116TH CONGRESS
2D SESSION

S. ______

To require the Centers for Disease Control and Prevention to collect and report certain data concerning COVID–19.

IN THE SENATE OF THE UNITED STATES

Ms. WARREN introduced the following bill; which was read twice and referred to the Committee on ______________

A BILL

To require the Centers for Disease Control and Prevention to collect and report certain data concerning COVID–19.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Equitable Data Collection and Disclosure on COVID-19 Act''.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) The World Health Organization (WHO) declared COVID–19 a ''Public Health Emergency of International Concern'' on January 30, 2020. By

late March 2020, there have been over 470,000 confirmed cases of, and 20,000 deaths associated with, COVID–19 worldwide.

(2) In the United States, cases of COVID–19 have quickly surpassed those across the world, and as of April 12, 2020, over 500,000 cases and 20,000 deaths have been reported in the United States alone.

(3) Early reporting on racial inequities in COVID–19 testing and treatment has renewed calls for the Centers for Disease Control and Prevention and other relevant subagencies within the Department of Health and Human Services to publicly release racial and demographic information to better inform the pandemic response, specifically in communities of color and in Limited English Proficient (LEP) communities.

(4) The burden of morbidity and mortality in the United States has historically fallen disproportionately on marginalized communities (those who suffer the most from great public health needs and are the most medically underserved).

(5) Historically, structures and systems such as racism, ableism and class oppression, have rendered affected individuals more vulnerable to inequities

and have prevented people from achieving optimal health even when there is not a crisis of pandemic proportions.

(6) Significant differences in access to health care, specifically to primary health care providers, health care information, and greater perceived discrimination in health care place communities of color, individuals with disabilities, and LEP individuals at greater risk of receiving delayed, and perhaps poorer, health care.

(7) Stark racial inequities across the United States, including unequal access to stable housing, quality education, and decent employment, significantly impact the ability of individuals to take care of their most basic health needs. Communities of color are more likely to experience homelessness and struggle with low-paying jobs or unemployment. To date, experts have cited that 2 in 5 Latino residents in New York City, the current epicenter of the COVID–19 pandemic, are recently unemployed as a direct consequence of COVID–19. And at a time when sheltering in place will save lives, less than 1 in 5 Black workers and roughly 1 in 6 Latino workers are able to work from home.

(8) Communities of color experience higher rates of chronic disease and disabilities, such as diabetes, hypertension, and asthma, than non-Hispanic White communities, which predisposes them to greater risk of complications and mortality should they contract COVID–19.

(9) Such communities are made even more vulnerable to the uncertainty of the preparation, response, and events surrounding the pandemic public health crisis, COVID–19. For instance, in the recent past, multiple epidemiologic studies and reviews have reported higher rates of hospitalization due to the 2009 H1N1 pandemic among the poor, individuals with disabilities and preexisting conditions, those living in impoverished neighborhoods, and individuals of color and marginalized ethnic backgrounds in the United States. These findings highlight the urgency to adapt the COVID–19 response to monitor and act on these inequities via data collection and research by race and ethnicity.

(10) Research experts recognize that there are underlying differences in illness and death when each of these factors is examined through socioeconomic and racial or ethnic lenses. These socially

determinant factors of health accelerate disease and degradation.

(11) Language barriers are highly correlated with medication noncompliance and inconsistent engagement with health systems. Without language accessibility data and research around COVID–19, these communities are less likely to receive critical testing and preventive health services. Yet, to date, the Centers for Disease Control and Prevention does not disseminate COVID–19 messaging in critical languages, including Mandarin Chinese, Spanish, and Korean within the same timeframe as information in English despite requirements to ensure limited English proficient populations are not discriminated against under title VI of the Civil Rights Act of 1964 and subsequent laws and Federal policies.

(12) Further, it is critical to disaggregate data further by ancestry to address disparities among Asian American, Native Hawaiian, and Pacific Islander groups. According to the National Equity Atlas, while 13 percent of the Asian population overall lived in poverty in 2015, 39 percent of Burmese people, 29 percent of Hmong people, and 21 percent of Pacific Islanders lived in poverty.

(13) Utilizing disaggregation of enrollment in Affordable Care Act-sponsored health insurance, the Asian and Pacific Islander American Health Forum found that prior to the passage of the Patient Protection and Affordable Care Act (Public Law 111-148), Korean Americans had a high uninsured rate of 23 percent, compared to just 12 percent for all Asian Americans. Developing targeted outreach efforts assisted 1,000,000 people and resulted in a 56-percent decrease in the uninsured among the Asian, Native Hawaiian, and Pacific Islander population. Such efforts show that disaggregated data is essential to public health mobilizations efforts.

(14) Without clear understanding of how COVID–19 impacts marginalized racial and ethnic communities, there will be exacerbated risk of endangering the most historically vulnerable of our Nation.

(15) The consequences of misunderstanding the racial and ethnic impact of COVID–19 expound beyond communities of color such that it would impact all.

