

Congress of the United States
Washington, DC 20510

April 29, 2020

Robert Redfield
Director
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear Director Redfield:

The racial disparities in coronavirus disease 2019 (COVID-19) incidence and fatalities become more apparent with each passing day, and Congress has recognized the importance of understanding this discrepancy by requiring, in legislation passed just last week, that the Centers for Disease Control and Prevention (CDC) disclose race, ethnicity, and other demographic data related to COVID-19.¹ In addition to releasing the information that is now required by law, we strongly urge the CDC to improve the accuracy and comprehensiveness of this data and to help identify communities with the highest needs in order to inform the federal government's distribution of resources during the COVID-19 pandemic.

We have repeatedly called for more transparency about the unequal impact of the COVID-19 pandemic on communities of color.² As a result, the *Paycheck Protection Program and Health Care Enhancement Act* now requires the Department of Health and Human Services (HHS) to issue a report within 21 days, and every 30 days thereafter, disclosing demographic breakdowns by "race, ethnicity, age, sex, geographic region, and other relevant factors of individuals tested for or diagnosed with COVID-19," COVID-19 hospitalizations, and deaths.³ The CDC began disclosing some of this data, including race and ethnicity breakdowns for cases and hospitalizations, on April 17, 2020.⁴ The CDC's data show that Black patients are being

¹ *Paycheck Protection Program and Health Care Enhancement Act*, Title I, Public Health and Social Services Emergency Fund, <https://www.congress.gov/116/bills/hr266/BILLS-116hr266eas.pdf>.

² "Lawmakers Urge HHS to Address Racial Disparities in Access to Testing and Treatment during the Coronavirus Pandemic," March 30, 2020, <https://www.warren.senate.gov/oversight/letters/lawmakers-urge-hhs-to-address-racial-disparities-in-access-to-testing-and-treatment-during-the-coronavirus-pandemic> ; "Warren, Markey, Pressley Call on CMS to Release Demographic Data of Medicare Beneficiaries Treated for COVID-19," April 10, 2020, <https://www.warren.senate.gov/oversight/letters/warren-markey-pressley-call-on-cms-to-release-demographic-data-of-medicare-beneficiaries-treated-for-covid-19> ; "Senator Warren Introducing Bicameral Legislation to Require Federal Government to Collect and Report Coronavirus Demographic Data – Including Race and Ethnicity," April 14, 2020, <https://www.warren.senate.gov/newsroom/press-releases/senator-warren-introducing-bicameral-legislation-to-require-federal-government-to-collect-and-report-coronavirus-demographic-data--including-race-and-ethnicity>.

³ *Paycheck Protection Program and Health Care Enhancement Act*, Title I, Public Health and Social Services Emergency Fund, <https://www.congress.gov/116/bills/hr266/BILLS-116hr266eas.pdf>.

⁴ Centers for Disease Control and Prevention, "COVIDView," April 17, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html>.

disproportionately affected by the pandemic, accounting for about 30% of COVID-19 cases,⁵ despite being only around 13% of the population.⁶ This aligns with state and local data on the race and ethnicity of COVID-19 patients, which show that Black, Hispanic, and American Indian/Alaska Native (AI/AN) communities are bearing the brunt of cases and fatalities.⁷

We are encouraged that HHS and CDC have heeded our calls to release information about these racial and ethnic disparities, and we look forward to their expanded reporting as required by the new legislation. However, we continue to have concerns about the comprehensiveness of this data. In the CDC's April 24 report, more than half of COVID-19 cases did not include information on race or ethnicity.⁸ The *Paycheck Protection Program and Health Care Enhancement Act* included \$1 billion in funding to support CDC's data collection and surveillance systems.⁹ As the pandemic progresses, we urge you to work with state, tribal and local public health systems to modernize and improve surveillance and increase our nation's capacity to collect complete, timely, and accurate data on each patient. In order to fully assess and address the ongoing threats from the COVID-19 pandemic, it is essential that our data captures a complete picture of its health outcomes and impacts. We are particularly alarmed by reports of the lack of dedicated CDC funding and resources to tribal governments and organizations to build public health infrastructure in Indian Country, including specifically for improved disease surveillance and data collection.¹⁰

In addition to including all relevant data on race and ethnicity, we urge you to include disability status, socioeconomic status, and primary language in the "other relevant factors" category of the required reports.¹¹ People with disabilities are at elevated risk for complications from COVID-19 because they may have underlying medical conditions or need close contact

⁵ Centers for Disease Control and Prevention, "Cases in the U.S.," April 24, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>

⁶ Census Bureau, "Quick Facts," <https://www.census.gov/quickfacts/fact/table/US/PST045219>.

⁷ Washington Post, "The coronavirus is infecting and killing black Americans at an alarmingly high rate," Reis Thebault, Andrew Ba Tran, and Vanessa Williams, April 7, 2020, <https://www.washingtonpost.com/nation/2020/04/07/coronavirus-is-infecting-killing-black-americans-an-alarmingly-high-rate-post-analysis-shows/?arc404=true>; Boston Globe, "Boston releases coronavirus data that point to stark racial disparities among those infected," Kay Lazar, April 9, 2020, <https://www.bostonglobe.com/2020/04/09/nation/boston-releases-coronavirus-data-that-point-stark-racial-disparities-among-those-infected/>; New Mexico Department of Health, "State launches portal with more COVID-19 data," April 27, 2020, <https://cv.nmhealth.org/2020/04/14/state-launches-portal-with-more-covid-19-data/>; Arizona Department of Health Services, Coronavirus Disease 2019 (COVID-19) Data Dashboard, <https://www.azdhs.gov/preparedness/epidemiology-disease-control/infectious-disease-epidemiology/index.php#novel-coronavirus-home>.

