and it's not going to deter people from taking it. So just really looking at, again, assessing those barriers to people participating in a survey and working to address those barriers and also being accountable, being accountable to the communities that you're collecting the data from, because again, it's that community's data really. And they, Janie talked about the many different ways that community partners are able to use that data, and it's really valuable. So closing the loop, giving data back to communities and reporting back and following up with them is important.

**JO:** This is Janie. So I think even a year or two ago, Google Translate was not incredibly accurate and it certainly is not perfect. However, I've been hearing more and more that it is quite good. And an option that you may consider, especially if you want something like a survey tool translated into multiple languages, is having Google Translate do that first pass and then passing it along to a native speaker to review. So you may end up shortening that time, maybe lowering your cost. So that is potentially a cost-effective way to allow the survey to be available in multiple languages. So that's the first thing.

And the second thing is when you are involving community in the planning process or looking at a survey tool, it does take more time. And so some people will point to that and say, this is a reason not to do this. And I would just challenge them to say, how can you start to really make this part of your practice where you are making sure you're building in that time on the front end to get that voice? Because if you have enough, have done enough planning on the front end, you often are able to incorporate their feedback before launching something like a survey or a focus group questionnaire, whatever it is you're trying to develop. But it is so invaluable and the amount of effort it takes to kind of pre-plan is absolutely worth the outcome that you get by hearing from those folks.

**ST:** I think our listeners will definitely be able to use some of those strategies that you both just mentioned. It's really great that we're able to provide sort of actionable steps that can be taken. On a similar note, how can organizations ensure that data-driven decisions do not unintentionally exacerbate inequalities?

**JO:** This is Janie. So I would say the first thing, and the topic of this podcast discussion, is data gaps. So taking a look at the data that you're using to make decisions and trying to really understand, are there significant data gaps? If we're trying to make decisions, programmatic decisions that impact certain communities, do we actually have feedback from those communities? So that's kind of the starting place. I think the next piece is recognizing and being willing to accept that we are not infallible, that we make mistakes. I think a lot of large institutions, especially, may have the best intentions, but there are those unintended consequences. And it can be challenging and hard to hear when you've very carefully planned something and then maybe even right away you hear from folks that they want it to look different or it's not having the intended impact. But it's so important that you remain open to that feedback and that you remain willing to make changes.

And again, I understand the barriers that some people can face when they try to be nimble, so whether it's funding, contracts, whatever the case may be. But I think the more and more we exercise this muscle of getting that feedback, having it be an iterative process that we build, the better we're going to get at it. And if we as a collective in public health can be really stubborn, for lack of a better word around this, and say, no, this is so important, this has to happen. We can't point to time constraints anymore, we can't point to contracts anymore and say, these are valid reasons to not involve community. The more we do that as a group, the more it will just become standard practice, that we have to figure out a way to do it.

**JO:** So I'm hoping that, podcasts like this, and certainly there's a lot of great work going on around the state and the nation, but I'm just hoping that we can continue on that path. And then the last thing that I will say, and it connects to all of this, especially understanding unintended consequences, is having those constant check-ins. So a lot of times, and I think probably everyone listening has been in the position of, you have some feedback and you may not necessarily want to share it until prompted, and so just having someone ask to say, how's this going? We thought that this approach would be good. We designed this program this way because of xyz. Is this working out the way that we thought? What could we do better?

And again, like I'm saying, being willing to receive the answer. So it's not appropriate to ask the question if you know that there is no wiggle room, that you cannot make changes. It is only appropriate to ask the questions when you know that you are able to take that on board and make changes. And I will say if you can't make the change that cycle, whatever that means for you and your world, communicating that back to people and saying, I can't make the change this time because we have a five-week survey period. I can't redesign the tool in these next few weeks. However, I am taking notes and the next time we do this, I'm going to use that feedback. So just being really clear about if there is a limitation or a restraint that for this cycle you can't overcome, just making sure you let people know that in the future you will be integrating their feedback.

**ST:** Do you have any success stories or case studies that illustrate the impact of data equity on public health outcomes? Maris, we can start off with you.

