

## NATIONAL SUMMIT SERIES: SUMMIT 2

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# Creating an Interoperable and Modern Data and Technology Infrastructure

JANUARY 25, 2022

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SUMMARY REPORT

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# Introduction

## Lights, Camera, Action: The Future of Public Health National Summit Series

A new summit series launched in December 2021 to explore and advance the future of public health with the theme of *Lights, Camera, Action: The Future of Public Health*. This national summit series not only presents a comprehensive and critical view of the current landscape of public health in the United States but—more importantly—it convenes public health workers and key stakeholders across disciplines and across the nation to collaboratively construct a harmonized, strategic and action-oriented approach to move the field forward following decades of underinvestment and two years of a devastating pandemic.

The theme of the summits—*Lights, Camera, Action*—provides a framework through which the field can transform itself to meet the present and future needs of public health in the United States.

- **Lights** are the guiding lights from recent research, recommendations and action plans from leading public health organizations. These exemplars in practice and policy showcase the nation's current gaps and identify solutions to rebuild public health infrastructure.
- **Camera** refers to framing public health through the lens of the pandemic and its impact on the public's trust in the field. Today, there is a need for the United States to refocus the camera to rebuild trust and transform public health. The camera also emphasizes the need for everything public health does and touches to be framed through an equity lens.
- **Action** represents the steps public health officials and partners can take to address the issues illuminated by the lights and captured through the camera lens. Public health officials at all levels of state, local and national governments have a role to play in shaping a public health system built for today's needs and tomorrow's challenges.

The *Lights, Camera, Action National Summit Series* is a collaboration of the CDC Foundation, the National Association of County and City Health Officials (NACCHO), Association of State and Territorial Health Officials (ASTHO) and Big Cities Health Coalition (BCHC). Support for the summits is generously provided by partners United Health Foundation, the Robert Wood Johnson Foundation and the Pew Charitable Trusts.

The summit series grew out of a coalition of organizations brought together by the Bipartisan Policy Center to develop a five-year road map for public health leaders and elected officials. Their goal is to influence strategic investments and decision-making to build a more robust and sustainable public

health system. The reports that came out of that coalition, [Public Health Forward: Modernizing the U.S. Public Health System](#) and [The Future of Public Health: A Synthesis Report for the Field](#), provided the foundation for these summits.

Many of the themes and suggestions that emerged from this summit reflect those in the *Public Health Forward* and *The Future of Public Health* reports while also adding details of individual and shared experiences of summit presenters and participants.

The four virtual convenings of the summit series are focused around key priority areas: (1) workforce development; (2) data and technology; (3) financing, law and governance; and (4) cross-sector partnerships and community engagement. The overarching objective of the summits is that together we can write a new script and produce a new future for public health in America.

This summary report provides an overview of the discussion in the second virtual convening held on January 25, 2022. In addition, a video recording of the second summit is available on the summit series website at [www.futureofpublichealth.org](http://www.futureofpublichealth.org), along with relevant resources for each summit and the series overall. A summary report and video recording of the first summit is also posted on the website, and similar reports will be available following the other summits as well.

This report highlights key observations and themes for action identified by summit speakers and participants that stakeholders can use to guide their efforts to advance the future of public health in the United States.

## Creating an Interoperable and Modern Data and Technology Infrastructure

*“Today we are focusing the lens on creating effective, equitable, modernized public health data systems—a modern data and technology infrastructure that uses actionable intelligence. Harnessing the power of today’s technology to collect and analyze data in a timely fashion to manage public health threats and conditions is a key action in the new script we must write for the future of public health.”*

**JUDY MONROE**, MD, PRESIDENT AND CEO, CDC FOUNDATION

The second of the four virtual convenings of the *Lights, Camera, Action: The Future of Public Health* summits focused on data modernization and technology. Throughout the second summit, speakers and attendees discussed the data and technology challenges faced by public health and how the field can overcome them together. Speakers acknowledged this moment is a turning point for public health in the United States. The renewed attention to the field creates a window of opportunity to fundamentally transform public health infrastructure for an equitable and sustainable future. Summit speakers and panelists described the “hard” technical skills and the technological infrastructure needed to write this new script for the future of public health.

*“The Data Modernization Initiative is a national effort, supported by CDC, with the ultimate goal or north star to move our nation from siloed and brittle public health data systems to connected, resilient, adaptable and sustainable ‘response-ready’ systems that can help us solve problems before they happen and reduce the harm caused by the problems that do happen. Data modernization is really about helping us to get better, faster, actionable intelligence for decision-making.”*

**DANIEL JERNIGAN**, MD, MPH, DEPUTY DIRECTOR FOR PUBLIC HEALTH SCIENCE AND SURVEILLANCE, CENTERS FOR DISEASE CONTROL AND PREVENTION

Summit speakers and panelists also discussed the “soft” people skills and the human capital infrastructure needed to produce this future for public health. Using as examples methodologies that have gained new prominence during the pandemic, such as wastewater surveillance, speakers

described how the process of learning from these data as well as public health sharing their learnings with local communities in real time built the relational foundation of trust needed for equitable, sustainable partnerships in this work.

*“The structural racism that exists in the way our spaces are organized is something we can really focus on, using these [wastewater surveillance] data to illuminate that type of risk—that exists because of that structure—in ways that are not necessarily reflected in other data streams.... I hope we can use these strategies to help illuminate some of those structural issues...and that data would be more and more publicly available so communities can use that to advocate for themselves, to say, ‘this is the risk that I’m experiencing in my community, and I want to make sure my leaders know about that.’ I hope to see it used in that way even more going forward.”*

MARLENE WOLFE, PHD, MSC, EMORY UNIVERSITY

Following the summit plenary, invited breakout group sessions were held for decision makers around the country to strategize how to transform these ideas into action. These breakout group sessions approached the summit topic of data and technology infrastructure modernization from six perspectives aligned with the strategic priorities outlined in the [CDC Data Modernization Initiative Strategic Implementation Plan](#): 1) building the right foundation; 2) accelerating data into action; 3) developing a state-of-the-art data workforce; 4) supporting and extending partnerships; 5) managing change and supporting governance; and 6) assuring health and wellness for everyone, everywhere. An accelerating action report will follow this event summary report with more details on actions to be taken at each level in the short, medium and long term. Check the [summit series’ website](#) for these and other resources for each summit.

Throughout the discussions in the plenary session, the breakout groups and the active chat, several key themes surfaced for how to modernize public health data and technology. This report frames these topics through the summit series’ theme.

- **Lights:** Relationship-building and trust-building will be key to public health’s effective utilization and application of modernized data and technology.
- **Camera:** Equity and sustainability must be foremost in public health’s approach to building an interoperable and modern data and technology infrastructure.
- **Action:** Democratizing public health data and technology to advance health equity can be achieved through transformations in the workforce and in leadership that will enable the field to adapt to the digital age and translate data into equitable action.

## LIGHTS:

# Relationship-and Trust-Building for Equitable and Sustainable Data Modernization

### LIGHTS

- The Role of Relationship- and Trust-Building in Sustainable Data Modernization

Historical and Current Reasons for Mistrust

Data as a Common Good for the Public's Health: Building trust through communication of data

Guiding Lights

When one thinks of data modernization and technology infrastructure, relationships and trust are not the first things that come to mind. However, in this second virtual convening of the *Lights, Camera, Action* summit series it became abundantly clear that is what makes public health data and technology different. While modernizing technical infrastructure is undeniably essential to achieving public health's goals, all transformations must be driven by the desire to improve the public's health.

Behind all the numbers in data and technology are human beings, families, communities and organizations whose values, beliefs and actions are shaped by social, environmental, political and historical factors. This second virtual summit shined a light on the fact that it is necessary to take all these factors into consideration for public health to optimize its data and technology infrastructure effectively and equitably. This can be done through thoughtful and intentional relationship- and trust-building, even though these efforts can—and will—move at a much slower pace than technological advancement demands.

## The Role of Relationship- and Trust-Building in Sustainable Data Modernization

*“The soft issues around data are now way more important than the technical issues. We can solve the technical issues.”*

DALE SANDERS, HEALTH CATALYST

### Innovation through partnerships

A recurring theme throughout summit 2 was that technology is not the most important element needed for modernizing public health data and technology infrastructure; the more essential component is meaningful partnerships. Cross-sector partnerships between multiple, diverse stakeholders are crucial for actualizing the vision of a modernized public health data system, as one breakout group participant pointed out:

*“It will take multiple partnerships and trust for this to be successful. There are so many stakeholders who we have to win over. It’s not about the technology. We know the technology works, and the framework is there, but now we need to win over the stakeholders who are funding, using the systems, and sharing the data. The partnerships between entities, payers, public health and providers will move the needle, overcome challenges and make a difference in health equity.”*

In a plenary spotlight session on actionable intelligence from the field, the speaker told the summit audience the COVID-19 exposure notification tool he was presenting would not have come out nearly as well if the department had developed it on their own, as originally planned. Instead, the partnerships they built with key players in the private sector and in academia allowed them to produce a powerful tool for advancing public health.

*“This wouldn’t have been possible if we tried to do this all by ourselves. We had actually headed down a path of a custom solution. And by instead partnering with Apple and Google and Microsoft and APHO and MITRE, we’ve been able to come up with a product that’s so much better than we would have done on our own. And by evaluating with our academic partners, we’re able to keep making improvements and show the public health impact this new tool has had.”*

**BRYANT KARRAS**, CHIEF INFORMATICS OFFICER AND SENIOR EPIDEMIOLOGIST,  
WASHINGTON STATE DEPARTMENT OF HEALTH

Beyond cross-sector and public-private partnerships, however, the most important challenge facing public health in its efforts to modernize the field’s data and technology infrastructure is building trust with members of the communities it serves. Dr. Gail Christopher highlighted the key role foundations can play in facilitating the necessary trust-building for such relationships.

*“Foundations can be real catalysts for these types of innovation...making sure that local communities have the resources to do the innovative work that has never been done before, to create the partnerships and alliances and the cross-sector collaboration.... Yes, we need the federal investment—and we need cross-sector collaboration—but we also need those innovative investments at the state and local level with communities to help build up that trust and that capacity and those relationships to do what, quite honestly, has never been done before and seize this moment.”*

**GAIL CHRISTOPHER**, MD, BOARD CHAIR, TRUST FOR AMERICA’S HEALTH

While funding and investment to advance this work are very much needed, one breakout session participant noted the requirements tied to funding often create obstacles to the trust-building process that is essential to accomplishing the work being funded.

*“Looking back to the early days of the pandemic, before we had received a single dollar, it was easy to pull off partnerships.... In order to get anything done we had to partner with community members on a voluntary basis and pull a coalition together. Now that the money is coming in, and there’s pressure to spend and be operable within a year, it’s harder to move fast as a community and as a coalition. You end up having to make quick decisions and move unilaterally, and that’s not the way to build a sustainable partnership.”*

Sustainable partnerships require allyship. As Dr. Abigail Echo-Hawk explained in the plenary, there are many leaders in communities across the country who are engaging in public health work and looking for partners to improve the health of their communities. What is required of public health is to truly engage with communities most impacted by health inequities and learn from them how public health can use its power to lift up their work and provide needed supports so they can achieve their goals.