(16) Race and ethnicity are valuable research and practice variables when used and interpreted appropriately. Health data collected on patients by

race and ethnicity will boost and more efficiently direct critical resources and inform risk communication development in languages and at appropriate health literacy levels, which resonate with historically vulnerable communities of color.

(17) To date, there is no public standardized and comprehensive race and ethnicity data repository of COVID–19 testing, hospitalizations, or mortality. The inconsistency of data collection by Federal, State, and local health authorities, and the inability to access data by public research institutions and academic organizations, poses a threat to analysis and synthesis of the pandemic impact on communities of color. However, research and medical experts of Historically Black Colleges and Universities, academic health care institutions which are historically and geographically embedded in minoritized and marginalized communities, generally also possess rapport with the communities they serve. They are well-positioned, as trusted thought leaders and health care service providers, to collect data and conduct research toward creating holistic solutions to remedy the inequitable impact of this and future public health crises.

(18) Well-designed, ethically sound research aligns with the goals of medicine, addresses questions relevant to the population among whom the study will be carried out, balances the potential for benefit against the potential for harm, employs study designs that will yield scientifically valid and significant data, and generates useful knowledge.

(19) The dearth of racially and ethnically disaggregated data reflecting the health of communities of color underlies the challenges of a fully informed public health response.

(20) Without collecting race and ethnicity data associated with COVID–19 testing, hospitalizations, morbidities, and mortalities, as well as publicly disclosing it, communities of color will remain at greater risk of disease and death.

SEC. 3. EMERGENCY FUNDING FOR FEDERAL DATA COLLECTION ON THE RACIAL, ETHNIC, AND OTHER DEMOGRAPHIC DISPARITIES OF COVID–19.

To conduct or support data collection on the racial, ethnic, and other demographic implications of COVID–19 in the United States and its territories, including support to assist in the capacity building for State and local public health departments to collect and transmit racial, ethnic, and other demographic data to the relevant Department of Health and Human Services agencies, there is authorized to be appropriated—

(1) to the Centers for Disease Control and Prevention, $12,000,000;

(2) to State and territorial public health agencies, distributed proportionally based on the total population of their residents who are enrolled in Medicaid or who have no health insurance, $15,000,000;

(3) to the Indian Health Service, Indian Tribes and Tribal organizations (as defined in section 4 of the Indian Self-Determination and Education Assistance Act), and urban Indian organizations (as defined in section 4 of the Indian Health Care Improvement Act), $3,000,000;

(4) to the Centers for Medicare & Medicaid Services, $5,000,000;

(5) to the Food and Drug Administration, $5,000,000;

(6) to the Agency for Healthcare Research and Quality, $5,000,000; and

(7) to the Office of the National Coordinator for Health Information Technology, $5,000,000.

SEC. 4. COVID–19 DATA COLLECTION AND DISCLOSURE.

(a) DATA COLLECTION.—The Secretary of Health and Human Services (referred to in this Act as the ''Secretary''), acting through the Director of the Centers for Disease Control and Prevention and the Administrator of the Centers for Medicare & Medicaid Services, shall make publicly available on the website of the Centers for Disease Control and Prevention data collected across all surveillance systems relating to COVID–19, disaggregated by race, ethnicity, sex, age, primary language, socioeconomic status, disability status, and county, including the following:

(1) Data related to all COVID–19 testing, including the number of individuals tested and the number of tests that were positive.

(2) Data related to treatment for COVID–19, including hospitalizations and intensive care unit admissions.

(3) Data related to COVID–19 outcomes, including total fatalities and case fatality rates (expressed as the proportion of individuals who were infected with COVID–19 and died from the virus).

(b) APPLICATION OF STANDARDS.—To the extent practicable, data collection under this section shall follow standards developed by the Department of Health and Human Services Office of Minority Health and be collected, analyzed, and reported in accordance with the standards promulgated by the Assistant Secretary for Planning and Evaluation under title XXXI of the Public Health Service Act (42 U.S.C. 300kk et seq.).

(c) TIMELINE.—The data made available under this section shall be updated on a daily basis throughout the public health emergency.

(d) PRIVACY.—In publishing data under this section, the Secretary shall take all necessary steps to protect the privacy of individuals whose information is included in such data, including—

(1) complying with privacy protections provided under the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996; and

(2) protections from all inappropriate internal use by an entity that collects, stores, or receives the data, including use of such data in determinations of eligibility (or continued eligibility) in health plans, and from inappropriate uses.

(e) INDIAN HEALTH SERVICE.—The Indian Health Service shall consult with Indian Tribes and urban Indian organizations on data collection and reporting for purposes of this Act.

(f) REPORT.—Not later than 60 days after the date on which the Secretary certifies that the public health emergency related to COVID–19 has ended, the Secretary shall make publicly available a summary of the final statistics related to COVID–19.