**MB:** Yeah, so one recent example. Going back to the community health needs assessment, in the past, we had asked kind of standard demographic questions, race, ethnicity, age. So, it was pretty standardized for our surveys. And when we started talking to community partners about how we could improve the CHNA data and make it more accessible for community, more useful for community partners, one of our partner agencies that works with a lot of immigrants and refugees and New Americans in Kent County said, yeah, we don't have any data. There's no data in the CHNA for the community that we serve. We are able to get data broken down by race and ethnicity and report the needs of the community that way. But those are very different than what we're hearing from people in our community.

So the needs that people who are born here, they have very different experiences in terms of accessing healthcare, things like that, than for someone who's new to this country. So they had all this anecdotal information about the unique barriers and needs of their community, but this wasn't getting reported up to health systems because it wasn't quantified. And a lot of times people rely on that quantifiable data to drive decision-making. So after speaking with them and understanding that it's really important to ask about immigrant or refugee status in the CHNA so that we're able to have that additional level of disaggregation for the data. So we updated our demographic questions and that in combination with working with these partners to engage members of those communities, so we got a large enough sample size to disaggregate data for them was huge. The success of that.

**MB:** But ultimately we were able to collect data for New American communities and show that there were some pretty unique needs that they faced and include this in the Community Health Needs Assessment report, funnel it up to health systems. And show them that quantified data that they really want when it comes to decision-making.

**JO:** This is Janie. I think Maris did a really nice job summarizing that. The only thing that I will add is related to closing the loop, which we mentioned several times, but the CDC has a data equity landing page, and hopefully we can link that in the podcast as well. But one of the data equity principles that they support is facilitating data sovereignty. So the way that they define data sovereignty, they say facilitate data sovereignty by paving the way for communities to govern the collection, ownership, dissemination, and application of their own data. So just wanted to again mention the importance of making sure that if you are collecting information from groups, that you're connecting them back with that information.

I think oftentimes large institutions act as unintentional gatekeepers to data. Maybe we have more secure networks or whatever it is, especially if it's identifiable data. I would say in public health, we're more often than not working with the identified data, but even so, we, after collecting all this information, we, Maris primarily creates a really wonderful CHNA report that's publicly available, but all of the backend data in theory, in past cycles has kind of lived with us. So this 2023 cycle was the first time that we really intentionally sent it out to partners before being asked. We absolutely have been responsive to data requests.

Previously there were a lot of different entities reaching out, saying, could we have data for these specific populations, if we collected information on them. But I would say this was the first cycle that we were really proactive about connecting people back with their information and then asking, was this a good way for us to share the data with you? All the things I said earlier about just the data literacy piece of it all, but I just really like that idea of data sovereignty and making sure that we are proactively sharing data back with them and just really continuing to underscore the fact that it is available and that we want to share it.

**ST:** As we wrap up today, I want to end by asking if there is one piece of information that you would like for our listeners to keep in mind or take away about data equity as they move on with their day, what would it be?

**JO:** This is Janie. I can start. I think the biggest thing I would want people to take away from this is that data equity is critically important, that the decisions we make contingent on the data we have are so important. The way that we design our programs, we just need to make sure that they're reflective of the communities that have the highest health disparities. We certainly, especially as folks that are trying to create a healthy community for all, we don't want to unintentionally create scenarios where programs are not providing equitable access to everybody. So I would say that's the first piece. It is critically important.

**JO:** And I think you asked for just one piece, but that's not how I do things. So I've got one more thing, and that is that relationship building is just the most important part of this work. And if you're not sure where to start, like if you're thinking to yourself, I don't know what data equity looks like in my community or I don't know what surveying for these different populations could look like, I just encourage you to have a conversation with a partner. And maybe you don't have a big data collection effort coming up right now, but having those conversations early, because then when you do have that opportunity in the future, you've already begun to lay that foundation. They know who you are, you've shared with them why you may be collecting information. And it can just make all the difference. So trying to have those conversations well in advance, and not just the month, week, day that you launch a large initiative.

**MB:** Forming those partnerships, but really letting community kind of take the lead with it and following their expertise and listening to their expertise is huge. They just bring a whole different lens and insight into the work and really being flexible and accommodating, trying to support community partners the best you can, and making sure that they're involved in all the steps in the process.

**ST:** Thank you both so much for joining us here today to share from your experiences and provide some insight on this topic. To our listeners, we hope that you've learned more about data equity and public health, and feel free to check out the transcript as well as resources in the podcast notes. Funding for this podcast is provided by the Health Resources and Services Administration. With that, we will end here for today. Stay safe and stay curious, everyone.

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