⁸ Centers for Disease Control and Prevention, "COVIDView," April 24, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html>.

⁹ *Paycheck Protection Program and Health Care Enhancement Act*, Title I, Public Health and Social Services Emergency Fund, <https://www.congress.gov/116/bills/hr266/BILLS-116hr266eas.pdf>.

¹⁰ Great Falls Tribune, "Native American tribes have been hit hard by coronavirus. Now they're battling red tape to get help," Nora Mable, Christal Hayes, and Jeanine Santucci, April 27, 2020, <https://www.greatfallstribune.com/story/news/2020/04/27/coronavirus-indian-country-hit-hard-tribes-battle-red-tape-montana-little-shell/3011150001/>.

¹¹ *Paycheck Protection Program and Health Care Enhancement Act*, Title I, Public Health and Social Services Emergency Fund, pg. 17, <https://www.congress.gov/116/bills/hr266/BILLS-116hr266eas.pdf>.

with others to meet their basic needs.¹² In some cases, state policies have prioritized non-disabled people for scarce resources such as ventilators, leading to concerns about discrimination, while people with disabilities who live in group homes or long-term care facilities may be at increased risk for infection.¹³ It is therefore essential to closely monitor the impact of the pandemic on people with disabilities. Information about primary language and socioeconomic status are similarly crucial to identifying disparate impacts and targeting resources appropriately.¹⁴ The intersections of race or ethnicity, disability, and socioeconomic status can also provide important information to medical and public health professionals, and to others seeking to share accurate public health information with affected communities.

In addition, we urge you to work directly with Indian Health Service to better coordinate disease surveillance strategies in tribal and urban Indian communities, while continuing to ensure that tribal data sovereignty is respected and preserved. Data collected by local, state, and federal governments has historically misrepresented, misclassified, and omitted AI/AN populations in their analysis and reports.¹⁵ The incorrect and inaccurate data ultimately affects the overall health and well-being of the AI/AN population, and also adversely impacts delivery of funding and resources to tribal and urban Indian communities. American Indians/Alaska Natives suffer from disproportionate COVID-19 health risks, which include higher rates of cancer, diabetes, and cardiovascular disease.¹⁶ This pattern is likely to be repeated during the COVID-19 pandemic, with AI/AN data not being reported or being included in the “other” data category. It is vital that state and local public health agencies perform the tasks of data collection and analysis accurately by funding and working collaboratively with tribal and urban Indian communities. We also strongly urge you to work closely and collaboratively with the CDC/Agency for Toxic Substances and Disease Registry (ATSDR) Tribal Advisory Committee, tribal governments, and the Tribal Epidemiology Centers to identify and implement recommendations to bolster public health surveillance, data collection, and reporting in Indian Country.

We also know that data alone is not enough. As we learn more about the inequities in how different communities are experiencing this pandemic, the federal government has a responsibility to direct support, information, and resources to the communities that are being hit the hardest. We strongly urge the CDC and other relevant agencies and community leaders to launch public information campaigns that speak to the specific needs of communities of color and people with disabilities. Given the history of mistrust of the medical system in many communities of color, often stemming from generations of mistreatment, it is essential to enlist

¹² Centers for Disease Control and Prevention, “Coronavirus Disease 2019 (COVID-19): People with Disabilities,” April 7, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>.

¹³ The New York Times, “‘It’s Hit Our Front Door’: Homes for the Disabled See a Surge of Covid-19,” Danny Hakim, April 17, 2020, <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>.

¹⁴ Letter to CDC Director Redfield from Atlanta Mayor Hardie Davis Jr., et al, April 3, 2020, <https://www.wemustcount.org/the-letter>

¹⁵ American Journal of Public Health, “Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area,” Melissa A. Jim et al, April 2014, https://www.researchgate.net/publication/261799829_Racial_Misclassification_of_American_Indians_and_Alaska_Natives_by_Indian_Health_Service_Contract_Health_Service_Delivery_Area.

¹⁶ CNN, “The risk to Native American nations from Covid-19,” Kent Sepkowitz, April 7, 2020, <https://www.cnn.com/2020/04/07/opinions/native-american-nations-risk-from-covid-19-sepkowitz/index.html>.

trusted messengers to communicate the importance of taking appropriate preventative measures and seeking treatment.¹⁷

We know that the disparities in our society did not begin with the COVID-19 pandemic, but this crisis has exposed the deep inequality in the health and economic security of our communities. It is therefore essential to use all available data to identify its disproportionate impact on marginalized communities and to let this data guide our response and to mobilize resources to the communities that are most in need. We continue to urge the CDC to make this a priority and look forward to working with your agency to continue providing it the resources it needs to make this effort successful.

Thank you for your attention to this urgent matter.

Sincerely,

Elizabeth Warren
United States Senator

Ayanna Pressley
Member of Congress

Robin L. Kelly
Member of Congress

Kamala D. Harris
United States Senator

Karen Bass
Member of Congress

Barbara Lee
Member of Congress

Edward J. Markey
United States Senator

Jeffrey A. Merkley
United States Senator

¹⁷ Politico, "Trump coronavirus response feeds distrust in black and Latino communities," Laura Barron-Lopez, April 21, 2020, <https://www.politico.com/news/2020/04/21/race-coronavirus-outreach-197470>.

Cedric Richmond
Member of Congress

Cory A. Booker
United States Senator