



April 24, 2020

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Azar:

We are writing on behalf the Lawyers' Committee for Civil Rights Under Law ("Lawyers' Committee"), a non-partisan, nonprofit organization, formed in 1963 at the request of President John F. Kennedy to enlist the private bar's leadership and resources to combat racial discrimination. On April 6, 2020, the Lawyers' Committee, with the support of close to 400 medical professionals, submitted a [letter](#) to the United States Department of Health and Human Services ("HHS") and its related subagencies asking for the release of race and ethnic demographic data for COVID-19 tests, cases, and outcomes by April 20, 2020. We made these requests in light of increasing evidence that African Americans, and other people of color are being infected and dying from COVID-19 at higher rates than their white counterparts.

Last Friday, on April 17th, the Centers for Disease Control and Prevention (CDC) for the first time issued nationwide race and ethnic demographic data related to patients hospitalized with [COVID-19](#). Days later, on April 20th, the CDC released limited race and ethnic demographic data for COVID-19 [mortalities](#). To date, the CDC has *not* released race and ethnic demographic data related to COVID-19 testing. Thus far, there are significant gaps in the data released by the CDC for both COVID-19 cases and mortalities.

The race and ethnic demographic data released by the CDC for COVID-19 mortalities is incomplete. First, while the data *is* disaggregated by state and compares the distribution percentage of COVID-19 deaths by race to the percentage of each race of the population (which enables a state by state comparison of racial disproportionality), the data only includes information for states that have more than [100 COVID-19 deaths available for analysis](#). As a result, the agency has only released information for 19 states and New York City, New York, even though at least 31 states are publicly [reporting](#) this data. By excluding some states, this limited data set may underreport the overall disproportionate rate at which African Americans are dying from COVID-19. For example, although the data set does not include South Carolina, the state has reported 135 COVID-19 related deaths, [53.6%](#) of whom were African American.¹ In addition, the data released by the CDC notes that [23,358](#) people have died from COVID-19. Websites that

¹According to American Community Survey data, African Americans make up [26.6%](#) of the population in South Carolina.



track similar data have reported twice as many COVID-19 related deaths. For example, the [Coronavirus Resource Center](#), managed and controlled by Johns Hopkins University and Medicine, notes that 49,954 people have died from the virus. Similarly, [The New York Times](#) mortality database reports that COVID-19 has claimed the lives of over 44,000 people.

The case data is even more inadequate. The CDC reports that as of April 22, there are [828,441 COVID-19](#) cases in the United States. Of those cases, demographic information (age, race or ethnicity) is only available for 619,695 cases (74.4%). Only 35.9% of the cases with demographic information specify the patient's race. Unlike the mortality data, this data was not disaggregated by state, making it impossible to determine the degree of racial disparity in confirmed cases by state. Currently 38 states are publicly reporting this data, and it would be immensely valuable to have the CDC report national confirmed case data for all states on its website.

The CDC has yet to release race and ethnic demographic data for COVID-19 tests. This data is critical to the African American community, and other communities of color, to ensure that testing and treatment is being administered equitably across racial lines. Prior to March 22nd, the CDC routinely tracked this data for patients through the agency's COVID-19 [Case Report Form](#). These forms were submitted for patients who tested positive for COVID-19 *and* for patients suspected of having the coronavirus/Persons Under Investigation ("PUI"). On or around March 21st, however, the CDC issued new guidelines pertaining to the collection of this critical data. Currently, the CDC only requests COVID-19 Case Report Forms for positive COVID-19 cases and for specimens submitted to the [CDC for testing](#). Thus, the CDC no longer collects race and ethnic demographic information from jurisdictions that conduct their own COVID-19 testing or for PUI(s). The agency's guidelines have resulted in an incomplete data set and, as a result, it is impossible to gauge whether African American communities, and other communities of color, are being tested for COVID-19 at the same rate as their white counterparts.

