Webinar on Ensuring the Future of Essential Health Data for All Americans

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Speakers

- Moderator: Joel Gurin, President, Center for Open Data Enterprise
- Dr. Alonzo Plough, Vice President for Research-Evaluation-Learning and Chief Science Officer, The Robert Wood Johnson Foundation
- Denice Ross, Former U.S. Chief Data Scientist
- Charles Rothwell, Former Director, National Center for Health Statistics
- Dr. Anne Schuchat, Former Principal Deputy Director, Centers for Disease Control and Prevention
- Meeta Anand, Senior Director of Census and Data Equity, The Leadership Conference on Civil and Human Rights and the Leadership Conference Education Fund
- Dr. Margot Brown, Senior Vice President of Justice and Equity, Environmental Defense Fund
- Dr. Sylvia R. González, Director of Research, UCLA Latino Policy and Politics Institute

Note: A video of the webinar can be viewed here.

Joel Gurin: Welcome everyone to this webinar on ensuring the future of essential health data for all Americans. I'm Joel Gurin, president of the Center for Open Data Enterprise or CODE. We're a nonprofit organization based in Washington whose mission is to harness the power of open and shared data for the public good. In order to implement our mission, we do public information outreach like this webinar and research papers, websites, and so on.

A lot of our work has focused on health. We've done projects multiple times with the Department of Health and Human Services and with other independent health organizations, with a particular focus on data on the social determinants of health. We're grateful to be holding this webinar with support from the Robert Wood Johnson Foundation (RWJF) and in partnership with the National Conference on Citizenship (NCoC).

Why are we here today? I think everybody on this call is committed to developing a better and more equitable system for improving health, focusing not only on health care but on all the social and demographic factors that impact health. And we know that we

are now at a moment where we are at risk of losing a lot of the data that we have relied on at a federal level. There have been dramatic changes at the Department of Health and Human Services, and across many federal agencies that relate to the nation's health, that collect key data sets and scientific data that's now at risk.

Today, we're going to talk about what we can do about that. We have a phenomenal panel who are going to be giving many different perspectives on how they see the challenges of the current moment and the actions that can be taken.

So let's get started. I'm going to go around, give each of our panelists a brief introduction, and then ask them a question to talk about to give their perspective.

Let me begin with Dr. Alonzo Plough. Dr. Plough has been a national leader in public health for over 25 years. He's the Vice President for Research-Evaluation-Learning and the Chief Science Officer at the Robert Wood Johnson Foundation, where he's responsible for aligning all of the foundation's work with the best evidence for research and practice. He oversees grantmaking portfolios focused on innovation and emerging issues. Dr. Plough, welcome and thank you for being here. We would very much like to thank the Robert Wood Johnson Foundation for supporting this project and turn to you to help welcome our audience and open the discussion.

This project is one of many that the foundation is supporting to protect and improve America's health data. Could you please tell us why this is such an important concern for the foundation right now and describe some of the things you're doing to address it.

Dr. Alonzo Plough: Thank you for the good work that you've been putting in on this. The crisis of the elimination of critical public health data has quickly emerged as a top priority for the Foundation to address. We had been working optimistically before January of this year with the CDC and others on our mission to improve public health, building on the public health data we had to make it more accessible. We were learning from the experiences of COVID to develop a better, more community connected, more granular and more effective way to engage with the data and communities.

After January 20th, the protection of our existing data became primary. I'm responding from my position at the Foundation but my mindset is my 30 years as a director of county and large city health departments. For us to see the elimination of what is so critical to the practice of governmental public health made this rise to a top priority for the Foundation, one of only five across the entire Foundation. So we have now made a cohort of rapid response grants to about a dozen organizations, and CODE is one of those, to assess the scope of the problem.

We've moved to see who is archiving data and support some of these reactive approaches to the immediacy of the problem. And there have been great discussions, one of which was just before this meeting today. Now our focus has begun to change into what it is going to mean to develop a sustainable alternative or ancillary data

systems to make up for the missing federal data support at state, local, and regional levels.

As we've been saying in philanthropy, we can keep certain research on life support for data, but the orders of magnitude difference between our funding and the federal funding that's gone is huge. We're committing to doing what we can. The good news is that there is a great convergence and interest in active meetings of the philanthropic sector around the data issue in health and other areas.

