



Strengthening our Response: Robust Disaggregated Data Collection and Reporting

Summary

There is broad recognition that COVID-19 does not affect all people and communities equally – in fact, the pandemic has laid bare not just structural inequity of our health care system, but also the life and death consequences of underlying health conditions spawned by a legacy of racism and inequity. Early data, while incomplete, shows the prevalence and mortality of COVID-19 among [Black](#) and Hispanic/Latinx people as well as [American Indian](#), Native Alaskan, [Asian American](#) and Pacific Islander populations is higher than among Whites. While available data on COVID-19 incidence and mortality are improving, collection and tracking remain limited due to a long-standing under-resourced public health system at all levels of government. In order to address the alarming trend of mortality among people of color, we need robust data, monitoring and transparency to ensure public policy is both responding and accountable to those who are most affected by COVID-19.

Congress must pass legislation that directs HHS and CDC, as well as the entities that make up COVID-19 surveillance systems, to collect, analyze and report data that is disaggregated across race, ethnicity, primary language, sex, gender identity, sexual orientation, age, socioeconomic status, disability status, zip-code and other demographic information that is transparent and accessible and is used to best tailor programs and policies to meet the needs of consumers.

The Problem

Black and brown people across the country are at greater risk of dying from the pandemic. Community-level data in places like Chicago and New York City reveal mortality rates for Black and Latinx residents [that are two times higher](#) than for Whites. There are several factors that explain this greater risk:

- People of color are disproportionately affected by chronic illness;
- Longstanding and unfair barriers to accessing health care such as structural racism – have led to inter-generational stress, poverty and poor health outcomes;
- People of color are more likely to live in crowded places such as urban settings or multiple family dwellings. These congregated spaces are at high risk of COVID-19 spread;
- People of color are more likely to be essential workers, serving in roles as transportation or other service employees, making them higher risk for COVID-19 exposure; and
- People of color have higher uninsured rates than Whites, and may lack access to testing and treatment.

The Solution

In order to protect people of color across our country and keep our communities healthy, Congress must invest in robust data collection, monitoring and transparency. While the CDC has taken steps recently to improve data collection, without sufficient investments the reporting remains insufficient and incomplete. Therefore, Congress must direct key agencies to collect data, providing guidance on types and level of data collected, and invest in the community level workforce, infrastructure and knowledge required to operationalize data collection at the local and state levels. Steps for doing so include:

- **Creating a COVID-19 Portal for Reporting.** As outlined in the HEROES Act, Congress should require the HHS secretary to establish and maintain an online portal that would assist in rapid reporting (biweekly) from health systems on health system capacity, medical supply chain issues and other key data.

- **Requiring HHS to work with the CDC to ensure data disaggregated by race, ethnicity, primary language, sex, gender identity, sexual orientation, age, socioeconomic status, disability status, county, and other demographic information is transparent and accessible (web-based).** HHS and other agencies should participate in using all available data collection sources to report data. This data should be collected and reported by the standards under Section 4302 of the Affordable Care Act. In addition, this should include data related to:
 - COVID-19 testing, including the number of individuals tested and the number of tests that were positive;
 - Treatment for COVID-19, including hospitalizations, intensive care unit admissions and patient length of stay.
 - Health outcomes for COVID-19, including fatalities and related illness such as ongoing respiratory infection.
- **Requiring HHS to take all necessary steps to ensure consumer privacy in collection, reporting and monitoring of data.** As new technologies are developed to manage the pandemic, we must balance the need for data and monitoring with privacy.
- **Investing in the modernization of key federal agencies' information technology (IT) capacity.** Congress should appropriate at least \$4 million to modernize IT systems for health inequities data as outlined in the HEROES Act, while investing in additional public health data infrastructure resources through the appropriations process.
- **Including Tribal funding to research health inequities, including COVID-19.** As included in the HEROES Act, Congress should appropriate \$25 million in funding for the Indian Health Service (IHS) to establish a nationally representative panel (no later than 60 days of enactment) to develop processes and procedures to conduct research and field studies to improve understanding of tribal health inequities, while ensuring tribal data sovereignty.
- **Congress should appropriate \$100 million in grants to state, local and territorial health departments to increase their capacity.** This HEROES Act provision could be strengthened by including multi-year funding for data infrastructure so that local public health entities could upgrade antiquated IT systems and educate those who use them to collect data on best practices. Further, Congress should require that a portion of these local funds are used to deploy community health workers (CHWs) and other community-based partners to increase local capacity to build trust and ensure accuracy in data collection.
- **Ongoing Reporting to Congress on COVID-19 data.** Congress must require HHS to report to Congress about COVID-19-related testing, hospitalization and mortality rates by racial and ethnic demographics, including reporting on proposed evidence-based response strategies to reduce COVID-19-related inequities. This reporting should begin no later than August 1, 2020 and should continue on a biweekly basis until 60 days post-public health emergency.
- **As in the [Equitable Data Collection and Disclosure on COVID-19 Act of 2020](#), create a Commission on Ensuring Health Equity during the COVID-19 Public Health Emergency, including federal, state, local, territorial and tribal officials along with independent experts, to provide guidance on how to better collect, develop and analyze racial and other demographic data in responding to future waves of the coronavirus.** Congress should authorize additional emergency supplemental funding to the CDC, state public health agencies, the Indian Health Service, and other agencies to conduct or support data collection on racial, ethnic, and other demographic implications of COVID-19.

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