

Creating a 21st Century Equity-Centered Public Health Data System

Federal policy recommendations from the National Commission to Transform Public Health Data Systems to engage communities, policymakers at all levels, and other partners to modernize the nation's public health data infrastructure

Two years after the start of the COVID-19 pandemic, and with more than one million lives lost, our public health data system is still not equipped to produce real-time data necessary to respond to an evolving virus or prepare for a future public health threat. The urgency is real. Data capturing the varying needs of all our communities help to fuel the most effective policies. While various data modernization efforts are underway, there is a pressing need to accelerate federal action that emphasizes equity to ensure that every person—no matter who they are, where they live, or how much money they make—is represented in our public health data.

The Issue

Our public health data problems have existed for decades with limited funding to address them, lack of federal and state coordination, and systemic hurdles. 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 recommendations in October, 2021.

The Commission provided specific and actionable solutions for a range of sectors including government, business, philanthropy, and more to create a public health data system that better addresses health equity.

Federal Government Recommendations

Improving the collection of data by race, ethnicity, income, education, gender, and disability can help to lay the groundwork for fully seeing people, populations, assets and gaps. This will allow for the necessary granularity to address the specific health equity challenges within particular groups. A robust modernized data system also connects the dots between public health and other sectors including education, jobs, and housing offering a more expansive view of all that shapes health. The Commission found that to advance health equity, a strong cross-sector commitment for data sharing and use is needed with a strong federal role to shape standards and support state and local efforts.

Due to incomplete and disparate data collection and inconsistent reporting, it took far too long to see and respond to the disproportionate impacts of the pandemic on Black, Latino, and other underrepresented communities. This lack of data impeded us from saving lives and affected our ability to ensure those hardest hit by COVID-19 were prioritized at every stage of the pandemic—from testing to hospitalization to vaccination.

CONSIDERATIONS FOR POLICYMAKERS

COLLECT BETTER DATA BROKEN DOWN ACROSS POPULATION GROUPS (RACE/ETHNICITY, GENDER, DISABILITY) AND GEOGRAPHIC LEVELS TO OFFER A MORE COMPLETE PICTURE OF HEALTH DISPARITIES.

- Oversample historically underrepresented populations in national surveys (e.g., those funded by HHS) so that we get national data that is more representative going forward.
- Encourage a set of data collection standards at state and local levels tied to federal grantmaking.
- Update and clarify the Office of Management and Budget (OMB) standards for the classification of federal data on race and ethnicity that includes the influence of gender, class, citizenship and other factors of inequality.

A year into the pandemic, data were not publicly available and basic demographic characteristics such as race and ethnicity were unknown for 51% of COVID-19 cases.

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.

ENSURE PUBLIC HEALTH MEASURES ADDRESS STRUCTURAL RACISM AND OTHER INEQUITIES. FEDERAL LEADERSHIP IS CRITICAL FOR SETTING UP STANDARDS TO MEASURE HEALTH EQUITY.

- Building on the Equitable Data Working Group established by Executive Order, 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.
- Ensure that community input is represented in data collection, interpretation and decisionmaking.

There is no national standard to measure health equity or assess performance to achieve health equity.

MAKE SHARING AND POOLING DATA ACROSS SECTORS THE DEFAULT FOR AGENCIES RECEIVING FEDERAL MONEY.

- The Department of Health and Human Services (HHS) should create interagency level for data standardization to improve coordination among different sectors to advance health equity.
- Federal funding for data infrastructure should be prioritized to systems that are standards based and interoperable.

PRIORITIZE AND ACCELERATE IMPLEMENTATION OF THE EVIDENCE ACT FOR IMPROVED TRANSPARENCY, QUALITY, AND AVAILABILITY OF FEDERAL AGENCY DATA.

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. The resulting wide variability in public health infrastructure has had critical cascading effects for health equity.