*“It is imperative to bring the message of where the embedded systems of racism are and offer solutions, which include community engagement. I work with health departments across the country, engaging them and working toward systems change in everything from the way that they collect data to the way their epidemiologists are trained and the resources they need.... There are so many of us out there...advocates and folks working on the ground, and what we need is people who will support us and stand with us. I often go into rooms, give this message, and afterward I get a bunch of emails like, ‘Good job, good job.’ Tell me, then. Work it, then. Let’s move forward those plans. I know thousands of people across the country who are waiting for that kind of allyship, that kind of accomplice within county health departments to state departments to the federal government. This is our time, this is our opportunity, we will see change if we make the move now.”*

**ABIGAIL ECHO-HAWK, MD, DIRECTOR, URBAN INDIAN HEALTH INSTITUTE**

### Considerations for stronger partnerships

Plenary speakers and summit participants offered many lessons learned about building meaningful partnerships that will provide the strong foundation needed for data sharing and data-driven solutions. One of the most common refrains was that relationship-building must start early—long before a moment of crisis arises.

*“Building relationships before you need to share the data is what actually is helpful. Because you’ll present the data, you’ll have it, you’ll be able to share with the community members—but if you don’t have those relationships ahead of time, they’re not going to start listening to you just because you have data.”*

**KIMBERLY REPP, PHD, MPH, CHIEF EPIDEMIOLOGIST, WASHINGTON COUNTY, OREGON**

In the breakout groups, participants offered advice on what is needed for relationship-building that facilitates meaningful data exchange and how to get there.

- *“One thing we learned the hard way: we didn’t have the right type of data for action at the community level that allows us to engage with racial/ethnic minorities.... There is no systematic public health approach to engage BIPOC groups in a meaningful way. We need a long-term solution to build engagement and advance change, which will take time.”*
- *“We said this after 9/11 and the anthrax episode: ‘The time of crisis is not the time to hand out business cards to community groups.’ Public health is so poorly funded, but it’s got to get out and know the community. Trust is built on relationships, and relationships take time to build.”*
- *“Strengthening the local relationships and trust that will be needed to undergird and enable data partnerships shouldn’t wait for the federal and state technical guidance and help. Some things need to happen in tandem at multiple levels. Some early local steps may include: 1) identify existing networks and partnerships, including local Accountable Health Communities; 2) identify past relational harms, broken trust, especially with community groups; 3) build from current relationships; and 4) do local stakeholder/partner mapping, asset mapping and power mapping.”*

### Building public trust in public health data and technology

Understanding the value of building relationships that enable meaningful data exchange is so important because relationship-building is rarely factored into planning and budgeting of time and resources when it comes to data and technology infrastructure. As one summit participant noted in the plenary chat: *“Relationship-building is resource-intensive, too.”*

One of the plenary speakers provided a rich illustration of this fact when asked, *“How can public health build a sustainable sense of trust so patients and the public are willing to share information that impacts health and wellness?”* Her candid response was:



## LIGHTS

The Role of Relationship- and Trust-Building in Sustainable Data Modernization

- **Historical and Current Reasons for Mistrust**

Data as a Common Good for the Public's Health: Building trust through communication of data

Guiding Lights

*“Through interviewing and speaking to thousands and thousands and thousands and thousands of community members during COVID-19, doing active case investigation or contact tracing, really having that one-on-one contact and explaining, ‘this is what we’re going to do with this. We acknowledge that we’re asking you very sensitive personal questions. This information will be used to help prevent illness in our community;’ has been very helpful. Because, when you put an elected official up, they may just think they’re talking points or something like that. But that one-on-one contact, although it’s a tremendous amount of work, really has changed the view of transparency of what we’re doing with our data and public health. And we’ve had a significantly different engagement with our interview teams and contact tracing teams after a few thousand rounds of interviewing.”*

**KIMBERLY REPP, PHD, MPH, WASHINGTON COUNTY PUBLIC HEALTH**

Once public health has established the foundation for meaningful partnerships through relationship-building, the trust-building required for solutions-driven data sharing can begin in earnest. As one of the plenary panelists pointed out, that trust-building begins with explaining why the data are needed and what public health is going to do with it.

*“Why do we need the data in the first place and, importantly, how do we communicate to the public as well as policy makers who fund us that getting these data are important to turn it into insight, to turn it into actionable information? Communicating that ‘why’ is important, and that’s how we start to build trust. And when the public and policy makers trust us with their data and see the benefit from those data streams that we’ve worked so hard to integrate and harmonize and gain new understanding from in a rapid way, then we start to build a sustainability model wherein the public is seeing the benefit of this approach and this infrastructure. We start to have sustainable funding streams that let us do more and expand and be more responsive than we were in the past.”*

**ETHAN BERKE, MD, SENIOR VICE PRESIDENT AND CHIEF PUBLIC HEALTH OFFICER, UNITEDHEALTH GROUP**

## Historical and Current Reasons for Mistrust

Whenever public health wants to partner with a community for data collection and analysis, their approach must be informed by a deep understanding of how history may have taught the community to mistrust the field. Fundamental to these reasons is a centuries-long history of institutionalized structural racism.

### Institutionalized structural racism

As Dr. Gail Christopher pointed out in the plenary session, all the talk about social determinants of health (SDoH) really falls flat if public health fails to acknowledge the root causes of a long-held but scientifically baseless belief in the existence of race and racial hierarchy. Much like the pandemic has revealed and provided an opportunity to correct the flaws in public health’s systems, the racial reckoning sparked by the public outrage in response to the murders of African Americans including Breonna Taylor and George Floyd provides the field with an opportunity to change its course toward a more equitable future.

*“Now we talk about social determinants, and that’s become a good mantra, a good buzzword. But we fail to really acknowledge how much social determinants in this society are driven by our legacy of a belief in racial hierarchy. So we have to take the opportunity that COVID-19 has laid bare, the opportunity to tie the racial reckoning with the opportunity to drive toward equity in ways that reflect and honestly capture the history of how racial hierarchy has been institutionalized in all of our systems, particularly at community levels.”*

**GAIL CHRISTOPHER, MD, TRUST FOR AMERICA'S HEALTH**

In terms of public health data modernization, changing course means unpacking the ways in which inequity and racial hierarchy are embedded into every level of our data systems—from data collection to how the data are interpreted and used. As summit attendees noted in the plenary chat and breakout sessions, data systems reflect the biases of the times in which they were developed and the people who developed them, and therefore they require constant re-evaluation and updating:

- *"We need to address the history of structural and systemic racism, including the way questions are worded and framed. Data will continue to reflect inequities if the questions continue to reflect historically racist systems."*
- *"Machine learning and artificial intelligence frequently reflect the bias from the people that build it. That means public health systems have to be constantly reviewed to assure that they are as equitable as their intent was when designed. And you do that by good monitoring and analysis after it's been in place."*

### Disaggregation of data and small sample analysis

One way that data systems have historically excluded communities is by determining that some groups are too marginal to be counted or their data sets too small from which to extrapolate meaningful analysis. In the case of American Indians, this exclusion is demonstrative of institutionalized racism—not only because it elides the historical culpability of the government for the very fact that the population is so small but because it prevents public health from working with impacted communities to implement data-informed solutions to address inequities.

As Dr. Abigail Echo-Hawk explained in the plenary:

*"In the American Indian/Alaska Native community we often call ourselves 'the asterisk nation.' That's because we're often the little asterisk at the bottom of the data that says 'not statistically significant.' Well, I say that's what embedded racism looks like. Because I know with small population methodology you can come up with those data and numbers. You simply didn't do the work, because it's easier [not to] and it costs more money to do. And so that lack of allocation of resources, that lack of just saying you know there was enough data and not looking for how you do that has really caused inequities. So, we have to disaggregate data by those who are most at risk because of the country that we live in. It is an absolute responsibility for us to do that."*

ABIGAIL ECHO-HAWK, MD, URBAN INDIAN HEALTH INSTITUTE

A data expert on the panel with Dr. Echo-Hawk agreed that small samples can be analyzed with some of the new technology available, and he explained how it can and must be done:

*"When we think about some of the technology to support this, some of the things we really need to make sure we're doing it right—as we bring data together, there are ways to do it. And, as Abigail said, sometimes it's a little more work. But you get better data when you do that. And now we can query across data sets and bring data together without necessarily bringing all of those data together in one place. There are ways to bring in privacy-preserving record linkages, for example, to link data across federated data sets and allow public health the capacity to then query those data and look at what's going on. And then you have better data, where you don't necessarily run into those small sample size issues because we're bringing the data together in a way that doesn't allow for re-identification."*

JIM DANIEL, AMAZON WEB SERVICES

### Misuse of data: Privacy concerns and data sovereignty

One of the primary challenges in data modernization for equity is that marginalized communities, for reasons referenced above, have very valid concerns when it comes to sharing their data. Part of trust-building then requires an acknowledgment of the ways data can and has been misused, along with taking steps and setting policies in place to assure marginalized communities that their data will not be weaponized against them.

Much like doctors take an oath to do no harm, the overarching goal of public health—particularly when it comes to data collection, analysis and utilization—must be to prevent harm to the communities the field wishes to serve. This starts with acknowledging the real threat that data can and has been used to cause harm. Participants in the summit plenary articulated this fact in the chat:

- *"I have totally seen that where I used to work, about the Tribal Health Department not wanting to share their data, rightfully so, because of how our systems have used those data and developed 'solutions' by non-tribal members to impose upon them and other disrespectful things done with those data."*
- *"We have to stop ignoring the idea that all of this data collection and sharing can be used to HARM people. And if we don't start focusing on and addressing/preempting these harms, none of this will work."*
- *"It will be important to consider how data will be used with an aim toward protecting the community, not harming it. At a community level, it will be important to understand potential harms certain data collection might have on a population, if misused/misinterpreted. Otherwise, trust can be eroded, and it will be harder to collect desired data.... [We must] reinforce the notion that harms could happen with data collection when we don't consider how it will be used."*

To this end, there are particular privacy concerns that must be taken into account for trust-building. With data disaggregation, for example, while it is important to disaggregate data to a granular level for targeted solutions, small and marginalized populations need assurances that their identities will be protected so their data are not used for harm. Summit participants commented on their current struggles with navigating this difficult balance between disaggregation and protecting privacy in the plenary chat:

- *"How do we disaggregate data in a way that doesn't potentially identify someone? That is what my team is struggling with now."*
- *"How do we protect the privacy of easily identifiable individuals while still meeting their health needs/interests? For example, I am the only male over 50 with a particular rare condition in my entire state. There is no practical way to deidentify me in a way that I can't be re-identified, without eliminating reference to the disease, and there are a variety of unique characteristics about the health condition."*
- *"To disaggregate data, especially real-time, we need to build rules and culture standards that help us manage the risk of exposure/identification. Looking forward to growth in this area."*

Another important issue is the notion of data sovereignty. This is particularly relevant for tribal communities, whose legal authority for data sovereignty is frequently overlooked, as Dr. Echo-Hawk explained:

