

United States Senate
WASHINGTON, DC 20510

July 15, 2020

The Honorable Seema Verma
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

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

Dear Administrator Verma and Director Redfield:

We write to urge you to immediately begin collecting and publicly releasing demographic data on residents and workers of nursing homes who are diagnosed with the coronavirus disease 2019 (COVID-19). The information available strongly suggests that COVID-19 is disproportionately affecting communities of color in nursing homes, similar to the way the disease is affecting those communities in the general population. Given the high number of COVID-19 infections and deaths in long-term care facilities, it is critical that the data collected and released by your agencies on cases in nursing homes includes demographic information such as race, ethnicity, age, sex, primary language and disability status. Such information is necessary to accurately understand and mitigate the impact of this crisis and appropriately direct resources.

The coronavirus pandemic continues to have a disproportionate and tragic impact on people of color.¹ People of color are more likely to work in jobs that cannot be done from home and to have chronic health conditions that putting them at higher risk for complications if they contract the virus.² According to the Centers for Disease Control and Prevention (CDC), Black

¹ 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/>.

² Health Affairs, “COVID-19 and Racial/Ethnic Disparities in Health Risk, Employment, and Household Composition,” Thomas M. Selden and Terceira A. Berdahl, July 14, 2020, <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.00897>.

and Hispanic/Latino people are significantly more likely to be hospitalized with COVID-19.³ The Centers for Medicare & Medicaid Services (CMS) recently released Medicare data showing that Black seniors and people with disabilities were hospitalized at a rate four times than that of white individuals, while the hospitalization rate among Hispanic individuals was two times as high.⁴ While this release tracked hospitalizations, it lacked information on nursing homes and other care settings.

An independent analysis by the *New York Times* found that these disparities also apply within long-term care settings: facilities serving significant numbers of Black and Hispanic residents were twice as likely to have had COVID-19 infections, even after controlling for facility size, location, and quality rating.⁵ This analysis covered only 22 states and the District of Columbia, however. Further, as highlighted in testimony by University of Chicago Professor R. Tamara Konezka before the U.S. Senate Special Committee on Aging, recent analysis from 12 states uncovered "...a strong and consistent relationship between race and the probability of COVID-19 cases and deaths. Nursing homes with the lowest percent white residents were more than twice as likely to have COVID-19 cases or deaths as those with the highest percent white residents."⁶ Additional research based on data from 30 states confirms that having a high percentage of Black residents increases the likelihood that a nursing home will have COVID-19 cases.⁷

These disparities are of particular concern because of the high rates of infection and death from COVID-19 within nursing homes and other long-term care facilities. Most recently, CMS has reported more than 35,000 deaths of nursing home residents and workers during the pandemic,⁸ yet this is surely an undercount of the true fatalities, as CMS only required facilities to report cases and deaths beginning in May 2020. The agency has not required retroactive reporting or otherwise compiled such data,⁹ and independent experts and news organizations estimate total deaths linked to long-term care facilities exceed 55,000.¹⁰ In several of our states, residents and workers of nursing homes and other long-term care facilities make up more than 65% of all COVID-19 fatalities.¹¹

³ Centers for Disease Control and Prevention, "COVID View," June 12, 2020, pg. 9,

<https://www.cdc.gov/coronavirus/2019-ncov/covid-data/pdf/covidview-06-12-2020.pdf>.

⁴ Center for Medicare and Medicaid Services, "Trump Administration Issues Call to Action Based on New Data Detailing COVID-19 Impacts on Medicare Beneficiaries," June 22, 2020, <https://www.cms.gov/newsroom/press-releases/trump-administration-issues-call-action-based-new-data-detailing-covid-19-impacts-medicare>.

⁵ New York Times, "The Striking Racial Divide in How Covid-19 Has Hit Nursing Homes," Robert Gebeloff, Danielle Ivory, Matt Richtel, Mitch Smith, Karen Yourish, Scott Dance, Jackie Fortier, Elly Yu, and Molly Parkter, May 21, 2020, <https://www.nytimes.com/article/coronavirus-nursing-homes-racial-disparity.html>.

⁶ Testimony of R. Tamara Konezka, Ph.D., submitted for the record at a hearing on "Caring for Seniors amid the COVID-19 Crisis," May 21, 2020, https://www.aging.senate.gov/imo/media/doc/SCA_Konezka_05_21_20.pdf

⁷ Abrams HR, Loomer L, Gandhi A, Grabowski DC. Characteristics of U.S. Nursing Homes with COVID-19 Cases. *J Am Geriatr Soc.* 2020, <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.16661>.

