

Congress of the United States
House of Representatives
Washington, DC 20515

January 25, 2022

Rochelle P. Walensky, MD, MPH
Office of the Director
Centers for Disease Control and Prevention (CDC)
1600 Clifton Road, NE
Atlanta, GA 30333

Dear Director Walensky:

We write to urge the CDC to publicly report findings on the prevalence of Long COVID, including disaggregated demographic data. This data will help direct Congressional action to support those with Long COVID along with their families and communities.

Long COVID, also referred to as post-COVID conditions and Post-Acute Sequelae of SARS CoV-2 infection (PASC), is a serious illness that can affect the function of multiple organs months after a person contracts COVID-19. According to the CDC, people living with Long COVID may experience a combination of symptoms, ranging from fatigue and brain fog to muscle pain and diarrhea to difficulty breathing and heart palpitations.¹ Because of the debilitating effects of Long COVID, HHS and the Department of Justice have recognized the condition as disability under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Patient Protection and Affordable Care Act.² An official estimate of how many people experience Long COVID is necessary to ensure resources are available to support their recovery.

In December 2020, Congress appropriated \$1.15 billion for the National Institutes of Health to research the long-term health consequences of COVID-19.³ We applaud the progress you have made in establishing the Researching COVID to Enhance Recovery (RECOVER) Initiative.⁴ The multidisciplinary approach represents a significant step in the direction of fully understanding Long COVID and the breadth and depth of its public health impact. While we understand that this research is ongoing and will need to adapt to the evolving nature of the pandemic, it is critical that Congress and the American public are able to gain insight into current data and emerging trends—including an overview of the vast array of symptoms individuals may experience, disaggregated by demographic groups—in order to inform policymaking and protect the public’s health.

¹ *Post-COVID Conditions*. CENTERS FOR DISEASE CONTROL AND PREVENTION (Sept. 16, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.

² *Guidance on “Long COVID” as a Disability Under the ADA, Section 504, and Section 1557*. U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES (July 26, 2021), <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>.

³ *NIH launches new initiative to study “Long COVID”*. NATIONAL INSTITUTES OF HEALTH (Feb. 23, 2021), <https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid>.

⁴ *RECOVER: Researching COVID to Enhance Recovery*. RECOVER (2022), <https://recoverycovid.org/>.

Preliminary studies indicate that women are uniquely vulnerable to Long COVID.⁵ Further, we know that COVID-19 has disproportionately harmed certain communities more than others, and we suspect that Long COVID will mirror this trend. For example, people who are Black, Latino, and American Indian or Alaska Native are at least twice as likely to be hospitalized and die from COVID-19 than white people.⁶ These communities have historically faced racial discrimination and inequities in social determinants of health, contributing to greater risk of COVID infection. Accordingly, these communities of color are at greater risk of suffering from Long COVID.

To fully confront the ongoing pandemic, Congress needs disaggregated demographic data on the prevalence of Long COVID. CDC must publish findings on race, ethnicity, age, gender, previous disability, and other demographic characteristics. People across the country are experiencing long-term symptoms of COVID-19, and Congress deserves answers on the size and scope of this crisis.

Thank you for your consideration.

Sincerely,



Ayanna Pressley
Member of Congress



Don Beyer
Member of Congress

⁵ *What doctors wish patients knew about long COVID*. AMERICAN MEDICAL ASSOCIATION (Oct. 22, 2021), <https://www.ama-assn.org/delivering-care/public-health/what-doctors-wish-patients-knew-about-long-covid>; *These Groups Are at Higher Risk of Developing Long COVID-19*. HEALTHLINE (Sept. 20, 2021), <https://www.healthline.com/health-news/these-groups-are-at-higher-risk-of-developing-long-covid-19>.

⁶ *Hospitalization and Death by Race/Ethnicity*. CENTERS FOR DISEASE CONTROL AND PREVENTION (Nov. 22, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html>.