*"I see this embedded racism consistently, where I see states and the federal government not recognizing tribal public health authority. Tribes and some urban Indian organizations hold tribal public health authority, which means they should be treated in the same way as a state public health department, and yet we fight every single day for this to be upheld. We see it as embedded racism where they question whether or not we have the qualifications, whether or not we should have the right to not share the data with them, and whether or not we have the rights for the analysis and dissemination of those data. And unless we address the embedded systems of racism, we are going to replicate systems of inequity and we will not see the change that we need."*

**ABIGAIL ECHO-HAWK, MD, URBAN INDIAN HEALTH INSTITUTE**

A summit attendee member of the [Indigenous Data Sovereignty Networks](#) proposed the use of [FAIR and CARE principles of Indigenous data governance for data management and stewardship](#) in the plenary chat. And another speaker shared a success story of how her health department developed a good working relationship with tribal health authorities for data sharing:

*"I would be remiss given my work with tribal communities to not socialize the idea of data sovereignty and how critical it is working with tribal communities. We actually mask all our tribal data, and we have a great relationship with two tribes. This was the agreement we've come to. And when they say we can unmask it, we will unmask it. We have a good relationship, yet when I bring up data sovereignty people in my department look at me quizzically."*

**THERESA CULLEN, MD, PIMA COUNTY HEALTH DEPARTMENT**

## LIGHTS

The Role of Relationship- and Trust-Building in Sustainable Data Modernization

Historical and Current Reasons for Mistrust

- **Data as a Common Good for the Public's Health: Building trust through communication of data**

Guiding Lights

Finally, while public-private partnerships can play a vital role in advancing public health data modernization and technology infrastructure, it is necessary to acknowledge potential conflicts of interest when engaging private corporations—some of whose entire profit model operates in the currency of the public's data—in the management of sensitive personal information. As summit participants noted in the plenary chat, people will be hesitant to participate without clarity on how their data will be used. To address these concerns, it will be necessary to engage the most marginalized communities from the beginning of the process.

- *"Lacking clear messaging about data usage and shaky rollout of new tech will prevent people from using tech and improving public health. Many of these efforts were stymied by shady data-sharing practices and lack of trust because of their development by Big Tech."*
- *"Inclusion should happen at the initial thinking, planning and development of new data sets and not be an afterthought. Many of the companies who are contracted to do this work do not have diverse thinkers in the room. [Dr.] Abigail [Echo-Hawk] is correct to involve all of the populations impacted."*

### Data as a Common Good for the Public's Health: Building trust through communication of data

*"The idea of common good is to take data that might have been hiding or burying certain truths about our health care system and unearthing it so that we can make it more accessible for the American people, which means applications that are meant for public health purposes. As they release the data that's held by our largely privately administered health care system, that is itself a vehicle for delivering on this vision of a common good—i.e., the more public health has legal authority to tap data sets and to release them to the American people that virtuous cycle will give us a little bit more openness and turn what was essentially an opaque system into a more transparent one."*

ANEESH CHOPRA, MPP, PRESIDENT, CARE JOURNEY

As described above, it is entirely reasonable for people to have concerns about engaging in data sharing with public health. Public health's investment of time and resources into building meaningful partnerships rooted in trust will establish a solid foundation for this work. But for communities who are still hesitant, another avenue for engagement is through the concept of data sovereignty and data governance. As noted by a breakout group participant:

*"The idea of data governance can be a ruse and a tool to drive community engagement. People have to agree that they want to be a part of this enterprise, and community engagement has to be a continuous public health practice. The principle of 'nothing about me without me' is a great way to foster community engagement and dialogue."*

A breakout group participant also added that frequent communication about how data are being used can nurture ongoing partnerships:

*"Sharing data, discussing ideas/action steps routinely (monthly, as an example) to address what is being 'seen' as a community will drive systems change and create communities that are healthy and thriving. This helps to keep ensuring that stakeholders understand the value of the data and furthers their continued investment of time and resources."*

One of the plenary speakers shared an example of lessons learned in building meaningful, mutually beneficial partnerships from their success in sharing wastewater monitoring data with communities in real time:

*“Wastewater is an example of this really new type of data we’re presenting to communities and asking them to understand... We weren’t sure, at [the beginning], if it would work...so we had to prove it in stages: We can detect this in the wastewater. Now we’re showing over time that this is a really good reflection of cases in the community. Now we’re showing, during last winter surge, for example, that—as we maxed out our testing capacity for clinical testing—we didn’t max out our testing capacity in the wastewater, and so we were able to see the peak went a little bit higher than was detected in the clinical cases in some of our areas... And now, during this past surge, we have had people coming proactively to us and saying, ‘We actually need these data. Where’s the wastewater data? Can you help us explain it? Can you help us understand that?’ So, I think it’s really important that we have open minds to these sorts of new data streams that can provide us with really actionable data, but we do have to put the work into making sure our communities understand... That trust has really been a process, but now we’re able to provide it as an actionable service.”*

**MARLENE WOLFE, PHD, MSC, EMORY UNIVERSITY**

Dr. Wolfe went on to explain some of the key factors that made this project so successful. These include a project that was funded with the explicit purpose of identifying—through stakeholder analysis and power mapping—key community leaders and partners who could facilitate effective program implementation and communication of findings. Additionally, Dr. Wolfe emphasized how the deidentified nature of wastewater data is one of its key strengths to assuage concerns about privacy.

A poll taken during the plenary asked participants to identify the single biggest challenge to achieving an equitable data infrastructure. The most popular choice, selected by more than a third (35 percent) of respondents, was “fostering authentic engagement of communities in the generation, use or interpretation of health data.”

**POLL: A recent Robert Wood Johnson Foundation national commission report on equity-centered data noted “we have an opportunity now to create a data infrastructure that is centered on equity and that creates fair and just opportunities for everyone.” What do you consider the single biggest challenge to achieving an equitable data infrastructure? (Select only one.)**

	<b>% of total responses</b>
<b>Missing data on key demographics such as gender, race, sexual identity and other subgroups.</b>	<b>26%</b>
Connecting local data to local communications on health and wellness.	6%
Sharing data between health care and public health.	11%
Assuring timeliness of data.	2%
<b>Accessing social determinants of health data that lives outside of public health.</b>	<b>17%</b>
<b>Fostering authentic engagement of communities in the generation, use or interpretation of health data.</b>	<b>35%</b>
Other (please enter in the chat).	3%

Other responses provided in the chat included the lack of data on social determinants of health, lack of Indian Health Services data, IT departments restricting software and infrastructure accessibility, state legislatures and “right-wing politics.” There were several comments related to community engagement, specifically. These include:

- “Too much of the existing data defines people and communities by their deficits—exactly how they do not want to be defined.”
- “The inherent bias of those people creating the infrastructure.” / “Not enough perspectives among those creating the infrastructure.”
- “The lack of recognition of tribal/TEC (Tribal Epidemiology Centers) public health authority.”
- “A lack of community-led data collection.”

- “We need public health agencies to get or find capacity to work closely with affected communities in planning and interpreting data.” / “Agree: meaning-making with communities is so essential.”

## LIGHTS

The Role of Relationship- and Trust-Building in Sustainable Data Modernization

Historical and Current Reasons for Mistrust

Data as a Common Good for the Public’s Health: Building trust through communication of data

- Guiding Lights

## Guiding Lights

### Aspirational guidelines for the future of public health

Fundamental to the work of effective and equitable data and technology modernization are several recent articulations of goals for the future of public health in the United States. Resources that inspired this national summit series include:

- [Public Health 3.0](#)
- [Public Health 3.0 After COVID-19—Reboot or Upgrade?](#)
- [10 Essential Public Health Services \(updated 2020\)](#)
- [Public Health Forward: Modernizing the U.S. Public Health System](#)
- [The Future of Public Health: A Synthesis Report for the Field](#)

### Recommended resources for equitable and sustainable data modernization

The following reports provided a springboard for the conversations in the second virtual summit as well as a deeper dive into many of the issues that came to the fore in summit 2. The recommendations and implementation strategies in these documents are foundational to advancing an equitable, effective and sustainable modernized public health data infrastructure.

- [Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems](#)
- [Building Back Better: Transforming U.S. public health data and infrastructure to protect health and achieve health equity](#)
- [Data Modernization Initiative Strategic Implementation Plan](#)

Presenters and participants in the second virtual summit also recommended specific tools and resources for effective and equitable data modernization. Examples include:

- [Operationalizing the CARE and FAIR Principles for Indigenous data futures](#)
- [Urban Indian Health Institute Decolonizing data, for Indigenous people, by Indigenous people](#)
- [Morehouse School of Medicine’s Health Equity Tracker](#)
- [Leveraging Community Information Exchanges for Equitable and Inclusive Data](#)
- [Universal Community Planning Tool Project](#)

## CAMERA:

# Centering Equity, Interoperability and Sustainability in Data System Design

### CAMERA

- “Nothing About Us Without Us”—Equity in Data System Design and Governance

Interoperability Between  
Systems and Organizations  
Sustainability

After highlighting the importance of relationship-building and trust-building for effective data modernization, it is time to refocus the camera. While COVID-19 has wrought devastation on communities around the globe, it has also provided public health with an opportunity to not only patch up some of the flaws the pandemic revealed in the field’s fragmented data systems but to rebuild and modernize those systems with a triple focus on equity, interoperability and sustainability.

A 2021 report from the Public Health Informatics Institute (PHII), [Building Back Better: Transforming U.S. public health data and infrastructure to protect health and achieve health equity](#), explains how COVID-19 has laid bare these opportunities.

*“Despite the progress made by some previous initiatives and innovations, the COVID-19 pandemic has brought to the forefront that fractured parts of the current system still exist and that short-term fixes will not suffice. It has provided the sense of urgency to undertake more overarching transformation.... As a use case, the COVID-19 pandemic can provide a better understanding and help communicate the challenges of non-interoperable systems. Moreover, it can reveal where and how to bridge gaps in the public health system. This means not only rebuilding existing data and infrastructure to be more responsive and timely but reimagining and retooling these systems in a way that supports equitable and evidence-based promotion of health and effective protection against health threats.”*

### “Nothing About Us Without Us”—Equity in Data System Design and Governance

The slogan, “nothing about us without us,” was a common refrain cited by presenters and participants throughout the second virtual summit. Made popular in public health in the 1990s by disability rights activists, “nothing about us without us” is relevant in terms of data and technology infrastructure modernization throughout the entire data life cycle. Stakeholders, especially the communities with the greatest public health needs, must be engaged from the start—in designing research questions, objectives, data collection, storage, analysis, translation, communication and utilization—to ensure the entire process reflects their priorities and is targeted toward what is most relevant for them. Such an approach may seem intuitive, but it is not always put into practice.