What is emerging with the Foundation's funding and a lot of our collaboration with our grantees is this movement to ask "What does this alternative data system look like? How can it have a more local, regional, granular presence? How can we not just react but think about this crisis as an opportunity?" So we're trying to work on both of those tracks. This will be a critical part of our funding as we move into trying to support organizations that can operate within the environment of what is missing in the data.

I would say there are four lanes for that:

- Classic public health surveillance data that supports governmental public health and community work;
- Hospital related and healthcare data;
- Environmental determinants data;
- And then the entire lane of social and economic determinants, such as housing.

I think it's time to disaggregate a bit and think about some of the specific work that's happening in each of those streams. And that's how the philanthropic funders are thinking about it.

Restoring trust in data in a situation like this becomes essential. Building that trust with a deep level of bottom-up community engagement in what these systems look like is paramount. I know the work that the Foundation will be doing, and we've got special board authorizations to do this work at scale, we'll be trying to connect. The trust is built in the base – to build a trusted set of systems that can help to patch what's missing.

I'll just end by saying for those of us who've been in public health for years, I never thought I would have to be funding work that deals with the federal disinformation and misinformation around public health messaging and the entire retreat of the federal government for evidence-based population health. But we are going to be working very actively in funding counterinformation to that trend.

Joel Gurin: Thank you so much for laying the table for what we're discussing. I think all of us on this just deeply, deeply appreciate what the Robert Wood Johnson Foundation is doing to take leadership in this area. There is an awful lot of work to be done and opportunities to do it.

Staying with that theme of where we are going forward in the future - and moving from looking not only at data preservation but also looking to future systems – I'm going to turn next to Denice Ross. Denice is the former US Chief Data Scientist and has held several other data leadership positions in and out of government. She's been an expert in data policy for more than two decades and is now leading a number of projects to address changes in federal data systems and strengthen our national data infrastructure.

Denice, thank you again for being here. You have such deep experience with federal data systems. You know their strengths and vulnerabilities. Could you please share with us what you think are some of the biggest risks to national data right now and some of the best strategies to be sure that the country has the data we need, particularly for data relating in one way or another to public health.

Denice Ross: Thank you, Joel. I have been watching closely what's happening with the federal data ecosystem, along with a group of federal data watchers across domains. And we've noticed three patterns, three main themes in the patterns of what's happening.

The first is the targeted removal of data elements that are not aligned with this administration's priorities. Just last week, Freilich and Kesselheim published an article in *The Lancet* that was entitled "Data Manipulation Within the US Government." They looked at data from HHS, CDC, and the VA that had been updated in the first two months of the administration. And they found that nearly half of those 232 data sets that had been updated were altered. Most of those were the targeted change from the word gender to the word sex. That was obviously in response to the executive order on gender ideology that came out of the White House. But we've also seen data about DEI disappear, such as race and ethnicity in the Office of Personnel Management's data on the federal workforce. And also data sets like NOAA's billion dollar disaster data set have been discontinued. So one pattern is this targeted removal of data.

The second pattern is the large-scale degradation of the federal data apparatus. This includes staffing cuts and canceled contracts - contracts to facilitate collection, processing, and analysis of the data, but also the technical services and software that are needed to keep data safe and to manage the workflows. And then, of course, there's the disbanding of scientific advisory committees. This is all going to have a much larger impact on the data we depend on and will be harder to recover from in the long term, this large scale degradation of the apparatus.

The third area, which Alonzo touched on, is trust in government. We know it's been declining for the last two decades. And trust impacts data in a couple of ways.

One is whether people will fill out forms and surveys, especially questions about demographics and other characteristics that might make them feel vulnerable. Talk of an autism registry, a national citizenship database, and the federal government requiring unfettered access to safety net data from states - those are all likely to have a chilling

effect on people filling out detailed questions in the forms and surveys that they receive. And we are hearing anecdotal reports of people not even seeking out services that they need out of fear of having their information in these systems.

Another trust issue is whether people believe the data that are released by the federal government. One of the most troubling findings in last week's *Lancet* article was that not only were half of the changes to the health-related data sets politically motivated, only 15 of the 114 adulterated data sets included documentation about the change. So that's obviously going to have some cascading impacts on trust in the data that are being published.