Indeed, the limited racial data in the two states where such data is available shows that minorities are not being tested at the same rate, which may be contributing to their higher case rates and mortality rates. As stated in a joint [op-ed](#) from the president of Johns Hopkins University and the President and CEO of the Urban League published by the Washington Post on April 23:

[In Illinois](#) African Americans make up an alarming 38.1 percent of coronavirus deaths and 24.2 percent of confirmed cases – both far out of proportion to their share of the population. What's worse is that only 13.2 percent of those tested are black, suggesting that African Americans are being drastically underserved by the effort to control the spread of the disease. The same is true of Latino residents in [Kansas](#): Their rate of infection is more than double that of non-Latino Kansans, yet they are being tested at a significantly lower rate.

If members of minority groups are not being tested at a rate commensurate to the threat they face, the country loses the opportunity to quarantine those who test positive before they have



had the chance to spread the virus. And conducting contact tracing to find out who else is at risk is impeded.

The limited data released by the CDC is deficient, but aligns with the alarming trend that we've observed in recent weeks – that African Americans are disproportionately suffering from the coronavirus. According to the CDC, African Americans make up [33.5%](#) of race specified COVID-19 cases and [33.1%](#) of people who have been hospitalized with COVID-19, even though African Americans are only [13.4%](#) of the U.S. population.

Complete and accurate national race and ethnic demographic data related to COVID-19 cases, tests and outcomes is critical to the development of robust health interventions that are responsive to the needs of communities of color, and to stem the ongoing community spread of this unprecedented and dangerous virus. Black communities, and other communities of color, have historically suffered from systemic discrimination and bias including in our healthcare system, resulting in lower rates of insurance coverage, worse care, and poorer health outcomes. This is compounded by the fact that our communities have disproportionately higher rates of diabetes, [heart conditions](#) and asthma; underlying health conditions that [increase the risk](#) of complications from COVID-19. Without clear data, officials and lawmakers are ill-equipped and unable to develop targeted public health responses and strategies to address the unique needs of communities of color.

HHS and its subagencies are charged with ensuring that racial disparities do not persist in the administration of healthcare services, even in a pandemic. Although the CDC has taken some preliminary steps in response to the letter we submitted on April 6th, HHS must not further delay and act now to prioritize this public health crisis. To that end, we demand that HHS:

- 1) Promptly release all race and ethnic demographic data for COVID-19 cases disaggregated by state.
- 2) Promptly release all existing data related to COVID-19 tests for all states disaggregated by race and ethnicity.
- 3) Promptly release existing COVID-19 mortality data by race and ethnicity for all states.
- 4) Prioritize mandating and reporting comprehensive, accurate, and robust race and ethnicity data collection for all tests, cases and outcomes, in collaboration with all HHS subagencies.
- 5) Provide concrete protocols and guidance to aid state public health officials in consistently collecting and reporting race and ethnic demographic data for all tests, cases and outcomes.
- 6) Develop concrete action plans to address racial disparities in Black communities and other communities of color by:



- a. targeting these communities to provide free access to widespread testing and healthcare;
- b. ensuring essential workers have personal protective equipment (PPE);
- c. ensuring hospitals in these communities are adequately resourced and have the necessary equipment to care for patients.

The Lawyers' Committee for Civil Rights Under Law will continue to vigorously push the federal government to prioritize the urgent needs of the communities we serve with the strong support of our vast medical network. We request a written response by May 1, 2020 explaining the actions HHS is undertaking to address our concerns and prioritize the urgent needs of the communities we serve. If you have any questions, please contact Dariely Rodriguez, Director, Economic Justice Project, or Dorian Spence, Director, Special Litigation at health@lawyerscommittee.org. Thank you for your time and consideration.

Sincerely,

Kristen Clarke
President & Executive Director

Cc: U.S. Surgeon General Jerome Adams (via email - surgeongeneral@hhs.gov)
Dr. Robert Redfield, CDC (via email - olx1@cdc.gov)
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