*“We need to not be public health data snobs, to say there’s only one way to collect the data, and our way is the right way, and that’s the only way we’ll get it published and be in the MMWR (Morbidity and Mortality Weekly Report). We need to have humility to figure out what don’t we know, and what are we not selecting, and we need to think more broadly.”*

KAREN REMLEY, MD, MPH, DIRECTOR, NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

In a breakout group session, one of the participants echoed Dr. Remley’s comments on public health data snobbery:

*“We are snobs in public health when it comes to data. When we talk about data democratization, do we actually believe the data our own patients and participants we serve give to us? I don’t think we do.... We want highly curated, clean data sets that are handed to us from CDC or God and use that. And the reality is there’s so much signal out there that we’re just wasting and not taking advantage of.”*

The openness to different perspectives and different kinds of data requires a change in mindset for public health. The last few decades have produced a seismic shift in the professionalization of the field, with accreditation of health departments and schools of public health increasing exponentially. But this professionalization has also pulled the field away from its roots in the community. Over the same period, health inequities have exacerbated across the board. This moment of data and technology infrastructure transformation and modernization provides an opportunity to reconnect with those community roots and collaborate with communities in building sustainable infrastructure to eliminate those inequities.

In a breakout group session, one participant explained how decades of experience as a data specialist have taught him that the people are what matters: the data life cycle is and must be centered around the community and its needs.

*“My observation from the last 40 years as a data person: over time we learn it’s about the people. While we want to look at narrow specifics and data, if we look at data as a life cycle it begins with what pieces of data we want. We need to think about who has those pieces and what is the purpose. If we look at the end of the cycle/use of the data information, we forget about the other stuff, and that leaves us with the lack of community connections. We don’t know what the community wants. As epidemiologists, we think only about the data. We need to back up and think about the data life cycle. It starts with the community.”*

### Engaging stakeholders from the start

Data systems and tools need to be developed with community utility and functionality in mind, as described by summit participants in the plenary chat and the breakout groups:

- *“Most of these tools being developed are using the same data sources with little operational sustenance for local communities. They look cool but are highly unfunctional for meaningful interventions.”*
- *“These kinds of technologies need to be thought about with accessibility in mind when they are being developed. We do not want to develop things that are only usable by a segment of society—a segment of society that is not homeless, does not speak another language, is not incarcerated. The people who can’t use it may be most at risk for some of the health threats that we want to address.”*

Designing a data system with equity and sustainability in mind begins with understanding what are the priorities of the communities public health is trying to serve—meeting their needs through actionable data that build trust for sustainable partnerships.



*“[We need] to have a sound understanding of what the community priorities are. And that’s a broad brush, but knowing that going into it, you can look to see which of those questions are relevant or able to be answered by the kind of information you have. But it’s essential to have the community at the table and setting what those priorities are.... That’s in the central part of ensuring that the questions are going to be reflective of what’s meaningful to the community.”*

LAUREN SMITH, MD, MPH, CHIEF HEALTH EQUITY AND STRATEGY OFFICER, CDC FOUNDATION

## Data and technology needs for state, tribal, local and territorial health departments

It is impossible to talk about modernizing public health data and technology infrastructure without including the diverse needs of state, tribal, local and territorial health departments (STLTs). Just as the communities public health wishes to serve need to be engaged from the start of data system design, so do public health departments at every level.

Participants in the plenary chat and breakout sessions described challenges they’ve observed with the top-down approach to data system design:

- *“The fundamental principle that came out of the patient rights movement, ‘nothing about me without me’—applying that principle at the local level, [a] public health jurisdiction needs to engage communities that are most impacted when thinking about data systems, how the data they release might be best used and shared with the community.... At the state level, state health departments don’t make decisions about local jurisdictions—restructuring and rebuilding collaboration between state and local health departments. At the federal level, state and local health departments are partners in governmental enterprise (not just a special interest group).”*
- *“Are state, tribal, local and territorial health departments in some way being involved in the design, testing and execution of the public health side of these data solutions? I’m so excited about the potential utility to really modernize and revolutionize our understanding and use of data for population health purposes, but I also know that the boots-on-the-ground perspective will be critical to STLTs, especially, being able to use the end product.”*
- *“I was talking to our state health leaders, and they said, ‘We had this IT consulting team come in and give us recommendations that we want to move forward with.’ I asked if they talked to some big city health departments or local health departments, and they said ‘no.’ So there were plans being made at the state level without perspective from city or local levels. And locals are getting money directly from CDC and are making their own plans. We heard some today from CDC and the Office of the National Coordinator for Health Information Technology (ONC), but I suspect there needs to be sharing to have alignment. Otherwise we’ll have 50 plus ways to do things, and it will be a redundant way to do things with the funding money coming in.”*
- *“When we consider the conversations around public/private partnerships and academia...the problem that still exists is these decisions/access points are still in a pyramid/patriarchal approach as though investments at the federal level are supposed to filter down to the state and local levels, and then hopefully filter down to the community-based organizations. This needs a dynamic change and re-posture to recognize that...in data modernization it hasn’t translated to the local perspective.”*

Just as the overall design structure of data and technology infrastructure needs to be democratized, so does the funding. As one summit attendee noted in the plenary chat, funding equity is also an essential component of a modernized data system design:

*“I would like to advocate for funding equity related to technology. Smaller states may have smaller populations, but the technology and infrastructure costs are the same no matter the size of a state’s population. So, when funding bands are created the smaller states often are less capable to achieve data modernization.”*

## Equitable data governance structures

Data governance is another element of data system design that needs to be constructed with an eye to equity. A 2021 report published by a national commission convened by the Robert Wood Johnson Foundation, [Charting a Course for an Equity-Centered Data System: Recommendations from the](#)

[National Commission to Transform Public Health Data Systems](#), acknowledged that technological change requires a thoughtful approach to governance. Data governance needs to be both flexible and strong to ensure adaptability and safeguard the trust public health has worked so hard to build.

*“The rapid pace of innovation in information technology and changes in what, how, when and why data are collected, and by whom, raise important questions. What governance structure is the best guide for our current public health data system? How can we ensure that new governance structures are nimble enough to address future health data considerations? A strong governance structure could prevent inappropriate use of public health data, when individual users are not good stewards of the resources to which they have access.”*

A promising approach to equitable data governance that is rooted in the community is the concept of a nonprofit community data trust model. This model achieves multiple goals of equitable data system transformation because it not only liberates data and makes it easily accessible to the people whose story it is telling but it also integrates data from multiple sources and systems, allowing for a social determinants of health approach to data. In the breakout group session on assuring health and wellness for everyone, everywhere, participants discussed the potential and some challenges of this concept:

- *“Because data exist within the public health agencies at the state and local levels, every nonprofit has program data, United Way has tons of data, everyone has data. I really want to position our organization as a community data trust so that we could maybe hold or have access to those data. If we can position ourselves as a nonprofit, a community-based organization in that role, instead of a state agency, we could also do a really good job of creating some system for community data governance and being able to influence how those data are used through counties or states, or even just nonprofits or collective impact initiatives. Then, once we position ourselves as a community data trust, giving the community a lot of power to make decisions.”*
- *“Community information exchanges (CIEs) are a great way to be thinking about the future of this work because it’s based in the community and driven by their governance. Having it be community-led, there’s so many elements of power dynamics and sustainability that make it so challenging for us to, from a community perspective, actually be equitable in the long term. We just have a lot of [lessons learned](#) from our experience—not necessarily solutions, but potential opportunities to be able to build off of some of the things that we’ve learned.... The value of encouraging a shared governance infrastructure that allows for multiple sectors and community members to participate, I think has been the most transformational for us.... If that’s something that could be adopted in other arenas, it creates accountability and transparency around these data that I think we’re all striving for.”*

## CAMERA

“Nothing About Us Without Us” – Equity in Data System Design and Governance

- Interoperability Between Systems and Organizations

Sustainability

## Interoperability Between Systems and Organizations

*“It’s so easy to access information through standardized interfaces that are very, very common across the internet; it’s less common in health care. What we’re trying to do is say, let’s get the health care system to be more aligned with the way the rest of the internet works.”*

**MICKY TRIPATHI**, PHD, NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

*“Not all data for public health are health data.”*

**ETHAN BERKE**, MD, UNITEDHEALTH GROUP

### Data from nontraditional sources

Throughout the second virtual convening, speakers and participants highlighted the need to incorporate broader data sets to refocus the lens of public health analysis through the social determinants of health. Summit participants offered additional suggestions for data sources relevant to health equity in the plenary chat and the breakout group sessions:

- *"If we really want to capture SDoH (social determinants of health) it will be important to look beyond just the intersection of public health and acute care systems but also to look at how to connect to social services system data as well. Heavy lift though."*
- *"I think understanding what data sources are out there for public health to use is important. I was a local epidemiologist for 14 years and I only just recently learned about the American Society of Civil Engineers report card, which has so much data that can be used for initiatives around built environment when addressing SDOH."*
- *"We are also finding that wastewater demonstrates clear inequalities in built environment along SDOH lines too."*
- *"211 data is underutilized by public health. We are working with United Way to build these data into public health data systems." / "We're working with 211 data to track service demand over time and by ZIP code. It's the best source of real-time data we could liberate to the public."*

The [report](#) from the National Commission to Transform Public Health Data Systems includes a recommendation for what kinds of data public health should seek in its pursuit of health equity.

*"Recommendation: invest in community-relevant and nationally significant metrics on structural factors that influence health outcomes, focusing on upstream causes of inequity by measuring how systems segregate, discriminate and exclude."*

The commission's report goes on to elucidate specific metrics public health should consider:

*"Data on the upstream factors that influence health are not regularly or consistently available to inform decision-making. A review of the Healthy People 2030 Leading Health Indicators suggests continued gaps in public health data, particularly with regard to economic stability, neighborhood and the built environment, education, and community and social context. Public health data should place more emphasis on social context and other key factors (e.g., education, housing instability, food insecurity) that have a large impact on populations with vulnerabilities and place less emphasis on traditional health data that focus primarily on disease and disease burden. Data on lived experiences and community history (e.g., narratives), finance (e.g., mortgage acceptance rates, redlining, school budgets, county budgets, disability discrimination, language access), and racism and discrimination could provide critical insights into some of the root causes of health inequities."*

Additionally, with the data and technology transformations that are already taking place, summit speakers and participants identified areas of opportunity for new data sources:

- *"Home testing is here to stay, and COVID-19 has made that possible and demonstrated the benefit.... I have no doubt we will see more home testing for other conditions that are important to public health data collection around sexually transmitted infections, other respiratory diseases.... We're seeing that market increase dramatically, and as it does our data visibility is going to start to decrease, because now tests are being done in living rooms and not tied into any large system.... So how do we leverage a lot of the technologies and interfaces others have been talking about and capture data from home and self-testing environments to inform public health?... I think there's an opportunity with a lot of the data structure work we've been talking about to recapture that and make sure that's included, particularly for populations that don't have access to these larger systems.... How do we hear their voice?"*
- *"One other paradigm shift we are already experiencing is the move from traditional document-based exchange (public health 'receiving' data from different sources) to data access at the source via API technologies. So, with the appropriate security, privacy protections and procedures, public health would be able to access the data they need, rather than waiting for the data to come to them."*

### Interoperability and integration of data sets

One of the polls conducted during the plenary asked summit participants what concrete actions they would prioritize in the next one to three years to assure that current investments in modernizing the health data system are sustainable. By far, the most popular response (39 percent) was "linking diverse data sets across public health, health care and non-health sectors."