As Alonzo mentioned, nothing can replace the role of the federal government for collecting and sharing data, especially data about public health. So with that in mind, there are three things that we can do to help shore up the flow of federal data.

The first one is to identify the public health data sets that you deem most essential. I encourage folks to think broadly about those data sets, not just data about health outcomes and disease surveillance, but also operational metrics. For example, how long does it take different states to get coverage to somebody after submitting a Medicaid application. Or data sets like clinicaltrials.gov or the NIH comparative genomics resource. And also data sets on the rates of the uninsured that might come out from the American Community Survey or National Health Information Survey.

The second, once you've identified those essential data sets, is to keep an eye on those data for any changes or opportunities for public input. One way to monitor the data is by signing up for our weekly notices at dataindex.us. We are tracking proposed changes to federal data collected through forms and surveys and also opportunities for public input through the Federal Register. We're doing that heavy lift so you all don't have to, you can focus on just making the case for why these data are important.

And speaking of that, the third recommendation I have is to be sure to tell the story about how these data benefit American lives and livelihoods. I would encourage you to visit essentialdata.us and submit a sentence describing why your favorite dataset matters. We're trying to shift the discussion from why these data are important for researchers to why these data matter for everyday Americans.

- One example would be when a working parent calls their state Medicaid office during their lunch break to renew healthcare coverage for their family and they wait on hold only 10 minutes instead of three hours. That's because CMS's data provides transparency and accountability on state call center wait times and the states don't want to look bad among their peers, so that encourages them to get their wait times down.
- Another example would be if a person with asthma is flying to a wedding and is wondering if they should mask up during their trip to reduce the risk of catching a

respiratory infection. They would visit the CDC's National Wastewater Surveillance System to inform that decision.
- And then lastly, with the dramatic changes in Medicaid requirements, journalists, policymakers and advocates interested in a first look at any impact on health insurance coverage would likely want to use a dataset like the National Health Interview Survey, which is administered by NCHS and the Census Bureau.

All that said, I think we are going to need to get creative about what our Plan B is. I'm grateful for the work of the Robert Wood Johnson Foundation and others coming together to think about what some alternatives might be to fill these essential data gaps and especially building the capacity of state and local entities to rise to the occasion.

Joel Gurin: Denice, thank you so much. And thanks to you and your colleagues who are doing foundational work on helping us all identify changes that may be coming in and push back as necessary.

You ended by talking a little bit about NCHS data, which is a perfect segue for us. Our next panelist is Charles Rothwell, who was director of the National Center for Health Statistics or NCHS from 2013 to 2019. He came to federal government service in 1987 as Associate Director of NCHS, where he later served as the Center's Director of Vital Statistics before becoming its director. Before entering federal service, he spent 13 years in the State Health Department of North Carolina, where he became the first director of the State Center for Health Statistics.

Charlie, thank you for joining us. The NCHS has been central to so much of what we know about health in this country. I wonder if you could describe, for folks who may not know, a bit about the scope of data that NCHS is responsible for and how you see the current situation, both in terms of the risks to federal health data and also the opportunity to address problems with data that we've seen in the past.

Charlie Rothwell: Thanks, Joel. I'll be glad to try.

First, let me briefly describe the role in data activities of the National Center for Health Statistics or NCHS. NCHS is one of 13 principal federal statistical agencies in our country's very, very decentralized federal statistical system. It collects data directly through its own surveys with in-person interviews, as well as through actual physical exams and associated lab testing. Through a collaborative system with all the states and territories, NCHS also collects the vital statistics of the U.S. - that is, all recorded birth and death records. NCHS also links their data with data sets across HHS and other departments.

These data are then used to measure the health of people across our country and important subgroups within our population and monitor trends in their health conditions and behaviors and characteristics. The data is also used to support other biomedical, public health, and health services research activitie. And finally, it's used to guide public

policies and programs and track the impact of policy changes. Its role is only to inform policy debate and the impact of policy changes through trusted and useful data.

