

October 3, 2022

Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
1650 Pennsylvania Avenue
Washington, DC 20504

Submitted electronically to: equitabledata@ostp.eop.gov

Re: Engagement and Accountability RFI

As the director of the [National Commission to Transform Public Health Data Systems](#), I appreciate the opportunity to submit comments to the Office of Science and Technology Policy (OSTP), on behalf of the Subcommittee on Equitable Data of the National Science and Technology Council, in response to its request for information on how federal agencies can better support collaboration with other levels of government, civil society, and the research community around the production and use of equitable data. Historic inequities must be considered in our approaches to develop equitable data systems.

Public health data systems take the pulse of our society, providing a snapshot of the strength and vitality of our population. And yet, for too long, that picture has been far from complete—in fact, it's been skewed in ways that have harmed the health of members of many of our diverse communities, especially those of color, those with disabilities, and those who are LGBTQ+. Decades of limited funding, lack of federal and state coordination, and systemic hurdles left a vulnerable public health infrastructure.

After COVID-19 laid bare the gaps in our public health infrastructure, including the disproportionate impact on communities of color, the Robert Wood Johnson Foundation (RWJF) convened a first-of-its-kind independent National Commission to Transform Public Health Data Systems to reimagine how data are collected, shared, and used to identify the investments needed to improve health equity. The 16-member Commission composed of diverse innovators and experts representing multiple sectors—healthcare, community advocacy, government, business, public health, and others—released [a set of recommendations](#) in October 2021 for centering both health equity and racial equity. The Commission offered three overarching recommendations for a blueprint for change: center health equity in narrative change, prioritize equitable governance and community engagement, and ensure that public health measurement captures structural racism and other inequities. I encourage you to read the full report of recommendations [here](#).

Highlighted below are recommendations of particular relevance to the questions raised in the request and place-based (i.e., local) grant programs that recently launched in response to the

Commission's recommendations to build a more equity-centered data infrastructure across the country.

Prioritize and accelerate implementation of the Evidence Act for improved transparency, quality, and availability of data.

In the request for feedback, a reference was made to accessing needed data from federal agencies and departments. We believe that more actors should have access to these data and not just researchers at R1 institutions that can afford to pay for access through the Federal Statistical Data Service. Thus, we encourage equity to be considered in the implementation of the Foundations for Evidence-Based Policymaking Act (Public Law No: 115-435). The law requires agency data to be accessible and requires agencies to plan to develop statistical evidence to support policymaking. As implementation activities of this law begin, such as those with the creation of the National Secure Data Service (NSDS), ensuring equitable access is paramount. For example, similar federal data services, such as the Census Federal Statistical Data Research Service, are cost prohibitive for academic researchers not affiliated with well-resourced institutions or colleges and universities. Costs to access the data need to be reduced or grants should be offered to help researchers at historically Black colleges and universities (HBCUs) and other less-resourced institutions access this critical data and uncover challenges in their communities.

In addition to equity in access, any kind of federal-level data resource should contain the right measures that help actors achieve their equity goals. Currently, the information that can be extracted from administrative files that can be useful for creating measures that can be used to explore how inequities in health and social outcomes can be reduced is far from clear. We encourage you to become more transparent with what is included in administrative data. Transparency is needed so potential data users know what they can access and what they can request. For data queries and data requests (when possible) there also needs to be appropriate capacity at the federal level to respond. Requests for federal data that are not met in a timely manner limit researchers' ability to have a clear and accurate picture of community conditions and therefore restrict actions to respond and make improvements. Further, data requests should be met with clean data. Many partners in the field have reported having to make multiple requests from governmental agencies before receiving the data they needed. Dedicated funding and staffing on the federal side will ensure improved community collaboration.

Establish and implement a coordinated state and federal investment strategy that includes regular fiscal support of state and local governments' efforts to accelerate data system modernization.

Federal and state funding for public health has declined over the past decade, and there has been weak support for federal funding specifically for data infrastructure. Grantees and partners in the field often cite ONC's BEACON Communities Initiative as one of the last programs that had a specific focus on building data infrastructure. That program launched in 2012, and since then, it is difficult to find a similar initiative that can sustain what has been built or that can help with the development of new data resources elsewhere. As a result of inconsistent funding, there is wide variability in public health infrastructure, and we believe this has had effects for health equity. While more direct and dedicated funding is needed, there are new funding resources that could be used to improve local data systems such as those available through the American Rescue Plan and the Infrastructure bill. Unfortunately, we have heard that acceptable expenses of grant dollars from these opportunities are not clear. Federal agencies should clarify the acceptable use of funds, making it explicit that support for data infrastructure is allowable and improve outreach so local communities are aware.

In addition, federal agencies could align federal grant reporting requirements that would encourage cross-sector collaboration and assist states and localities as they work to blend funding streams to maximize impact. Currently it is difficult for local agencies to coordinate outcomes, making blending and braiding funding difficult. The [Brookings Institution](#) has encouraged cross-sector collaboration that would enable public health departments and other entities to maximize the use of their funds to support data. We encourage you to draw from their resources to learn how federal departments can be supportive.

Collect better data broken down across population groups (race/ethnicity, gender, disability) and geographic levels to offer a more complete picture of health disparities.

Local government, community-based organizations, and others often fail to reach the most vulnerable groups because of a lack of data by race, gender, and other demographics and structural factors that separate people from health and opportunity. Without consistent disaggregated data, the research we draw upon to inform policies masks disparities that require attention from health providers and policymakers at all levels. Data disaggregation is key to ensuring that those who have been historically excluded are visible, and community input is essential to data collection and analysis.