**POLL: The recent multibillion-dollar investment to modernize public health data systems offers unprecedented opportunities to generate real-time, complete and actionable data to prevent disease, promote wellness and assure prosperity. What concrete actions would you prioritize during the next one to three years to help assure those investments translate into long-lasting improvements to the health data system? (Select only one.)**

	<b>% of total responses</b>
<b>Scaling solutions that enable real-time transfer of data across jurisdictions.</b>	<b>17%</b>
<b>Improving capacity within the workforce.</b>	<b>22%</b>
<b>Linking diverse data sets across public health, health care and non-health sectors.</b>	<b>39%</b>
Developing analytics for better decision-making.	5%
Ensuring governance to guide what data can or should be shared.	6%
Building equity throughout data systems.	10%
Other (please enter in the chat).	1%

Summit participants were invited to enter other suggestions in the chat. Their comments included several references to standardization such as a *“data dictionary,” “ensure high quality, granular data elements that can be shared across data sets,”* and *“standardizing (informed) consent capture and sharing.”* Other comments referenced all of the above in addition to supporting public health workers:

- *“These are all necessary, but making it happen is the magic.”*
- *“All of the above, plus really taking care of the workforce.”*

While public health data modernization is mainly focused on moving the field forward, it also must take into account the wealth of existing, historical data and how that can be integrated, as summit attendees pointed out:

- *“While we are talking about the new data...what about historical data sets? What kind of plans are in place to ensure they are also ready for providing wealth of data for forecasting analytics?”*
- *“Interfacing with myriad of legacy systems is a critical component.”*

One of the key elements for interoperability is shared standards. Summit participants acknowledged the need for data standards as well as some inherent challenges in the plenary chat and breakout sessions:

- *“Super important to establish a common data dictionary, from day one. Taxonomy, content validation, and format.”*
- *“While we have to be standardized, the standards do need to allow for some flexibility to be able to support local data collection needs and reporting.”*
- *“Having a national superset of data definitions with local subsets as needed would help scaling substantially.”*

Summit participants also highlighted some opportunities to ensure adoption of standards:

- *“Can we think about incentives for use of standards for incoming data streams (esp. health care, labs, vaccine sites) and to promote completeness and timeliness of electronic reports? Not just doing it, but doing it with a minimal level of quality.”*
- *“As an action, I would suggest that private companies such as United Health or others that have healthcare data also utilize a standard screening tool with their members for social determinants of health such as the Accountable Health Communities tool, which then would provide linkage at an individual level between the health outcomes and their determinants.”*

Standardizing data collection is also crucial for interoperability. Summit participants noted in the plenary chat aspects of data collection standardization that are particularly important for ensuring equity:

- *“How can we ensure we hold states accountable to capturing, analyzing, disseminating data on diverse community members: African Americans, Latin-X, Asians and LGBTQ populations?”*

- *"The processes for capturing race/ethnicity information must be evaluated and improved. The capture of this data must be a shared responsibility."*
- *"Will the data collected even address the lack of accurate racial and ethnicity elements for populations of African descent? Commonly, all data is grouped under African American/Black, without reference to country of origin. This will help to disaggregate data by communities."*
- *"It is also important to consider how some of those patient (demographic) characteristic definitions are ephemeral and can be misused in/over time (e.g., gender)."*

For guidance, summit participants pointed to existing models of public health data systems and data system transformation the field can learn from:

- *"Environmental health is part of public health that is most uniformly mandated by law. Most environmental health programs across the country have data collection systems created by the organization or purchased by vendors. When we talk about data modernization and transformation, recognizing that there is already a whole system in place in every part of the country, collecting septic data, restaurant data, hospitality industry data, school and ECE data, data related to day-to-day life—that would be a great place to start because most of the data are being collected because of the local statutes."*
- *"We talk generally about data modernization as though all aspects of public health data equally need to be modernized and made nationally consistent. What aspect could be seen as nationally useful and relevant? IIS (Immunization Information Systems) is an example. Everybody does immunization, and it's the biggest public health prevention-level service we offer. Doing it consistently and building that community of practice—like the All Kids Count initiative at CDC—helped build social capital... We need to look at and determine what is the next IIS? What is already almost consistent at all local levels and impactful for the national level? Need a clear starting point on where to focus our attention."*
- *"The airline industry is a good role model to study for becoming digital. It started in the 1990s. Competitors came together and agreed to create a digitized industry and compete otherwise. The ecosystem must be digitized, not individual organizations."*

A significant but debated concept for interoperability is a national patient identifier (NPI). Breakout group participants assessed the pros and cons of such a system:

- *"Having an NPI would make things easier to do cohort studies since infrastructure would be in place. We do a pretty good job with our various techniques, but it's not perfect. An NPI would make things easier, and this is a national policy issue."*
- *"I'm skeptical about national patient identifiers. Not against the concept but: 1) even if we had a national identifier, we'd still have many/most of our matching challenges and tools in play, and 2) individuals should have a right to partition their health records into 'personas' when they don't \*want\* data linked/lumped across different aspects of their care."*

## CAMERA

"Nothing About Us Without Us"—Equity in Data System Design and Governance

Interoperability Between Systems and Organizations

### • Sustainability

## Sustainability

As discussed in the first *Lights, Camera, Action* summit on workforce development, it is essential to focus on sustainability, especially at this moment as unprecedented levels of funding pour into public health. This is not the first nor the last pandemic. Funding will dissipate, but the needs will not. Presenters and participants in this second summit spoke to the imperative for focusing on sustainability as data systems and technology infrastructure are modernized and transformed. Their approaches to sustainability centered around sustained funding and community trust.

In the plenary chat and in the breakout group sessions, participants spoke of the need for planning for financial sustainability.

- *"There's so much money out here right now—not enough, but we need to figure out how to learn from how we're spending it now to inform the long-term infrastructure funding we need. If we don't capture that learning in a helpful way to inform that, we're going to lose this opportunity. We can get a lot of the short-term fixes done and start thinking about the long-term fixes, or we can lay the foundation for long-term work. We need to communicate that to the people making the decisions—that this is not going away. We need to build on this emergency funding to prepare us for the next pandemic or whatever."*
- *"Actionable intelligence systems are awesome, but when we use them, we have to discuss sustainability. One example that comes to mind is the National Retail Data Monitor for Public Health Surveillance. It was an awesome system developed by the University of Pittsburgh for looking at the sales of over-the-counter health-related products. Public health could not afford to pay for access to this system once the university funding ran out."*

A 2021 report from the Public Health Informatics Institute, [Building Back Better: Transforming U.S. public health data and infrastructure to protect health and achieve health equity](#), cautioned about sustainability in terms of in-house data systems knowledge:

*“The combination of centralized IT functions and increased reliance on contractors strips public health departments of in-house informatics expertise and can lead to an overreliance on technology vendors. In addition, the public health workforce must include not only those with technical skills but also those who can ensure that equity is a central focus of all efforts to improve the ways that public health data are collected, interpreted and used to inform practice and policies.”*

Similarly, in a breakout group session, one participant acknowledged that—while it is unavoidable that public health will need to bring in external consultants at times—caution must be taken to ensure what they are building is forward-thinking and sustainable:

*“I want to call out the real problem of proprietary interest, technical assistance arms that have rebuilt the same problems in the same place.... When your FTEs (full-time equivalents) are capped at the state level, what can you do? [But when we've hired consultants] there was no obligation they felt, or that we exercised, or that the feds said, to create platforms that could anticipate a future. Think about...how much money they wasted in HIEs (health information exchanges) and the early EHRs (electronic health records) and everything else. Public health has always had so much less, and social services even less.... I think feds could have standards, even if the money's out the door, to review state operations and contracts put in place, for the extent that they achieve x.”*

Additionally, presenters emphasized the need for sustainable community partnerships for successful ongoing data sharing and utilization. As the moment of crisis seems to fade, public health must continue to convey the value of data to ensure the flow of information continues uninterrupted, ensuring that the field and communities stay equipped to address ongoing and future public health challenges.

*“The data and the hooking the pipes together is incredibly important. But if we don't surround that with a story and robust communication about why we need to do this in the first place, and how people feel the benefit of it, it's short-lived.... The key to sustainability is people understanding the value and the benefit beyond when the crisis period is over.... And that comes down to people understanding what they get for what they give. So how do we communicate the value better? Communication is cheap, but don't underestimate its power in driving policy change that's long-lasting versus one-offs.... Sustainability is about making sure people understand long-term value, and I would say communication is a place where we have a huge opportunity for people to understand the importance of data.”*

**ETHAN BERKE, MD, UNITEDHEALTH GROUP**

## ACTION:

# Democratizing Public Health Data and Technology

### ACTION

- **Needed Transformations in Public Health Education, Training and Communication**

Adapting to the Digital Age

Translating Data into Action

After highlighting the importance of relationships and trust-building and refocusing the camera to center equity, interoperability and sustainability, public health needs to take action by democratizing public health data and technology to advance health equity. This will require fundamental transformations in the way the field approaches its work and its workforce.

*“In addition to modernizing the data systems, we also need to consider the transformation that will be ongoing to support and sustain these systems. Thus, we will also need a highly skilled workforce with the skills to embrace and apply a modern public health data and surveillance system.”*

JUDY MONROE, MD, CDC FOUNDATION

As one breakout group participant put it, COVID-19 has upended the status quo. As the field puts itself back together, public health must seize this opportunity to do it differently and improve upon the system that brought it into this crisis:

*“If we’re really truly talking about reinventing the way public health uses data, we’ve got to start thinking out of the box. We’ve got to stop thinking that the way we’ve been doing business for the last umpteen years is the only way to do business. If nothing else, COVID-19 is this gigantic disruptor. If we don’t learn from those disruptions, and if we just think we’re somehow gonna go back to the way it was, which wasn’t even right, we will be mistaken and unprepared for the future.”*

### **Needed Transformations in Public Health Education, Training and Communication**

In one of the breakout group sessions, a participant described the shifting ecology of data and offered suggestions for how public health can rise to the challenges posed by this new information ecosystem:

*“The field has to recognize the world of information has changed dramatically... Everybody who can do a YouTube channel is a public health communicator... We need a real 21st century sense of data ecology and public health that understands how the best of what we can do in science weaves into an ecology that’s just more complex.... We have to be open—historical contextualization, trust-building—with the trust comes a different collaboration around information that would lead a community...if they trusted you were in it together in some way that was authentic, that you wouldn’t use the data as a counternarrative... I think that is going to be the future of modernization, which is a broader range of information, including narrative life experience, 211 data and all the other institutions that hold social determinants of health data. How do we create a local fabric of knowledge-sharing people can trust that hopes to prevent things, but also helps us to respond?”*

This comment speaks powerfully to the role of trust-building in effective public health data modernization. One of the ways in which public health can prepare itself to be a trusted partner in data for equity is through education and training around structural racism.

### Acknowledging and correcting for structural racism in data collection and use

*“Unless we realize that the real-time data that are currently available are based on a system of embedded structural, individual and institutionalized racism that has effectively harmed communities of color and other communities, we’re working within a data system that continues to cause harm. So, we could have all the real-time data, all of the machine learning, everything that we ever wish for, but if we don’t address...the embedded systems of racism...negative outcomes will continue.”*

ABIGAIL ECHO-HAWK, MD, URBAN INDIAN HEALTH INSTITUTE

As referenced above, public health—by design and by omission—has a long history of institutionalized structural racism.