Some of the people hearing this Webinar may not really know the types of data that NCHS collects. It's data that provides the information for our life expectancy tables. It provides data for the leading causes of death and emerging changes in causes of death. It looks at the prevalence of selected diseases. It looks at changes in health insurance coverage and related health outcomes. It provides obesity rates. It provides birth rates. It provides infant mortality data. It provides nutrition data that's used for the national nutrition guidelines. It provides data for our children's growth charts. It monitors the changes in healthcare utilization. It provides data on reproductive health, et cetera, et cetera, et cetera. I think these are data that people understand and use and need.

What's unique about NCHS and many of the other agencies in the federal statistical system is that they have fixed schedules when they publish their reports, as well as the releases of the detailed data sets that are used to generate those reports. The availability of these data sets is absolutely critical to allow researchers and policy wonks to analyze the data in different ways and examine different issues, and also to assure everyone that we're not cooking the books.

So what's wrong, certainly at this particular moment, but in the past as well? Well, NCHS data collection is mostly survey-based, which was highly successful for decades. But now, with lowering response rates causing increased costs per interview, along with a lack of needed geographical granularity, survey reliability and usefulness is starting to come into question. Yet no innovation funding has been provided to examine how other existing and emerging data sources could be used to augment and perhaps replace these surveys. In fact, the NCHS budget has been cut, along with the budgets of many other HHS agencies - and many of those agencies actually fund NCHS data collection activities. Also, there's no longer an outside advisory committee assessing the usefulness of NCHS data products.

Staffing losses further delayed the timeliness of NCHS's data, which has for years needed to be improved through use of new technologies and data sources. And recently, there have been several proposed new locations for NCHS and HHS, which indicates that the current administration is unsure of the role of NCHS.

Now this concern is heightened by other federal fiscal agencies being essentially defunded as in the Department of Education or suffering significant cuts as in the USDA or the National Science Foundation and the Department of Energy. Also, there have been recent reductions in the economic data provided by the Bureau of Labor Statistics and the Bureau of Economic Analysis.

Clearly, the decentralized federal statistical system is in peril. In my opinion, it's not so much by design as by unintended consequences of broader moves in parallel

departments. Few people either in or out of government and either now or in the past know where the data actually comes from.

This is why there is now an outside study going on supported by the American Statistical Association (ASA) to consider ways to centralize the federal statistical system to improve its timeliness and data shared through new technologies and improved efficiencies. The failure of our ability to provide more granular, timely, and shared data to better inform policy action – for example, to combat diseases of despair, or provide direction during national disasters and the COVID pandemic - show that appropriate change needs to take place now.

I applaud the effort of ASA in this tumultuous time. Now is the time to make constructive changes that make sense to all parties interested in a more recognized source of useful and trusted data, monitoring the outcomes through shared data of our very interconnected and complex society.

Joel Gurin: Thank you so much, Charlie. I just want to highlight something you said. First, while Denice talked about changes to datasets that may be politically motivated, Charlie, you're pointing out that some of these changes may really be due to inadequate funding and support, which we're seeing across federal statistical agencies in many different ways. I know there are advocacy groups like Friends of NCHS that are now pushing for adequate funding because, as you said, the data is important to everybody. It's important to American businesses. It's important to healthcare professionals. So hopefully we can find some ways forward to push for what's needed there.

We're now going to turn to Dr. Anne Schuchat from the Centers for Disease Control and Prevention, which houses the NCHS. Dr. Schuchat is an internist and epidemiologist whose career at the CDC spanned 33 years. She was the agency's principal deputy director from 2015 to 2021 and served twice as acting CDC director from 2006 to 2015. She was the first director of CDC's National Center for Immunization and Respiratory Diseases, where she led the nation's immunization program and the global deployment of vaccines against pneumonia and meningitis.

Dr. Schuchat, thank you so much for joining us. The CDC is now facing cutbacks that can have a huge impact on public health, including impacts on immunization and preventive medicine, things that the CDC does on the ground. But there is also a concern that cutbacks could impact surveillance data. That includes both the data we need to track and fight infectious diseases and also data on things like the health effects of tobacco and other kinds of health risks. Could you please tell us about the surveillance aspect of CDC's work and what concerns you most about these current changes to our data resources.

Dr. Anne Schuchat: Thanks so much; I appreciate the chance to be part of this panel. The CDC's surveillance really underpins all of what we do in public health. But in contrast to some of the NCHS systems that Charlie was highlighting - and of course

NCHS is currently part of CDC - I wanted to focus on the more active part of public health surveillance. And that really starts at the local and state health department level.

