

July 27, 2020

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Charles Schumer
Minority Leader
U.S. Senate
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker of the House
U.S. House of Representatives
Washington, DC 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Pelosi, and Minority Leader McCarthy:

In order for local, state, and the federal government to improve their tracking and reporting of the impact that the COVID-19 pandemic has had on minority populations, the undersigned organizations urge Congress to dedicate additional resources to modernize public health data systems. We know that COVID-19 has disproportionately affected Blacks, Hispanics/Latinos, Asian Pacific Islanders, and Native Americans far more severely than it has white communities. If we as a nation are to address the health disparities that have led to these vastly different outcomes, we need comprehensive and timely data. However, the COVID-19 pandemic has demonstrated that our public health data infrastructure is not up to the task.

While we appreciate that the Centers for Disease Control and Prevention (CDC) provides weekly updates of COVID-19 data, the information collected and publicly available is insufficient. The data is not reported in a timely manner, and race/ethnicity information is unavailable for more than half of the reported cases.¹ Additionally, information on other important patient characteristics, such as pregnancy status, is seriously lacking. This data would be particularly helpful to pregnant women of color, who face significantly higher rates of adverse maternal health outcomes.

The inconsistency in the collecting and reporting of demographic data is due in large part to antiquated public health data systems at local, state, tribal, and territorial public health departments. Years of underfunding for these systems, and in public health in general, has led to a fragmented infrastructure in which not all the critical information is able to flow seamlessly and efficiently from providers and labs to public health departments and the CDC. This leads to missing or incomplete data that is essential in responding to a public health emergency.

Using the data that is available, the adverse impact of COVID-19 on communities of color has been in the press and in scholarly journals. A May article from the Journal of the American Medical Association² stated that the worst disparities have been among Blacks and Hispanics/Latinos, as

¹ <https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latino-african-americans-cdc-data.html>

² <https://jamanetwork.com/journals/jama/fullarticle/2766098>

well as, where data exists, among Native Americans and Pacific Islanders. According to the authors, prevalence and mortality estimates are being tracked regularly in various cities across the U.S. and show a consistent pattern of disparate outcomes based on race and ethnicity. In Chicago, rates of COVID-19 cases per 100 000 (as of May 6, 2020) are greatest among Hispanics/Latinos (1000) and Blacks (925), compared with 389 for white residents. Mortality rates in Chicago are twice as high among Blacks compared with Latinos and three times higher than white residents. New York City (as of May 7, 2020) reported more than twice the COVID-19 mortality rate among Hispanics/Latinos and Blacks than whites.

A recent analysis³ from Harvard University of data from the National Center for Health Statistics found that in addition to dying at higher rates than whites of COVID-19, Blacks, Hispanics/Latinos, American Indian/Alaska Natives, and Asian and Pacific Islanders are also dying at younger ages. Latinos aged 35 to 44 have a mortality rate nearly eight times higher than whites in the same age group; Blacks' mortality rate is nine times higher.

We appreciate that Congress provided \$500 million in emergency funding in the *Coronavirus Aid, Relief, and Economic Security (CARES) Act* for public health data surveillance and analytics infrastructure modernization. But as we have learned more about the disproportionate impact of COVID-19 on communities of color, it has also become quite clear that there are large gaps in the public health data infrastructure that require additional investment. As the number of COVID-19 cases continue to rise across the country and as Congress considers the next piece of legislation to address the pandemic, we urge you to include the *Saving Lives Through Better Data Act* (S. 1793) in that legislative package. The bill would establish a grant program for public health data system modernization and authorize \$100 million each for fiscal years 2020 through 2024.

Clearly, we need to address the inequities in our health care system and address the social determinants of health that have created the shocking disparities we have seen for years and that have come into sharp focus with COVID-19. Having accurate and comprehensive data about the impact of COVID-19 on minorities is an essential component to developing the policy solutions to tackle these racial and ethnic inequalities in health outcomes. We respectfully request that you include additional funding in the next COVID-19 legislative package to modernize the public health data infrastructure that is needed to improve the collecting and reporting of data.

Sincerely,

American Cancer Society Cancer Action Network
American Heart Association
American Kidney Fund
American Lung Association
Arthritis Foundation
Chronic Disease Coalition
Hemophilia Federation of America
JDRF
March of Dimes

³ https://cdn1.sph.harvard.edu/wp-content/uploads/sites/1266/2020/06/20_Bassett-Chen-Krieger_COVID-19_plus_age_working-paper_0612_Vol-19_No-3_with-cover.pdf

Mended Hearts & Mended Little Hearts
National Alliance on Mental Illness
National Coalition for Cancer Survivorship
National Health Council
National Kidney Foundation
National Multiple Sclerosis Society
National Patient Advocate Foundation
Susan G. Komen
WomenHeart: The National Coalition for Women with Heart Disease