Fieldwide training in the history of institutionalized racism as well as skills and tools for dismantling it will be essential to begin acknowledging, repairing and healing that legacy of harm. Multiple comments in the plenary chat, as well as many comments expressing agreement, suggested the need for such training:

- *“The reality is half of this country doesn’t believe or support a lot of what academia says about systemic racism. And you and me included work with those people too.”*
- *“Some of the comments in this chat really show the necessity for everyone in public health and data system work to have a foundational understanding of structural racism and how the social construct of race functions to produce inequities. Racial justice training needs to be a requirement across the board.”*

Another key step in democratizing data is transforming who interprets data, how it is translated and how it is used. Dr. Echo-Hawk explained that engaging affected communities at every step is especially crucial when it comes to disaggregating data, to ensure no further harm is caused.

Summit participants in the plenary chat agreed:

- *“A major transformation that we need to make is who is interpreting the data...whose story is being told with the data.”*
- *“Transparency of data AND interpretation is important. Misinterpretation can be extremely dangerous.”*

### Reframing health inequities data to preclude victim blaming

Furthermore, once public health workers are equipped with the historical knowledge of structural racism, they must use this knowledge to reframe the way data—particularly data on health inequities—are presented to the public. Without proper contextualization, data on health inequities are all too easily ascribed to failures in individuals’ decision-making or, worse, an inherent flaw or weakness attributed to an entire group. As Dr. Echo-Hawk explained:



*“[We] are not vulnerable...or at risk because there’s something wrong with us. We are at risk because we live in a country that has been effectively working to harm us, my people, for more than 500 years. So I’m at risk because I’m in the United States, not because I’m a Native American.”*

Dr. Mary Bassett, a member of the National Commission to Transform Public Health Data Systems, is quoted in the Commission’s report emphasizing this point:

*“We need better ways of capturing the concept of structural racism, but most of all we need the field to discipline itself to change the narrative of measured racial inequities to include racism and abandon reflexive pursuit of biological/genetic explanations.”*

MARY T. BASSETT, MD, MPH, COMMISSIONER, NEW YORK  
STATE DEPARTMENT OF HEALTH

As the Commission’s report recommends, public health must build the “*data system needed to shift the narrative to one that is just, positively oriented and equity-based (e.g., from deficit to strengths, from oppressive to restorative).*” The report goes on to suggest specific ways to reframe public health data narratives from an individualized, deficit-based perspective to a more restorative and structural, asset-based perspective.

*“The current public health data system disproportionately focuses on negative health outcomes (e.g., mortality and morbidity), and overlooks positive health and well-being measures (e.g., community cohesion, hope, civic engagement, prosocial behaviors, resilience). Without such information, the nation cannot track aspects of thriving and flourishing that are central to health and well-being. A future public health data system also must monitor the processes and outcomes of inequity, history, cumulative risk and cumulative trauma on health. The modern public health data system must look both upstream, at the structural drivers of health inequities, and over time, at intergenerational inequities.”*

One promising step in this direction is a trend in public health to preface any presentation of data disaggregated by race with an explanation that “race” is used as a proxy for the experience of the impacts of systemic racism, as one plenary speaker noted:

*“In public health we are starting to see the change of—we will not present data in any format without structuring it first in the social determinants of health, acknowledging the systemic and institutional racism that has led to this within our state, in our county, period. So, people can’t get to the data without working through that paragraph first. And that’s going to take a lot of time, but I think public health is absolutely responsible for framing every single piece of data we put out there in social determinants of health to fix this narrative of victim blaming.”*

KIMBERLY REPP, PHD, MPH, NATIONAL CENTER ON BIRTH DEFECTS  
AND DEVELOPMENTAL DISABILITIES

There have been a number of commentaries and suggested frameworks to standardize this practice, including an [invited commentary from Dr. Camara Jones](#) in the *American Journal of Epidemiology* in 2001 and, more recently, among many others, a *Health Affairs* [blog](#) in 2020 and a *Frontiers in Public Health* [journal article](#) in 2021.

### Contextualizing data with qualitative narratives

One particularly illuminating discussion took place in the breakout group on assuring health and wellness for everyone, everywhere, when participants discussed the use of qualitative data to contextualize numbers and health inequities.

- *“What we’ve really focused on is not just creating a map that shows inherently deficit-focused stories, not just data or information on a map.... How do we go out and partner with cultural preservation organizations working in different communities and in neighborhoods across the city, talk to people, collect stories and then actually lead with those stories and then contextualize them with history and data? So, what we’re really*

doing is almost about individual lived experience and then contextualizing up to the regional level, because when you talk about one person...[people think], 'but that's one person who probably didn't make a lot of great decisions.' But actually you can back that up with regional data and talk about how it's just one person among a bigger pattern.... We can back everything up that we say when we go from the stories to the data to what the actual action and recommendations are."

- "In terms of contextualization, I think that's a great example of where the qualitative data and those rich discussions can provide context for data the health departments are putting out there to combat a narrative of a particular neighborhood just being overrun by all these deficits. Because if you're that person or that family living in that neighborhood and all you see, all you hear from your health department are disparities and persistent health inequities, it just perpetuates hopelessness. I think the qualitative data is definitely important."

Summit speakers also called for more of an emphasis on intersectionality in data collection and analysis:

*"I'm happy to hear everybody talking about all of the different [factors]—racism, the structural components—they are all intersected. When you look at people with disabilities [for example], we know that Native Americans have the highest disability rate of any population in our country, rural people, people of color. So it has a significant impact, and we need to always be thinking about not just one group but how those groups work together—those social determinants, environmental determinants of health—and how we can change the way we collect data."*

**KAREN REMLEY, MD, MPH, NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES**

Summit attendees agreed in the plenary chat:

- "I think we need to do a better job of addressing issues related to intersectionality. It seems community keeps being lumped together, but there are several different types of communities that should be considered."
- "Intersectionality plays a huge role, and we seem to focus on one or two identities at a time instead of how multiple identities overlap."

### Recognizing, exercising and sharing the power of data and narrative building

*"Public health data is a new narrative; it tells a story. And if this story that's being told is only based on existing algorithms, which reinforce the elephant in the room—which is racism, structural and historic racism—then we're not going to really achieve equity and we're not going to move toward well-being in a positive sense. And so, I think the supports are recognizing the primacy of seeing data not only as information and as a system of surveillance and prediction but also as a narrative that is telling a very real story and making sure that story embodies our hopes and our aspirations for greater opportunity for all."*

**GAIL CHRISTOPHER, MD, TRUST FOR AMERICA'S HEALTH**

Another key component of equitable data modernization is recognizing that data tell a story, and public health—being the purveyor of data—has power in how it chooses to communicate those data. One summit participant put it bluntly in the plenary chat: "Data is **POWER**." The National Commission to Transform Public Health Data Systems' 2021 report includes a recommendation on data sharing and interpretation in which they describe the role of power in public health data.

*"Representation and power in health decision-making are integral to a modern, equity-oriented public health data system. Power means the authority to shape expectations, decisions and outcomes in public health. The current public health data system does not prioritize transparency, data access and use that support sustained civic engagement. Nor does it give deep consideration to the voices of historically marginalized and chronically underrepresented populations, which are required for truth, reconciliation and racial healing. This focus on equity in data use and decision-making is even more critical in the context of the greater volume, velocity and variety of data (often used to characterize 'big data'), the role of technology in data generation and manipulation (e.g., artificial intelligence, machine learning) and increasing challenges to civic engagement and democracy."*

## ACTION

Needed Transformations in  
Public Health Education,  
Training and Communication

### • Adapting to the Digital Age

Translating Data into Action

Once public health recognizes the power it holds in narrative-building around data, it is imperative that the field uses that power carefully to advance narratives that push for equitable systems change, as well as sharing that power to elevate the lived experience and needs of communities most impacted by health inequities.

## Adapting to the Digital Age

As public health dives into this new data and technology ecosystem, there will be a learning curve. Major transformations will be required in the public health workforce, the workplace and the head space of public health leadership. As one summit attendee put it:

*“It’s more of a conceptual paradigm shift that can help us move forward more than a Herculean technical shift.”*

### Addressing the needs of a modern public health data workforce

Throughout the second virtual summit, speakers and participants discussed how changes due to data and technology infrastructure modernization need to be reflected in the workforce. Part of the change needed to modernize the skills of the public health workforce when it comes to data is a change in mindset. As the Public Health Informatics Institute put it in its 2021 report, [\*Building Back Better: Transforming U.S. public health data and infrastructure to protect health and achieve health equity\*](#):

*“We should start thinking about public health practitioners—not as data gatherers—but as expert data users. And this will require a different set of skills.”*

A breakout group session participant provided more detail on just what skills are needed:

*“You need to look at the entire data cycle of how we collect data and consider how do we turn data into information (which is the job of informatics, in my opinion), and then how do we provide the right tools for epidemiologists to turn that information into knowledge and then wisdom.... You cannot just magically collect data and know what to do with it the next day. We need a cycle where we turn data into information into knowledge into action. We’re starting to implement that now with a shared MPI (master patient index) and an analytical environment, but we really need to get this data cycled figured out, get the roles and responsibilities we need, and ensure people know how to use these tools. A lot of our epidemiologists know SAS, but we’re finding these tools are not the best to work with this data, once data is in the analytic environment. This is where the focus should be.”*

This comment points to a challenge expressed by many summit participants of the need for people who have both data/IT knowledge and a public health perspective:

- *“Some folks understand technology, but most people in public health don’t, and more so don’t understand what technology is good for. I think the technology people also don’t know what the needs are in the public health field. We need an exchange of knowledge and information between public health and tech.”*
- *“What I’ve seen in the workforce and our needs is we have lots of people applying for data-oriented positions within our jurisdictions out of MPH programs, coming in with training in biostatistics and epidemiology but no exposure to informatics, application systems development and analytic database engineering.... On the IT side, folks come in with the data engineering or application system focus but no subject matter expertise or the real interest or focus in what the data user, from the analytic sense, requires. Often not speaking the same language, and our skill sets are not converging. For workforce development I’d like to see more public health implemented within training programs. Locally we have UCLA, with a medical informatics program that’s almost all health care but not public health. And we have a strong school of public health where there’s zero focus on informatics and data systems.”*

Breakout group participants offered up some innovative solutions to address these workforce needs:

- *"I was wondering if some of the tech firms could have a pro bono program to help health departments; embed people into health departments, not just consultants."*
- *"Right now, we're building on the hurricane response hub model. We trained over 90,000 people with this hub model that really works. If you don't duplicate everything in every state, but if you share resources across a region, it could really work. Take workforce innovation hubs, invite health departments—maybe they can't hire right now—we want these hubs to use every principle that works, like public health sharing agreements. Not all counties may have what they need in advanced data skill sets. Why don't we apply that and co-fund agreements to share staff for data purposes?"*
- *"Fellowship options for mid-level, already career staff, folks in public health departments—this would be a great place to carve out support. For example, train epidemiologists in data engineering.... They would benefit from more formal training in data engineering and mid-level fellowship that allows people to stay in place in their current roles and jobs in local and state health departments."*

Furthermore, changes in workplace culture add to the challenges in attracting needed talent.