Surveillance is very much a self-correcting enterprise; it's not a one-way thing. The idea is that surveillance provides information on trends, but also emerging issues and program effectiveness. And then it initiates response, whether it's a case of tuberculosis that needs active follow-up or a cluster of measles that may indicate a larger problem.

While state and local jurisdictions have the authority, there are many conditions that cross jurisdictional lines. You need to look no further than the current outbreak of measles that initiated in Canada, I believe, and then caused quite a number of problems in Texas and then 37 states that now have measles.

I want to focus on four areas briefly: the people, the systems, the governance, and the trust. I think trust is probably something each of us will touch on.

The people involved are local and state health departments, but they need linkage with their communities and they need linkage with the healthcare sector. The linkage between healthcare and public health has been a problem way before this administration. As the healthcare sector has gotten more technologically sophisticated, health departments have been really cut out. We could see in COVID that that was a huge challenge.

On the systems, it's well known that public health systems needed modernization. We knew that before COVID and COVID made it even more clear, but the resources that have gone in to try to modernize the public health systems have been interrupted. Some of that modernization got far enough that I think it can be maintained, but a lot of it hasn't.

About 80 percent of CDC's budget goes to state and locals, and a lot of the state health department's budget comes from the feds. The ability to update the systems to take advantage of technology is threatened right now. You can look to Minnesota's immunization registry modernization, which was going to help them really understand what was going on with immunization levels in a low-burden way and a timely way. That effort got curtailed when the resources were rescinded by the federal government.

The third area is governance and processes. The federal surveillance systems are really not federal. They are aggregations of state and local jurisdictions who have to agree on what they will report, when they will report it, and how they will report it. Agreements on case definitions, agreements on timelines, and agreements on which system to use are very much a labor-intensive coordination process. When the federal government decides that the federal agencies shouldn't communicate with states, this really interrupts the governance process.

Lastly, I want to mention trust because it's fundamental whether it's the initial event reporting from a patient or a clinician to the state and local system or from the state and

locals to the federal system. We need to be part of the same family to really make the surveillance data actionable.

I would also like to mention a couple of the systems that you probably know about:

- Syndromic surveillance that comes in from emergency rooms helps us understand what's going on with respiratory seasonal illness, and also understanding new problems like the e-cigarette or vaping-associated lung injury that came out of nowhere. We need the syndrome data from hospitals to understand when we are making progress or not.
- The PRAMS (Pregnancy Risk Assessment Monitoring System) is the only thing that interviews women before, during, and after delivery to understand the risk factors and protective behaviors that are so critical to maternal and child health.
- The Behavioral Risk Factors Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS) are how we track obesity, smoking, and more. All those systems are federally funded and in need of modernization. They may or may not be there in the future.
- We get fantastic data from NCHS about death certificates, but the injury surveillance systems can help us understand issues before people die. They can provide supplemental data that helps us understand what happened before the suicide, what happened before the homicide, what happened before the overdose - what were the factors that are key for us to know about so that we can intervene. And then all the injury surveillance that NIOSH does on the leading causes of injury and illness and death among workers.
- And finally, cancer registries, avian flu registries for farm workers, and other systems to monitor disease.

Those are the vital systems that CDC integrates or participates in that are threatened, either because we haven't resourced them, or because the partners we depend on at the local state level are really hurting, or because of ideological issues. We have a saying: What gets measured gets done. And what you stop measuring is probably going to get undone. The progress that we've made may really be threatened when we stop looking.

Joel Gurin: Thank you, Dr. Schuchat. You've described why this data is so critical in a way that impacts everybody. This is not abstract or academic research data: We're talking about data that's essential to the health of the country. Thank you for laying that out.

I want to turn now to Meeta Anand. Meeta is the Senior Director of Census and Data Equity for the Leadership Conference on Civil and Human Rights and the Leadership Conference Education Fund. She has also worked with the New York Immigration Coalition and has extensive experience in advocacy, strategic planning, and community engagement. She's a graduate of Harvard Law School and holds a master's degree from the Fletcher School at Tufts University. Meeta, thanks so much for joining us.