⁸ Center for Medicare and Medicaid Services, "COVID-19 Nursing Home Data," June 28, 2020, <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg>.

⁹ *Id.*

¹⁰ New York Times, "More than 40% of U.S. Coronavirus Deaths are Linked to Nursing Homes," July 7, 2020, <https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html>.

¹¹ Massachusetts Department of Public Health COVID-19 Dashboard, July 14, 2020, <https://www.mass.gov/doc/covid-19-dashboard-july-14-2020/download>; Pennsylvania Department of Public Health,

CMS had an opportunity to improve understanding of these deadly disparities for policymakers and the public when it began requiring nursing homes to report on infections, hospitalizations, and deaths from COVID-19 in May. However, these data do not include any demographic information about affected residents and workers, such as race, ethnicity, age, sex, primary language or disability status.¹²This information is crucial to understanding disparities both within and between long-term care facilities. Further, such data should be used to direct resources to the facilities at the highest risk and to provide appropriate guidance to providers, residents, and family members. Moreover, CMS's failure to require nursing home to report their data retroactively or otherwise secure this information from states and localities has left policymakers and the public completely in the dark about the pandemic's impact on some of our most vulnerable community members during its early months.

The COVID-19 pandemic has had a deadly impact on nursing homes and other long-term care facilities, and all evidence indicates that that impact has been disproportionately borne by people of color. We urge you to fully inform the national response to this crisis by expanding this data collection to include race, ethnicity, sex, age, primary language and disability status. We must ensure that this information is collected and shared with the public. Specifically, we urge you to follow the data collection standards set by the Office of Minority Health at the Department of Health and Human Services¹³ and add questions about race, ethnicity, sex, age, primary language, and disability status to the COVID-19 nursing home data collection under 42 CFR §483.80(g);¹⁴ publicly release this demographic information aggregated at the state and federal level; and devise reliable methods to collect this information retroactively. We also request detailed responses to the following questions by July 29, 2020:

1. What specific steps have CMS and CDC taken to collect demographic data from residents living in nursing homes who test positive for COVID-19?
2. What specific steps have CMS and CDC taken to collect demographic data and other information pertaining to COVID-19 cases and deaths in other congregate settings, including intermediate care facilities and psychiatric hospitals?
3. In what way have CMS and CDC coordinated with state and local health departments to improve data collection of COVID-19 cases, particularly concerning the collection of demographic information, including race, ethnicity, sex, age and disability status?
4. What plans have been developed to perform reliable retroactive reporting of COVID-19 data to the beginning of the public health emergency on January 31, 2020,¹⁵

"COVID-19 Data for Pennsylvania," July 15, 2020,

<https://www.health.pa.gov/topics/disease/coronavirus/Pages/Cases.aspx>.

¹² Center for Medicare and Medicaid Services, "COVID-19 Nursing Home Data," June 28, 2020,

<https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg>.

¹³ Department of Health and Human Services Office of Minority Health, "Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status,"

<https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=53>.

¹⁴ 42 CFR § 483.80

¹⁵ Department of Health and Human Services, "Secretary Azar Declares Public Health Emergency of United States for 2019 Novel Coronavirus," January 31, 2020, <https://www.hhs.gov/about/news/2020/01/31/secretary-azar-declares-public-health-emergency-us-2019-novel-coronavirus.html>.

- including demographic variables such as race, ethnicity, sex, age, primary language, and disability status, in nursing homes and other settings?
5. In what way have CMS and CDC utilized COVID-19 data to inform treatment and prevention strategies in nursing homes and other congregate settings?
 6. In what ways have CMS, CDC, Federal Emergency Management Agency, or other agencies utilized COVID-19 data to direct resources such as funding and personal protective equipment to the facilities most in need?
 7. When will CMS and CDC collect and publicly release COVID-19 demographic information aggregated at the state and federal level for residents in nursing homes and other congregate settings?
 8. To what extent can Medicare claims be used to analyze the demographics and other characteristics of COVID-19 patients in nursing homes and other congregate settings?

Thank you for your consideration of this urgent matter.

Sincerely,

Elizabeth Warren
United States Senator

Robert P. Casey, Jr.
United States Senator

Ron Wyden
United States Senator

Patty Murray
United States Senator