Current Office of Management and Budget (OMB) standards for race and ethnicity data required for federal programs are archaic and inadequate. They do not reflect the complexities of our current national demographics, nor do they identify data needed for both individual care and community health, such as Sexual Orientation and Gender Identity (SOGI). I applaud the recent announcement by the Office of Management and Budget (OMB) to review the Standards for the Classification of Federal Data on Race and Ethnicity and encourage the standards be updated and clarified to include the influence of gender, class, citizenship, and other factors of inequality. The

federal government can also play a key role by encouraging a set of data collection standards at state and local levels tied to federal grantmaking.

Oversampling historically underrepresented populations in national surveys, such as those funded by Health and Human Services (HHS), will also provide additional national data that is more representative of our population. And for all efforts, it is critical that we shift the narrative around data to reflect assets rather than deficits. The [Health Opportunity and Equity \(HOPE\) Initiative](#) is an innovative tool with measures that offer a unique look into the effects of 28 indicators that influence health at the state and national level broken down by race, ethnicity, and socioeconomic status. HOPE's measures provide a better understanding of what barriers stand in the way of equity and opportunity for specific groups and how states can tailor strategies for those most in need.

State leaders and advocates can use HOPE to ask, “What are other states doing right on creating equity and opportunity, how did they get there, and what might I do differently in my state?” These data show where babies are more likely to live past their first birthday, where residents can more easily access a doctor, where air quality is healthier, or where young children are more likely to enroll in pre-K.

Ensure public health measures address structural racism and other inequities. Federal leadership is critical for setting up standards to measure health equity.

We can extract broader lessons on how to build a public health data system grounded in equity that links more clearly to the community conditions that shape inequities, and that properly values an individual's lived experience by capturing data by race, ethnicity, income, education, gender, and disability.

There is no national standard to measure health equity or assess performance to achieve health equity. Currently, the public health data system minimally tracks information to guide the dismantling of structural racism and address other inequities that influence health. Despite increasing amounts of public health data being collected, data on the factors that influence health, such as housing instability, food insecurity and education, are not regularly or consistently available to inform decision-making.

Building on the Equitable Data Working Group established by Executive Order, we can create an interagency data council to improve measures to assess equity and racial justice and bring together different agencies to create interoperable social and public health data. A parsimonious set of metrics to analyze the health effects of structural racism would also provide critical benchmarks into root causes of health inequities. Any effort should ensure that community input is represented in data collection, interpretation, and decision-making.

Building a more equity-centered data infrastructure across the country: Emerging local Case Studies

The Commission's recommendations led the Robert Wood Johnson Foundation to invest more than [\\$50 million for a broad range of efforts](#) to fuel progress in building a modernized public health data infrastructure across the country where data are collected, analyzed, and interpreted with an eye toward equity. These on-the-ground case studies will demonstrate how a more equitable public health data infrastructure can help us see trends faster and track what's happening to who and why sooner.

A number of organizations, large and small, will serve as intermediaries dispersing funds to partners and/or subgrantees across the country on initiatives ranging from:

- Advancing state and local policy change to promote data disaggregation;
- Supporting HBCUs in expanding data collection capacity in Gulf Coast communities;
- Supporting researchers in the discovery of evidenced-based, data-driven tools that combat misinformation and disinformation in the public health space;
- Developing methods for interpreting public health data that are inclusive of community input, and more.

There are currently local partnerships in 14 states with more on the way. A full list is available [here](#). Here are a few examples:

- **Actionable Intelligence for Social Policy (AISP)** at the University of Pennsylvania selected its [first cohort of community site teams](#) to participate in their Equity in Practice Learning Community to center racial equity in data integration. The sites will build, test, and implement new models for incorporating community voice in key decisions about cross-sector data use, with an emphasis on health equity and racial justice.
- **Modernized Anti-Racist Data Ecosystems (MADE) for Health Justice** is a new [grant opportunity](#), administered by the de Beaumont Foundation, that seeks to accelerate the development of health-focused local data ecosystems that center principles of anti-racism, equity, justice, and community power. Up to five non-profit organizations will be funded to build and facilitate multisector teams tasked with creating local data ecosystems.
- **The CDC Foundation** awarded grants to [five local data equity coalitions](#) to use PLACES health data to design innovative solutions that address the social and structural factors that influence local community health outcomes.
- **The Public Health National Center for Innovations (PHNCI)** is convening its [21st century learning community](#), a group of 18 states working on statewide public health transformation. PHNCI will engage a subset of states in examining and implementing the Commission's recommendations.

- **The Gulf Research Program of the National Academies of Sciences, Engineering, and Medicine** [awarded planning grant awards](#) to two historically black universities to investigate how social determinants of health data can transform public health data systems to better address health disparities faced by communities in the Gulf of Mexico region.
- **The Leadership Conference Education Fund** will promote data disaggregation through state and local policy change by creating advocacy infrastructure to encourage policymakers at all levels to disaggregate ethnic/racial data beyond existing minimum federal standards.

In addition to the place-based efforts, [additional grantees](#) are working to address other systemic challenges that, if addressed, can move us closer to a data infrastructure anchored in equity.

I commend your efforts for seeking input on how the federal government can engage all of our communities to better support the production and use of equitable data. I hope my feedback will help inform your work and build an equity-centered public health data system. Together, we can help create a society where everyone has a just opportunity to live a long and healthy life.

Sincerely,

Gail C. Christopher, D.N.

Director

National Commission to Transform Public Health Data Systems