Breakout group participants proposed innovative approaches to meeting these challenges:

- *"This is a different talent pool than our normal public health recruits. We need to look at the value proposition. One state I was working with was excited about a new data scientist they had hired, and he quit in two weeks because he couldn't tolerate the laptop and the actual data structure or cloud setup. Thinking about the technical setup, thinking about the ways of working: do we have areas of the org that are operating in ways these folks are used to? Do we have career paths, whether that's sticking within public health and beyond, and how are those laid out? One of the states I worked in set up a center of excellence brought together group of 20 folks with this skill set. A community of practice was important."*
- *"This is a group of talent that tends to change jobs frequently. The notion of the 20- to 30-year public health professional might not work for the data scientist. Can we build a talent model that may have a couple-year fellowship from a university? With COVID-19, how can we use partnerships to access? Facebook data scientists volunteered for one initiative that made an important difference—lots of options out there."*
- *"When you talk about opening up the ability to hire people, especially as a public health agency you need every advantage you can get.... We need to think outside the box, if we cannot offer the same kind of money to these people but offer them state benefits—which are often better—and a decent salary, and say we don't care where you live, we can offer up a good deal."*

Not to be outshone by tech know-how, other "soft" skills were discussed in breakout group sessions that public health professionals will need to thrive in this new data ecosystem. The importance of relationships with community-based organizations (CBOs) for the effective utilization of data for health equity means the needed skills go beyond hard data science and technology to relational skills including trust-building and power analysis:

- *"Just thinking about the workforce in terms of, if health departments are going to be joining different tables where these conversations are happening, what kind of things do they need to equip themselves to be part of that? Whether it's understanding power dynamics and how to work with data. So, data literacy isn't just, here's how to use computers with data. It's, if I'm gonna go into a community, I need to understand how to navigate power dynamics. I need to understand how to build trust. I need to understand more about the context around the data, so I can encourage people to use it responsibly, but also let communities take the lead on that too."*
- *"Talking about data modernization, we usually focus on technical expertise. We do need technical expertise, but the staffing model needs to go beyond technical experts. We need to have adequate staffing to connect with CBOs on an ongoing basis (not just during a crisis or one time) where we address fundamental inequities."*

In the plenary session, panelists discussed the value of a playbook for public health in the era of data modernization for health equity:

*"Playbooks are highly effective, and the development of a playbook for local health departments, regardless of if they're small, moderate or large—reflective of what we know their concerns, their constraints are, especially as they relate to human and fiscal resources—is critical. That is the way we will accelerate this work by laying out: here's the foundational steps...domains that need to be addressed. And here's how you go from level 1 to level 5, with the recognition that, at the end, we have a learning public health system that is responsible and responsive to the needs of the community."*

**THERESA CULLEN, MD, PIMA COUNTY HEALTH DEPARTMENT**

Summit participants echoed Dr. Cullen's idea, with specific interests in equity and partnerships:

- *"It would be beneficial to have a toolkit or road map for how to ensure our data systems promote inclusivity and equity. Much of the time I feel we struggle to meet standards and implement the basics. We need some solid guidance on innovative tools and methods to supplement/enhance what we currently do."*
- *"Very detailed how-to guidance (like a playbook) that isn't only for the LHDs (local health departments) but also for partnering and the partner organizations. Support and expectations for community member leadership and participation in the partnership."*

### Needed culture shifts within public health

Adapting to the digital age requires changes not only in frontline public health worker skills, expertise and working environments but at higher levels as well. Conversations throughout the summit plenary and breakout groups emphasized the need for a cultural shift in public health leadership and practice. Summit participants discussed the importance of change management, and how that begins with changing the mindsets of those in leadership roles:

- *"You can't underscore the power about culture. Driving new talent into the field of public health, there has to be a cultural change from the top in terms of how leaders are able to reimagine their organizational capacity for change. It really gets to thinking about how organizations operate. How do we support the cultural transformation required in addition to the infrastructure and 'technical skills'? How do we support and upscale existing talent? How are there opportunities for retraining, uptraining to strengthen the skill set related to supporting people to become more advanced data professionals?"*
- *"It's important for health departments to think about where they are in this bigger data ecosystem, to view themselves not as gatekeepers but more facilitators. They have a lot of power and influence and the ability to convene people. Bring people together to encourage organizations to share data...making sure there is this shared, community-informed data governance around health data broadly, not just data about the pandemic but other data sets as well."*

Fundamentally, data sharing and interoperability is about trust. As breakout group participants explained, in this way the problem is not technical; it's cultural. Data sharing and interoperability require a fundamental shift in thinking in the field that will change how public health enters into partnerships and how it views itself:

- *"Interoperability isn't a technical problem, and we're hiding behind this as a technical problem. This is easy to solve technically, but this is a social problem and a cultural problem between organizations. Interoperability requires a two-way exchange... in tech terms, two computers or file formats talk to each other and have to like each other. If that's not the case with organizations, technology won't help. Public health is guilty as any other sector because we get in a turf war between ourselves and other sectors. If we're going to talk about interoperability, we need to talk about what does that mean, and what are we willing to give up? What's the partnership we want, and who do we want to partner with?... [There are] opportunities to redefine what we mean by a partnership and how it benefits. It all comes back to the interoperability question though. The public sector has to trust the private sector that it's not an evil moneymaking organization, and the private sector has to trust the public sector, too, that the data they're giving aren't used in a way that harms their interests."*
- *"Some of the fear is, releasing this data, what if it doesn't always tell a good story? And we're always on the defensive of trying to defend the information that we have. It also goes back to having it be normalized... If public health is collecting the data, it needs to focus now on sharing those data more in the community so that it does become normalized, and people understand how data is collected and it's not perfect. 'Here are some of the challenges, and here are some of the things that you need to understand about the data,' but it shouldn't preclude us from moving forward to be more open and transparent in what it is we're doing with the community."*

In one breakout group, participants offered suggestions for how to navigate such change management:

- *"The cultural change needs to move from a total risk-mitigation, data-protection mode to a more open, inclusive and curious culture of innovation."*
- *"Data and information are 'need to share,' not 'need to know.' I took my personal interpretation of data out of it. I said, here's the data, whatever leadership does with it, that's on you. Because of that cultural shift, I built a trust with leadership where they'd rather work with my team for all sorts of data purposes, not just COVID-19-related but HR concerns, finance concerns, etc. Having that culture shift allowed us to be a more data-driven organization because we're less likely to have those domain, 'owner of the data,' 'hold onto the data and not share' attitudes."*

## ACTION

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- Translating Data into Action

## Translating Data into Action

*“What we want to be able to do is flip the current ratio of data wrangling to public health action... Too much time is spent data wrangling, and that leaves too little time to be able to actually turn that into public health action... Everything we’re trying to do is to say, ‘how do we flip that equation so that data, data wrangling, data normalization and the ability and access to have quality data is in the background?’ And what comes to the foreground is the actionable intelligence, the ability for you to be able to do things with the data that help you to improve public health at large.”*

MICKY TRIPATHI, PHD, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Public Health Informatics Institute report reflects Dr. Tripathi’s desire to allow for more time to learn to use data to inform public health decision-making as opposed to gathering it:

*“STLT (state, tribal, local and territorial) agencies spend a large amount of their energy and resources on being data gatherers—identifying, developing or procuring and maintaining the information systems that allow them to gather and provide the data that is required from them and by them. The limited workforce and resources in most health departments means that insufficient time and resources are available for developing their skills as expert data users capable of extracting to inform daily decisions that effectively serve their communities and target populations.”*

## Identifying the most appropriate data and technology for actionable intelligence

*“Our challenge in the world of public health has been assuming just more data is better, that that will solve the problem.”*

ETHAN BERKE, MD, UNITEDHEALTH GROUP

As Dr. Nirav Shah pointed out in a spotlight session on accelerators of actionable data, the technology exists to meet public health’s data infrastructure needs. The field just needs to find the right partners.

*“Technology has solved a lot of these problems. It may have not reached us, when we’re still thinking of servers or on-premise expensive investments, or maybe moving to the cloud when everyone else has already moved to the edge. There are things that we can do and folks are out there willing and able to help us in public health—if we ask.”*

NIRAV R. SHAH, MD, MPH, SHARECARE

At the same time, several plenary speakers warned their colleagues of the distraction of “sparkly data” and “shiny tools.” Instead, they argued, the field must focus on what is truly needed and when, only devoting time and resources to tools and systems when they will truly advance health equity:

*“I just want to make sure we’re clearly focusing on what do we want to do to keep people safe and optimizing for those particular actions...and not get too wrapped around the axle. There’s lots of really sparkly data out there that we could go after. We need to figure out how to optimize what those data are and how they could be used to help people going forward.”*

DYLAN GEORGE, PHD, CENTERS FOR DISEASE CONTROL AND PREVENTION

*“Real-time data can be more expensive to access than data that’s not real time. And when we’re thinking about chronic disease and other types of conditions that our public health department might follow, it’s not always critical that’s real time, and we need to think about when we actually need it, and when we’re going to make it actionable, so we can build the systems to support that and only pay for what we need.”*

JIM DANIEL, AMAZON WEB SERVICES

## Democratization of data

The concept of data democratization was discussed regularly throughout the second virtual convening. One breakout group participant provided a particularly vivid example of data democratization in action and its impact on improving health equity:

*“We saw a significant impact in Louisiana when we released our death data pretty early on in the COVID pandemic, which showed racial disparity affecting African American community members much more than white community members.... We put the data out, it created a conversation and community members saw that data and said, ‘Nobody’s going to do this, certainly not in a state like Louisiana, for us. We need to protect ourselves.’ And what we saw was some of the highest rates of masking amongst communities of color, again, high rates of vaccine uptake. There was an internal debate within the Office of Public Health about these data not being clean, having a significant number of people whose status was unknown. We took the step of sharing data with like 20 percent of people without an identified race because we said, ‘what we’re seeing is concerning and important enough that we cannot wait for perfection. We need to share this with the community and then we’ll continue to update it over time.’ And so, we made the proper caveats. There’s a strong need for public health to both improve messaging but also to be less guarded with the data and allow the public to view those data.”*

One of the most common suggestions for data democratization was disaggregation of data for hyperlocal utility. Breakout group participants provided examples of the importance of granular data for health equity action at the local level:

- *“We learned early on: we’re a county of about 10.3 million people, we have 88 incorporated cities, and hundreds of unincorporated neighborhoods. So, when we first started producing data it was more for information and not about action. When we talked with community partners, we realized that in order for it to translate to action, data have to be at a much more local level, and much more exact. So, the spatial aspect of it has been very important for us.”*
- *“It has to start from the local level up. To me, the big lesson of COVID-19 and for all of us in public health practice, that’s the level of granularity. You need to really have an equity-informed and social determinants approach to inform your practice. And those data, the nuances, what needs to be disaggregated, just aren’t going to come in 50 states, lowest-common-denominator, federal data approach, with all of the inherent data lags that come with that.”*

Another aspect of data democratization is making sure everyone can have access to powerful forecasting analytics and capabilities, regardless of where they live. Dylan George spoke of how the Center for Forecasting Outbreak Analytics hopes to democratize data in this way:

*“The Center for Forecasting Outbreak Analytics is going to figure out how to use improved advanced analytics and predictive analytics to actually provide the evidence base that will be needed to support decisions at the federal, state and local levels.... The capacity we’re trying to build is not only for those that happen to be near universities, or have a major national laboratory in their backyard, but it’s a capacity and capability we’re trying to build for all Americans across the board.”*

**DYLAN GEORGE**, PHD, U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

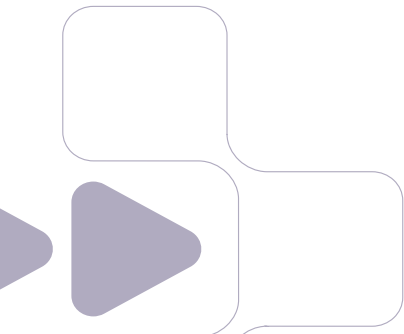
Data democratization also comes down to empowering communities most impacted by health inequities to engage in planning for improvement of their own community’s health. The Public Health Informatics Institute report proposes the use of tools, like the [Universal Community Planning Tool](#), to “help communities create local, data-informed visions and community health improvement plans that meet their unique needs and reflect the meaningful and transparent engagement of community members.”