The Leadership Conference is doing a lot of work to protect disaggregated data, the kinds of data that let us analyze the needs of Americans by race, ethnicity, gender, sexual orientation or disability. The Leadership Conference has launched the Data Disaggregation Action Network, or D-DAN, to improve data quality and access. I'd like you to talk a bit about why disaggregated data is so important and how you all are identifying risks to this data and some possible solutions.

Meeta Anand: Thank you so much, Joel. The Data Disaggregation Action Network works at both the federal and state levels to improve the collection and dissemination of data disaggregated by race and ethnicity. We also do some work around sexual orientation and gender identity.

We're focused largely on Statistical Policy Directive number 15, or SPD15, released by the Office of Management and Budget (OMB) in March 2024. SPD15 gives the format and rules and regulations that federal agencies must use in collecting race and ethnicity data. It was the first revision in 27 years to the race and ethnicity data collection standards that apply across federal agencies. Through SPD15, race and ethnicity has become one question, i.e., what is your race and or ethnicity? It also added the MENA category, which is the Middle East North African category. So now when you look at it, you'll see one column that has all the choices, including Hispanic and MENA, and people can select as many as they choose.

We're watching how SPD15 will be implemented in federal agencies and in the U.S. Census. A lot of our work focuses at the national level on the Census Bureau, because as we know, the denominator is affecting everything that we're doing and also sets the frames for a lot of the work that we're talking about.

When the Census Bureau released SPD15 revisions, one of the most powerful components of that release was the third requirement, beyond combining race and ethnicity and adding the MENA category. The third requirement was the mandatory collection of detailed data. This is epically changing and deeply important, and actually the other two categories only get supercharged by having the addition of the detailed data. People who work with MENA communities tell you that that's only a meaningful data category if you get the detailed data.

Right now, we are seeing the combined question and the MENA category being implemented, but we're not seeing the detailed data. No one's surprised because people are going to call it too burdensome and we're in an administration that opposes anything that smacks of regulatory burdens. So we are trying to advocate for that at the federal level, and we're encouraging our state partners to go full speed ahead in implementing SPD15, especially looking at implementing requirements for disaggregated data. Our latest report on this is on our website, wearethedata.us.

We're also seeing a range of other threats. We're seeing issues with resources – funding and staffing - across the federal government. It affects the Census Bureau, through less

outreach to communities to fill out surveys. Denice Ross talked about the loss of advisory committees. Everyone has talked about trust: Declining trust in surveys, trust issues about data sharing, and general politicization.

We're seeing legislation in Congress not only to add a citizenship question to the Census but to add an immigration status question and to exclude non-citizens from apportionment counts. These are deliberate attempts to ignore the 14th Amendment and to start having skewed data sets. We've already seen a depression in survey response rates with everything that's happening already, and this will just aggravate that.

What are we doing to help? We've launched D-DAN, as I said, where we're trying to provide resources and community to our local partners to do this work. We are doing advocacy around the pernicious legislation that we're seeing. We have our Roadmap to 2030 website, which gives actionable steps people can do towards the Census. We have a data preservation working group on preserving race and ethnicity work. You can sign up to join one of the four subcommittees that are doing the work.

We are putting together an advocacy toolkit to help people understand how to do this work. If you think people don't pay attention to advocacy, that's not true. The National Crime Victimization Survey had stopped asking the SOGI question, despite statutory requirements to do so, and after we started pointing this out, they put the question back. Now, we don't have a complete victory there, but we had part of a victory there, so having people write comments is meaningful.

I think we all need to come together and start establishing a framework of data governance and data principles that we can all agree to in understanding what privacy and confidentiality mean in this context. Because until we restore public trust, all of us can work in our silos, but we all know that the issues we have are not going to be solved until everyone starts having trust and belief in the importance of public data and that it be used for the public good.

So, finally an Easter egg for people who know me well. I really want to put together an action called Day Without Data. If you think this is a great idea, please reach out to me. I think we can make everyone understand what central importance data have in our lives, not just in terms of AI trying to eat up the data and create algorithmic futures that we don't want, but in terms of how it is currently helping our day-to-day lives.

Joel Gurin: Thank you, Meeta, for that fantastic overview and for the essential work you all are doing.