(g) REPORT.—Not later than 60 days after the date on which the Secretary certifies that the public health emergency related to COVID–19 has ended, the Department of Health and Human Services shall compile and submit to the Committee on Health, Education, Labor, and Pensions and the Committee on Finance of the Senate and the Committee on Energy and Commerce and the Committee on Ways and Means of the House of Representatives a preliminary report—

(1) describing the testing, hospitalization, mortality rates, and preferred language of patients associated with COVID–19 by race and ethnicity; and

(2) proposing evidenced-based response strategies to safeguard the health of these communities in future pandemics.

SEC. 5. COMMISSION ON ENSURING HEATH EQUITY DURING THE COVID–19 PUBLIC HEALTH EMERGENCY.

(a) IN GENERAL.—Not later than 30 days after the date of enactment of this Act, the Secretary shall establish a commission, to be known as the ''Commission on Ensuring Heath Equity During the COVID–19 Public Health Emergency'' (referred to in this section as the ''Commission'') to provide clear and robust guidance on how to improve the collection, analysis, and use of demographic data in responding to future waves of the coronavirus.

(b) MEMBERSHIP AND CHAIRPERSON.—

(1) MEMBERSHIP.—The Commission shall be composed of—

(A) the Director of the Centers for Disease Control and Prevention;

(B) the Director of the National Institutes of Health;

(C) the Commissioner of Food and Drugs;

(D) the Administrator of the Federal Emergency Management Agency;

(E) the Director of the National Institute on Minority Health and Health Disparities;

(F) the Director of the Indian Health Service;

(G) the Administrator of the Centers for Medicare & Medicaid Services;

(H) the Director of the Agency for Healthcare Research and Quality;

(I) the Surgeon General;

(J) the Administrator of the Health Resources and Services Administration;

(K) the Director of the Office of Minority Health;

(L) the Director of the Office of Women's Health;

(M) the Chairperson of the National Council on Disability;

(N) at least 4 State, local, territorial, and Tribal public health officials representing departments of public health, who shall represent jurisdictions from different regions of the United States with relatively high concentrations of historically marginalized populations, to be appointed by the Secretary; and

(O) racially and ethnically diverse representation from at least 3 independent experts with knowledge or field experience with racial and ethnic disparities in public health appointed by the Secretary.

(2) CHAIRPERSON.—The President of the National Academies of Sciences, Engineering, and Medicine, or designee, shall serve as the chairperson of the Commission.

(c) DUTIES.—The Commission shall—

(1) examine barriers to collecting, analyzing, and using demographic data;

(2) determine how to best use such data to promote health equity across the United States and reduce racial, Tribal, and other demographic disparities in COVID–19 prevalence and outcomes;

(3) gather available data related to COVID–19 treatment of individuals with disabilities, including denial of treatment for pre-existing conditions, removal or denial of disability related equipment (including ventilators and CPAP machines), and data on completion of DNR orders, and identify barriers to obtaining accurate and timely data related to COVID–19 treatment of such individuals;

(4) solicit input from public health officials, community-connected organizations, health care providers, State and local agency officials, and other experts on barriers to, and best practices for, collecting demographic data; and

(5) recommend policy changes that the data indicates are necessary to reduce disparities.

(d) REPORT.—Not later than 60 days after the date of enactment of this Act, and every 180 days thereafter until the Secretary certifies that the public health emergency related to COVID–19 has ended, the Commission shall submit a written report of its findings and recommendations to Congress and post such report on the website of the Department of Health and Human Services. Such reports shall contain information concerning—

(1) how to enhance State, local, territorial, and Tribal capacity to conduct public health research on COVID–19, with a focus on expanded capacity to analyze data on disparities correlated with race, ethnicity, income, sex, age, disability status, specific geographic areas, and other relevant demographic characteristics, and an analysis of what demographic data is currently being collected about COVID–19, the accuracy of that data and any gaps, how this data is currently being used to inform efforts to combat COVID–19, and what resources are needed to supplement existing public health data collection;

(2) how to collect, process, and disclose to the public the data described in paragraph (1) in a way that maintains individual privacy while helping direct the State and local response to the virus;

(3) how to improve demographic data collection related to COVID–19 in the short- and long-term, including how to continue to grow and value the Tribal sovereignty of data and information concerning Tribal communities;

(4) to the extent possible, a preliminary analysis of racial and other demographic disparities in COVID–19 mortality, including an analysis of comorbidities and case fatality rates;

(5) to the extent possible, a preliminary analysis of sex, gender, sexual orientation, and gender identity disparities in COVID–19 treatment and mortality;

(6) an analysis of COVID–19 treatment of individuals with disabilities, including equity of access to treatment and equipment and intersections of disability status with other demographic factors, including race, and recommendations for how to improve transparency and equity of treatment for such individuals during the COVID–19 public health emergency and future emergencies;

(7) how to support State, local, and Tribal capacity to eliminate barriers to COVID–19 testing and treatment; and

(8) to the extent possible, a preliminary analysis of Federal Government policies that disparately exacerbate the COVID–19 impact, and recommendations to improve racial and other demographic disparities in health outcomes.

(e) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated such sums as may be necessary to carry out this section.