Another summit poll taken during the plenary captured many elements of democratizing public health data and technology. It asked participants what areas of data modernization feel most critical in their daily work. More than a third of respondents (34 percent) selected “accelerating data into

action to improve decision-making and protect health,” while slightly less than a third focused on strengthening infrastructure. Additionally, 17 percent of respondents selected “managing change and governance to support new ways of thinking and working.”

POLL: Data modernization is a complex and exciting opportunity to improve health and wellness for everyone, everywhere. What area of data modernization feels most critical to your day-to-day role?	% of total responses*
<b>Strengthening and unifying critical infrastructure for a response-ready public health ecosystem.</b>	<b>30%</b>
<b>Accelerating data into action to improve decision-making and protect health.</b>	<b>34%</b>
Developing a state-of-the-art workforce.	9%
Supporting and extending partnerships.	8%
<b>Managing change and governance to support new ways of thinking and working.</b>	<b>17%</b>
Other (please enter in the chat).	1%

\*Response percentages add up to 99% due to rounding.





# Conclusion

The second virtual convening of the *Lights, Camera, Action: The Future of Public Health National Summit Series* brought together more than 1,500 public health workers from across the United States to discuss data and technology infrastructure modernization. Speakers shared their vision of what a modernized and interoperable data and technology infrastructure will look like:

*“So, what will be different because of the data modernization initiative? When the next emergency happens, we will have a foundation for data-sharing across all levels of public health for coordinated, scalable and timely case investigation, management and reporting. And we will have shared analysis capabilities for rapid identification of trends within and across jurisdictions, including forecasting and things like the social determinants of health, and a prepared data science workforce and a decreased burden on data reporters and public health staff. What we’ve been able to prove during the COVID-19 response is all of this is possible, we can see these capabilities in a not-too-far-off future, and importantly we know how to get there.”*

**DANIEL JERNIGAN**, MD, MPH, CENTERS FOR DISEASE CONTROL AND PREVENTION

At the same time, the perhaps-unforeseen undercurrent of all the discussions in the plenary session and the breakout groups was a demand for a culture shift within the field. As one breakout session participant explained:

*“It is a culture shift for the health departments to liberate and democratize the data. But the most exciting part of it is when you’re able to see community members use public health data, and having it being led by communities to drive action and good programmatic and policy changes at the local health department. So, I think that’s where it can get exciting. And it goes back to trust. Data use agreements, governance structures, charters—all those things can happen, but it really requires a lot of trust-building. I think it is a culture shift at the health department to go from that gatekeeper, curating, holding on tightly to the data to letting go of it, knowing that communities are your partners.”*

## **LIGHTS: Relationship- and Trust-Building for Equitable and Sustainable Data Modernization**

Guided by the resources referenced throughout this report, the field can produce a new future for public health that is rooted in equitable and sustainable relationships built on trust. Through meaningful partnerships with communities most impacted by health inequities, public health can establish a strong foundation of trust that will enable ongoing data sharing. This work will need to begin with shining a light on historical reasons for mistrust, including institutionalized structural racism and misuse of data, and writing a new script with community partners for data as a common good for the public's health.

## **CAMERA: Centering Equity, Interoperability and Sustainability in Data System Design**

Following the guiding principle, “nothing about us without us,” public health can design a modernized data and technology infrastructure by focusing on equity, interoperability and sustainability. Engaging stakeholders at every level, at every step of the process will create the foundation for equitable data systems and governance. Together with these stakeholders, public health can integrate a variety of data sources to paint a rich picture with, by and for the communities public health serves of their assets as well as their needs. Sustainability will require ongoing funding and sustained community trust-building.

## **ACTION: Democratizing Public Health Data and Technology to Advance Health Equity**

In order to take action to democratize public health data, public health will need to undergo transformations in education, training and communications to prepare itself to be a trusted partner in data for equity.

This work begins with education and training of the public health workforce on the history of structural racism and its impact on data, acknowledging and repairing the harm it has caused, and using and sharing the field's power to advance narratives that push for equitable systems change by elevating the lived experience and needs of communities most impacted by health inequities. Adapting to the digital age will require addressing the needs of a modern public health data workforce and change management to facilitate smooth transitions. Translating data into equitable action can be achieved by identifying the most appropriate data and technology for actionable intelligence and sharing that intelligence with impacted communities in real time.

Taken together, these efforts will allow public health to create an equitable, interoperable and sustainable modern data and technology infrastructure that will enable the field and its partners in the communities it serves to face current and future public health threats and, together, produce a new future for public health.

## **Themes for Action**

This summary report provides an overview of the feedback from the audience of summit 2, capturing a point in time of a very rich discussion with multiple partners. The following key themes emerged from the virtual convening as areas of potential action to move the field forward toward modernizing public health data and technology infrastructure:

### **Innovate through meaningful partnerships and early and ongoing stakeholder engagement**

- In partnership with communities most impacted by health inequities, cocreate a systematic public health approach to engaging with Black, Indigenous and people of color (BIPOC) communities, rooted in FAIR and CARE principles, to advance equitable systems change through data and technology.

- Re-envision how funding requirements can be designed to facilitate sustainable partnerships—e.g., reducing the impetus for grantees to make quick, unilateral decisions without engaging community partners.
- Systematically identify existing local networks and partnerships; past relational harms and broken trust, especially with community groups; build from current relationships and do local stakeholder/partner mapping, asset mapping and power mapping to set the foundation for meaningful data partnerships.
- Evaluate successful and unsuccessful cases of community engagement around innovative data on health inequities, such as COVID-19 wastewater surveillance, to identify and share best practices and lessons learned.

#### **Invest in building and sustaining trust for effective data sharing.**

- Make innovative investments at the state and local level with communities to help build and sustain the needed trust, capacity and relationships to advance equitable data modernization.
- Build into funding opportunities and requirements time and resources to invest in the needed ongoing relationship and community trust-building that will enable success and sustainability.

#### **Strengthen data, technology and informatics skills in the public health workforce.**

- Implement pro bono programs to embed tech and informatics experts into health departments.
- Develop structures for regional staff, skill and data-sharing through workforce innovation hubs, similar to the hurricane response hub model. Co-fund agreements to share staff for data purposes.
- Create fellowships for mid-level public health workers for cross-training and upskilling in data systems engineering and informatics.

#### **Ensure equity and sustainability in data and technology infrastructure modernization.**

- Establish requirements for periodic monitoring, analysis, and correction of data systems' and technologies' reflection of biases of their time. Likewise for standards for data collection and taxonomy.
- Establish rules and standards for application of small-population analysis methods with built-in privacy protections, including using privacy-preserving record linkages to link data across federated data sets, to correct for and prevent further marginalization of minority populations.
- When developing or procuring new data and technology systems and infrastructure, engage STLTs in their design, testing and execution to identify and implement changes to address particular needs and ensure alignment.
- When developing or procuring public-facing technologies, require accessibility assessments before purchase and/or implementation to ensure accessibility to marginalized populations such as people experiencing homelessness, non-native language speakers and people who are incarcerated.
- When determining funding for STLTs to support data and technology infrastructure modernization, ensure equitable distribution according to each agency's capacity and needs—recognizing that the costs of entry for technology are substantial regardless of the size of the population it will be serving.

#### **Acknowledge and repair historical harms.**

- Implement and incorporate into accreditation requirements fieldwide education and training on the history of institutionalized structural racism and how it has shaped data collection, analysis, translation and utilization.
- Incorporate education on Tribal Public Health Authority and FAIR and CARE principles for Indigenous data governance into all academic public health programs and require trainings for federal and STLT employees in regions where tribes are located.

## **Democratize collection and sharing of data for narrative building that advances racial justice and health equity.**

- Adopt and utilize a standard screening tool to capture social and structural determinants of health measures, such as the Accountable Health Communities tool, to enable linkage of health outcomes data with determinants.
- Conduct a systematic review of sources of data that can measure the root causes of health inequities in addition to community strengths and assets to contribute to a more holistic, structural and restorative approach to data collection, analysis and utilization.
- Conduct a systematic review of existing and attempted community information exchanges (CIEs) or community data trusts to identify best practices and lessons learned for equitable and scalable implementation.
- Develop an adaptable but scalable playbook to guide data and technology modernization that promotes inclusivity, meaningful community engagement and framing of inequities and solutions around structural determinants.

For more detailed recommendations for the future of public health, the cohosts and partners of this national summit series encourage a review of the reports that came out of the Bipartisan Policy Institute's bipartisan coalition, [Public Health Forward: Modernizing the U.S. Public Health System](#) and [The Future of Public Health: A Synthesis Report for the Field](#).

## **Summit Evaluation and Upcoming Virtual Convenings**

The final poll conducted at the end of plenary asked attendees how effective the summit was in meeting the objective: "Create an environment to facilitate growth and understanding necessary to support data solutions that assure real-time actionable intelligence that people, public health, communities and the private sector can use to prevent disease, promote wellness and assure prosperity." Nearly 88 percent of respondents said the summit was very effective or effective at meeting this objective.

Additionally, summit participants were asked whether they and their team will be able to take action based on the information from this summit over a range of time periods. More than 55 percent of respondents said they would be able to take action immediately or within two to six months.

The third virtual summit took place on February 23, 2022, with the topic of *Effectively Financing Governmental Public Health Functions and Strengthening Public Health Law and Governance to Support a Modern System*. The last summit on *Catalyzing Cross-Sectoral Partnerships and Community Engagement* was held on March 23, 2022. The [summit website](#) includes recordings, summary reports, accelerating action reports and other details on all of the virtual summits as that information becomes available.

The cohosts and partners look forward to learning from your contributions in the future as we plan together and write a new script for the future of public health.