I'd like to turn now to Dr. Margot Brown. She is the senior vice president of justice and equity at the Environmental Defense Fund where she has launched the Frontline Research Institute or FRI. She has a long history of work on environmental justice at the state and national level, including her work as deputy director of the EPA's Office of Children's Health Protection.

Dr. Brown, you're leading a growing initiative on climate and environmental justice at one of the country's largest environmental organizations. One of the first things the Trump administration did was to take down information and online tools for understanding climate and environmental impacts on frontline communities. What kinds of data do we need for the kinds of programs that you support and what can we do when government data like this disappears?

Dr. Margot Brown: Thank you, Joel, for inviting me to participate in today's conversation. And thank you to all of our attendees.

I'm going to talk first about what we know to be true at the Environmental Defense Fund and what we've done. And I'm going to start by quoting what Dr. Schuchat said: "What gets measured is what gets done." That is so critical. Because without data, we would have not been able to reveal the deep and often devastating connections between climate change and human health. And what we know at the Environmental Defense Fund is that this data has been transformational. It's driven climate solutions, it has saved lives and created public health interventions, and it's sparked action from city halls to Capitol Hill.

To advance really meaningful environmental and climate justice work, especially for frontline communities and historically overburdened communities, we need data that has three parts to it: It must be comprehensive, localized, and accessible. We need to look at cumulative environmental burden data and public health outcomes, at socioeconomic vulnerability and climate risk factor projections. And we're looking at community knowledge and really uplifting and upholding lived experience. It's not one of these factors, it's all of these factors. And it's so much data - it's not just one set of environmental data.

In 2023, here at the Environmental Defense Fund we created the U.S. Climate Vulnerability Index, which we refer to as the CVI. The CVI is an incredibly powerful tool because it integrated 184 data sets to assess over 70,000 Census tracts. The CVI reveals where risk of climate change intersects with the most severely socially and economically vulnerable communities. And it doesn't just show where climate resilience is needed. It shows how we can help policymakers and communities take targeted data-informed action.

The CVI was built with close community consultation. That's incredibly important. We didn't just create a tool that we thought was needed, as scientific experts at EDF. We created a tool based on the lived experience and deep expertise within communities. We got to 184 data sets because the communities came back and they said, we need you to include more information on education or crime or all of these different variables. And they urged that the tool integrate climate hazard data like heat and flooding as well as demographics, and an array of health indicators. The result showed communities at risk for climate change and highlighted gaps in adaptive capacity.

This is so important because one of the things that we try to do at the Frontline Resource Institute is to support the capacity needs of frontline leaders. We're not telling people what they need to do or what they should be measuring, but we're asking them, where are your gaps in capacity and how do we fill those gaps? And one way that we fill those gaps is through data. The CVI was originally built for policy development for community planning or advocacy to address climate impacts. It was also used to help target resources for vulnerable populations so they can use this data or that summary for grantmaking at various levels of locality, whether it's at the Census tract level, the county level, or at a national level.

The CVI has become incredibly important now. We built it as a tool that sat in parallel and had different roles than the government tools like CEJST or EJ Screen. These were complementary tools and we thought all of these tools could work together. And now that those government tools have been taken down, there is a very small handful of tools right now that are able to measure what the CVI is measuring. The great news is that it's an independent tool that was built with researchers at EDF and Texas A&M. The downside is that as federal data becomes more compromised, it's going to be much harder for us to update and implement that tool.

What we know at EDF is when administrations begin to restrict or dismantle public access to climate and health, as we're currently seeing, it's not just a setback, it is an erasure of lived experiences. It is an erasure of what we are seeing in real time with our own eyes. It also undermines our ability to hold polluters accountable, and it undermines our ability to allocate resources equitably and shape policy that delivers justice.

We believe now more than ever that we have to protect and invest in the data that tells the full story of our climate crisis and how it's going to affect our health, our communities, and our collective future. And we've got to make sure that folks maintain access to information so we don't just lose knowledge. We know we're going to lose knowledge through these government actions, but we can also lose the power to act. Because if what gets measured gets done, if we can't measure those things, then we lose the power to act and we lose our ability to demand justice. Thank you.

Joel Gurin: Dr. Brown, thank you so much. And thank you for putting together such a phenomenal tool and resource for folks to use.

