Congress of the United States Washington, DC 20515

April 8, 2020

The Honorable Alex Azar Secretary U.S. Department of Health & Human Services Mary E. Switzer Building 330 C Street SW Room 5123 Washington, DC 20201

The Honorable Robert R. Redfield, MD Director Centers for Disease Control and Prevention 1600 Clifton Road Atlanta, GA 30329

Dear Secretary Azar and Director Redfield,

The Congressional Hispanic Caucus (CHC), the Congressional Asian Pacific American Caucus (CAPAC), and the Congressional Black Caucus (CBC), collectively known as the Tri-Caucus, urges the Centers for Disease Control and Prevention (CDC) and the U.S. Department of Health and Human Services (HHS) to work with the Tri-Caucus to ensure there are no racial or ethnic health disparities regarding the testing and treatment of the novel coronavirus (COVID-19). Together, the Tri-Caucus represents millions of Hispanics, African Americans, and Asian Pacific Americans across the country.

Based on early regional data that is available, we are alarmed to learn that the virus is disproportionately affecting communities of color.¹ Unfortunately, the CDC has not released nationwide demographic data, which hinders our efforts to understand these emerging trends. We understand that the Person Under Investigation form allows for the collection of top-level race and ethnicity information but would like to verify when and if the CDC plans to publicly release these findings. We understand that reporting data prematurely can compromise the integrity of the data sets, but having timely and accurate data is critical for policy makers to inform essential legislation that will impact millions of Americans and future generations. We are very concerned with the current absence of nationwide demographic data and how the lack of data can hamper the response to COVID-19. Without this data, stakeholders are unable to adequately target both public health campaigns and ensure that providers have the resources needed to test and treat diverse populations.

We respectfully request the CDC to do the following:

• Identify the necessary steps and resources required to update its COVID-19 surveillance system, including the Person Under Investigation form to collect data disaggregated by race, ethnicity, primary language, gender identity, age, disability status and socioeconomic status in line with, at least, the <u>Section 4302</u> promulgated standards under the Affordable Care Act (ACA).

¹Sam Baker and Allison Snyder, *Coronavirus hits poor, minority communities harder* Apr 4, 2020 <u>https://www.axios.com/coronavirus-cases-deaths-race-income-disparities-unequal-f6fb6977-56a1-4be9-8fdd-844604c677ec.html</u> (last accessed April 6, 2020).

- Identify the necessary steps and resources you need in order to release nationwide demographic data publicly and in real time with an understanding that this data is variable.
- Identify the necessary steps and resources you need to provide Congress with reliable short-term and long-term demographic data than can be used by policy makers to address COVID-19 health disparities.
- Ensure all data collected is protected under existing Health Insurance Portability and Accountability Act (HIPAA) privacy protections and from all inappropriate internal use or negative consequences for patients by any entity that collects the data.
- Ensure all data is collected in line with the best practices outlined under the Section 4302 standards, with self-reporting being the preferred method as applicable.

Trends from preliminary data show that the highest concentrations of cases in New York City are in neighborhoods in Queens and the Bronx with large immigrant and minority populations and low average incomes. Metropolitan area trends illustrate that African Americans are making up significant shares of COVID-19 confirmed cases in various states across the country. Tribal governments are not being given the resources needed to address the crisis.² Asian Americans are facing racist attacks while disproportionately making up front-line health providers that are more exposed to the virus.³

It is imperative to collect and report nationwide demographic data that is disaggregated to fully confirm this trend. However, this trend does align with existing COVID-19 risk factors that are often more prevalent in communities of color.⁴ Unfortunately, Hispanics, Asian Americans, African Americans, Native Americans, Alaska Natives, and Native Hawaiians and Pacific Islanders suffer from health disparities and bear a disproportionate burden of disease, injury, premature death, and disability.⁵ We know that people of all ages with underlying medical conditions are at higher risk for severe illness, particularly underlying medical conditions such as diabetes, chronic lung disease, or moderate to severe asthma.⁶ Moreover, many members of our communities are unable to work from home, increasing their chances of exposure as the virus is thought to spread mainly from person-to-person contact.⁷ A report by the Economic Policy Institute based on federal labor data found that a disproportionately high share of Hispanic and Black workers are unable to work from home, in addition to low-income workers.⁸

Under section 4302 of the ACA, HHS is required to collect, analyze, and report disaggregated data for health care programs. Currently, the CDC COVID Case report form only collects high-level information and does not collect any disaggregated data by race, ethnicity, primary language, gender, disability status and socioeconomic status. We understand that making changes to health forms in the midst of a pandemic can be a challenge, so the Tri-

³ Gerstmann, Evan. Irony: Hate Crimes Surge Against Asian Americans While They Are On The Front Lines Fighting COVID-19 April 4, 2020 <u>https://www.forbes.com/sites/evangerstmann/2020/04/04/irony-hate-crimes-surge-against-asian-americans-while-they-are-on-the-front-lines-fighting-covid-19/#71223fa33b70 (last accessed April 7, 2020)</u>

⁶ Centers for Disease Control and Prevention, *Coronavirus Disease 2019 (COVID-19): At Risk for Severe Illness* Apr 2, 2020, https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html (last accessed April 6, 2020).

² Marshall, Joshua, *Tribal Nations* — *Highly Vulnerable to COVID-19* — *Need More Federal Relief* (April 1, 2020) https://www.cbpp.org/blog/tribal-nations-highly-vulnerable-to-covid-19-need-more-federal-relief (last accessed April 7, 2020).

⁴ Sam Baker and Allison Snyder, *Coronavirus hits poor, minority communities harder* Apr 4, 2020 <u>https://www.axios.com/coronavirus-cases-deaths-race-income-disparities-unequal-f6fb6977-56a1-4be9-8fdd-844604c677ec.html</u> (last accessed April 6, 2020).

⁵ Centers for Disease Control and Prevention, *Health Disparities Experienced by Racial/Ethnic Minority Populations* August 27, 2004 <u>https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5333a1.htm</u> (last accessed April 4, 2020).

⁷ Centers for Disease Control and Prevention, *Coronavirus Disease 2019 (COVID-19): Prevent Getting Sick* March 27, 2020 <u>https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/index.html</u> (last accessed April 6, 2020).

⁸ Donald Moore, *Poor and Minority Workers Are Least Likely to Be Able to Work From Home* March 20, 2020 <u>https://www.bloomberg.com/news/articles/2020-03-20/poor-and-minority-workers-are-least-likely-to-be-able-to-work-from-home</u> (last accessed April 6, 2020).

Caucus would like to work closely with the CDC and state health agencies to help provide adequate resources and support the best strategy to reach this goal without compromising data collection or the integrity of CDC data.

Having disaggregated data will provide invaluable insight into the pattern of the virus and make a substantial difference in how we tailor public health response efforts in districts and states across the country. This public health crisis is widening the health disparities faced by our communities, who already face exacerbated risk factors for COVID-19. Collecting this vital information can make the difference of life and death. We have an obligation to address this pandemic with all the resources at our disposal, and that includes comprehensive and real time disaggregated data.

Sincerely,

VIN CAST

Joaquin Castro Chair Congressional Hispanic Caucus

Judy

Chair Congressional Asian Pacific American Caucus

Karen Bass Chair Congressional Black Caucus