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(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R. ______

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

IN THE HOUSE OF REPRESENTATIVES

Ms. PRESSLEY introduced the following bill; which was 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 of 2021’’.

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 January 2021, there have been over 22,000,000 confirmed cases of, and 383,351 deaths associated with, COVID–19 in the United States.

(2) From the beginning of this pandemic, Black, Brown, and American Indian/Alaska Native (in this section referred to as ''AI/AN'') people in the United States have suffered the largest burden of illness, hospitalization, and death from COVID–19. The Centers for Disease Control and Prevention (CDC) reports that AI/AN people are 4 times as likely as White people to be hospitalized for COVID–19, and that Black and Hispanic/Latino people are 2.8 times as likely to die of COVID–19 as White people.

(3) Historically, structures and systems such as racism, ableism, and class oppression have rendered affected Black and Brown communities more vulnerable to inequities and have prevented people from achieving optimal health even when there is not a crisis of pandemic proportions, highlighting that racism and not race presents as a risk factor driving inequities in illness and death.

(4) Significant differences in access to health care, specifically to primary health care providers,

health care information, and greater perceived discrimination in health care place Black, Brown, and AI/AN communities, individuals with disabilities, and Limited English Proficient individuals at greater risk of receiving delayed, and perhaps poorer, health care.

(5) Stark racial inequities across the United States, including unequal access to stable housing, quality education, and decent employment, significantly impact the ability of Black, Hispanic/Latinx, and AI/AN individuals to take care of their most basic health needs. Black and Brown communities are more likely to experience homelessness and struggle with low-paying jobs or unemployment. An analysis by the University of New Hampshire found that in every month between March and August 2020, Black and Latino workers had significantly higher unemployment rates than White workers, even after adjusting for age and education status.

(6) Black, Hispanic/Latinx, and AI/AN communities 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.

(7) 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.

(8) Language barriers are highly correlated with medication noncompliance and inconsistent engagement with health systems. Without language accessibility data and research around COVID–19, communities with limited English proficiency 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.

(9) 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.

(10) 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.

(11) 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. A recent national study found that American Indian/Alaska Natives were 3.5 times more likely to be infected with COVID–19, however that data excluded 27 States as they had reported less than 70

percent of race/ethnicity data to the Centers for Disease Control and Prevention making it impossible to include them in the analysis thus creating a significant data gap for understanding the impact of COVID–19 on this vulnerable population.

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

(13) 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.

(14) To date, race and ethnicity data on COVID–19 cases, test, hospitalizations, deaths, and vaccinations is incomplete and lacking. The inconsistency of data collection by Federal, State, and local health authorities poses a threat to analysis and synthesis of the pandemic impact on Black, Hispanic/Latinx, and AI/AN communities. However, research and medical experts of Historically Black

Colleges and Universities and Tribal 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.

(15) 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.

(16) The dearth of racially and ethnically disaggregated data reflecting the health of Black, Hispanic/Latinx, and AI/AN communities underlies the challenges of a fully informed public health response.

(17) Without collecting race and ethnicity data associated with COVID–19 vaccinations, testing, hospitalizations, morbidities, and mortalities, as well

as publicly disclosing it, Black, Hispanic/Latinx, and AI/AN communities 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 Assist-

ance 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).

(4) Data related to COVID–19 vaccinations, including—

(A) the number of vaccines administered;

(B) the number of vaccinations offered, accepted, and refused;

(C) the most common reasons for refusal; and

(D) the percentage of vaccine doses allocated and administered to each priority group.

(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 confer with urban Indian organizations on data collection and reporting for purposes of this Act.

(f) SUMMARY.—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, vaccination 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.

(h) TRIBAL EXCEPTION.—Indian Tribes may opt out of any of the requirements of this section.

SEC. 5. COMMISSION ON ENSURING DATA FOR HEATH EQUITY.

(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 Data for Heath Equity'' (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 public health emergencies.

(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, or an urban Indian health representative, 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) at least 3 independent experts of racially and ethnically diverse representation 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 health outcomes;

(3) gather available data related to treatment of individuals with disabilities during the COVID–19 pandemic and other public health emergencies, including access to vaccinations, 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 treatment of such individuals;

(4) solicit input from public health officials, community-connected organizations, health care providers, State and local agency officials, Tribal 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 1 year after the date of enactment of this Act, 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 and in future public health emergencies, 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, 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, local, and Tribal response to public health emergencies;

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

(4) to the extent possible, an 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, an 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 vaccinations, testing, and treatment during the COVID–19 pandemic and future public health emergencies; and

(8) to the extent possible, an 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.