Our final panelist, Dr. Sylvia R. Gonżález, is Director of Research at the UCLA Latino Policy and Politics Institute, or LPPI, where she leads work at the intersection of environmental justice, health equity, and economic mobility. Her research focuses on what a just transition will look like for Latino communities and neighborhood data to drive policy change. She's a co-investigator for the new Latino Climate and Health Dashboard, a public tool that tracks environmental exposures in frontline Latino neighborhoods across California and brings deep expertise in community-engaged research.

Dr. González, to follow on some of the themes that Dr. Brown talked about, you're also working at the nexus of climate, environment, and health and the ways those factors impact communities, with a focus on communities in California. Could you please talk about how you see those issues playing out at a state level and how states and universities in partnership can help provide the data that we need to work on these issues.

Dr. Sylvia R. González: Absolutely. Thank you for the invitation and to everyone for being here today.

I want to go back to Denice's really important point about changing the narrative around why data matters, and I want to start my conversation today with my story about why data matters at the Latino Policy and Politics Institute. We focus a lot on narrative change, particularly around disaggregated data. We always say that the Latino community is not a monolith, that we have so many different communities and different experiences. For example, I'm a daughter of immigrants, a first generation researcher of color.

Today's discussion around data preservation isn't just some abstract idea. We are at a time when Latino communities, when immigrant communities are being persecuted through fear and being forced to be invisible. So the politically motivated erasure of data on health, on environmental justice, on disaster preparedness, on immigration status, on race - it's all very personal to the work that we do.

I often say that the data that we collect and work with, it's not just numbers, it's our family, it's our neighbors, it's the people that we really care about. So this topic is really about the erasure of our communities, of my community. To Margot's point, because we don't have access to these data, it often takes away the ability for frontline communities to speak about injustices, to uplift our experiences, as well as to uplift our contributions to American life, and that really contributes to the negative stereotypes that we often see being used to politicize different programs in different states.

Going back to your question, Joel, how do I see these issues playing out at a state level? Our team has been very proactive in advocacy to inform state level responses.

There were two specific issues: One, proactively to start identifying data sets that are at risk of disruption, and then two, prioritizing data sets that do not have local backups. Those are data sets that rely on federal portals for public dissemination and for archiving, and once they leave state repositories, they no longer exist at the state level. So the priority for us has been for state agencies to get their ducks in a row, proactively start identifying those data sets that are at risk of disruption. We found that most state agencies have not been thinking about data preservation despite the previous experience that we had in the first Trump administration. They were still caught off guard by federal cutbacks, and so we really do need to ensure that states are investing in understanding these dependencies.

The reality is that when federal regulations are weakened or dismantled, states are going to follow suit by not collecting essential data simply because they're no longer required to. There's no motivating factor without that statutory requirement. In California, our concern is really amplified by the pressure of a budget deficit that we have.

In terms of your second question on the role of universities, the footprint of universities is incredibly broad. UCLA alone has over 100 research centers spanning health, environment, STEM, social sciences. There are over 6,000 projects that are going on at the same time in any given year.

At LPPI, we have two big data infrastructure projects, the Latino Data Hub and the Latino Climate and Health Dashboard that we've recently launched to ensure that our community continues to have access to Census data, disaggregated data. I encourage you to visit those sites.

The other thing that LPPI has been doing is internal. We wouldn't be good researchers if we don't create a survey to understand what's happening at our university. We recently launched a survey across the different UCLA centers to document the impacts and build collaborative responses. So we're continuing to have those conversations internally. In terms of concrete roles for universities, there's still a lot of coordination that needs to happen very quickly. I think that universities can play a contributing role with statewide partners to ensure that state level data collection efforts continue and stay resilient regardless of any federal policy shifts, and then also continue to fill data gaps, whether it be through archiving and disseminating existing public data sources or collecting new data with our partners on the ground. And I want to emphasize, with our partners on the ground, using methodologies that are not extractive of our communities that are already vulnerable during these times.

Joel Gurin: Dr. González, thank you so much. I want to thank all the panelists for this incredibly rich discussion and all these different perspectives. They all converge on the same major issue, which is the great need for accurate, complete, reliable data for the nation's health, the challenges we're facing and the different creative ways that people in organizations are finding to address those. This is such important work and there is so much that we need to work on together. Thank you so much.