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(Original Signature of Member)

116TH CONGRESS  
2D 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. KELLY of Illinois 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.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Equitable Data Collec-  
5 tion and Disclosure on COVID-19 Act”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) The World Health Organization (WHO) de-  
9 clared COVID-19 a “Public Health Emergency of

1 International Concern” on January 30, 2020. By  
2 late March 2020, there have been over 470,000 con-  
3 firmed cases of, and 20,000 deaths associated with,  
4 COVID–19 worldwide.

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

10 (3) Early reporting on racial inequities in  
11 COVID–19 testing and treatment have renewed calls  
12 for the Centers for Disease Control and Prevention  
13 and other relevant subagencies within the Depart-  
14 ment of Health and Human Services to publicly re-  
15 lease racial and demographic information to better  
16 inform the pandemic response, specifically in com-  
17 munities of color and in Limited English Proficient  
18 (LEP) communities .

19 (4) The burden of morbidity and mortality in  
20 the United States has historically fallen dispropor-  
21 tionately on marginalized communities (those who  
22 suffer the most from great public health needs and  
23 are the most medically underserved).

24 (5) Historically, structures and systems, such  
25 as racism, ableism and class oppression, have ren-

1       dered affected individuals more vulnerable to inequi-  
2       ties and have prevented people from achieving their  
3       optimal health even when there is not a crisis of  
4       pandemic proportions.

5           (6) Significant differences in access to health  
6       care, specifically to primary health care providers,  
7       health care information, and greater perceived dis-  
8       crimination in health care place communities of  
9       color, individuals with disabilities, and LEP individ-  
10      uals at greater risk of receiving delayed, and per-  
11      haps poorer, health care.

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

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

7           (9) Such communities are made even more vul-  
8 nerable to the uncertainty of the preparation, re-  
9 sponse, and events surrounding the pandemic public  
10 health crisis, COVID–19. For instance, in the recent  
11 past, multiple epidemiologic studies and reviews have  
12 reported higher rates of hospitalization due to the  
13 2009 H1N1 pandemic among the poor, individuals  
14 with disabilities and preexisting conditions, those liv-  
15 ing in impoverished neighborhoods, and individuals  
16 of color and ethnic backgrounds in the United  
17 States. These findings highlight the urgency to  
18 adapt the COVID–19 response to monitor and act  
19 on these inequities via data collection and research  
20 by race and ethnicity.

21           (10) Research experts recognize that there are  
22 underlying differences in illness and death when  
23 each of these factors are examined through socio-  
24 economic and racial or ethnic lenses. These socially

1       determinant factors of health accelerate disease and  
2       degradation.

3           (11) Language barriers are highly correlated  
4       with medication noncompliance and inconsistent en-  
5       gagement with health systems. Without language ac-  
6       cessibility data and research around COVID–19,  
7       these communities are less likely to receive critical  
8       testing and preventive health services. Yet, to date,  
9       the Centers for Disease Control and Prevention do  
10      not disseminate COVID–19 messaging in critical  
11      languages, including Mandarin Chinese, Spanish,  
12      and Korean within the same timeframe as informa-  
13      tion in English despite requirements to ensure lim-  
14      ited English proficient populations are not discrimi-  
15      nated against under title VI of the Civil Rights Act  
16      of 1964 and subsequent laws and Federal policies.

17           (12) Further, it is critical to disaggregate data  
18      further by ancestry to address disparities among  
19      Asian American, Native Hawaiian, and Pacific Is-  
20      lander groups. According to the National Equity  
21      Atlas, while 13 percent of the Asian population over-  
22      all lived in poverty in 2015, 39 percent of Burmese  
23      people, 29 percent of Hmong people, and 21 percent  
24      of Pacific Islanders lived in poverty.

1           (13) Utilizing disaggregation of enrollment in  
2           Affordable Care Act-sponsored health insurance, the  
3           Asian and Pacific Islander American Health Forum  
4           found that prior to the passage of the Patient Pro-  
5           tection and Affordable Care Act (Public Law 111-  
6           148), Korean Americans had a high uninsured rate  
7           of 23 percent, compared to just 12 percent for all  
8           Asian Americans. Developing targeted outreach ef-  
9           forts assisted 1,000,000 people and resulted in a 56-  
10          percent decrease in the uninsured among the Asian,  
11          Native Hawaiian, and Pacific Islander population.  
12          Such efforts show that disaggregated data is essen-  
13          tial to public health mobilizations efforts.

14          (14) Without clear understanding of how  
15          COVID-19 impacts marginalized racial and ethnic  
16          communities, there will be exacerbated risk of en-  
17          dangering the most historically vulnerable of our  
18          Nation.

19          (15) The consequences of misunderstanding the  
20          racial and ethnic impact of COVID-19 expound be-  
21          yond communities of color such that it would impact  
22          all.

23          (16) Race and ethnicity are valuable research  
24          and practice variables when used and interpreted ap-  
25          propriately. Health data collected on patients by

1 race and ethnicity will boost and more efficiently di-  
2 rect critical resources and inform risk communica-  
3 tion development in languages and at appropriate  
4 health literacy levels, which resonate with historically  
5 vulnerable communities of color.

6 (17) To date, there is no public standardized  
7 and comprehensive race and ethnicity data reposi-  
8 tory of COVID–19 testing, hospitalizations, or mor-  
9 tality. The inconsistency of data collection by Fed-  
10 eral, State, and local health authorities, and the in-  
11 ability to access data by public research institutions  
12 and academic organizations, poses a threat to anal-  
13 ysis and synthesis of the pandemic impact on com-  
14 munities of color. However, research and medical ex-  
15 perts of Historically Black Colleges and Universities,  
16 academic health care institutions which are histori-  
17 cally and geographically embedded in minoritized  
18 and marginalized communities, generally also pos-  
19 sess rapport with the communities they serve. They  
20 are well-positioned, as trusted thought leaders and  
21 health care service providers, to collect data and con-  
22 duct research toward creating holistic solutions to  
23 remedy the inequitable impact of this and future  
24 public health crises.

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

8           (19) The dearth of racially and ethnically  
9 disaggregated data reflecting the health of commu-  
10 nities of color underlies the challenges of a fully in-  
11 formed public health response.

12           (20) Without collecting race and ethnicity data  
13 associated with COVID–19 testing, hospitalizations,  
14 morbidities, and mortalities, as well as publicly dis-  
15 closing it, communities of color will remain at great-  
16 er risk of disease and death.

17 **SEC. 3. EMERGENCY FUNDING FOR FEDERAL DATA COL-**  
18 **LECTION ON THE RACIAL, ETHNIC, AND**  
19 **OTHER DEMOGRAPHIC DISPARITIES OF**  
20 **COVID–19.**

21           To conduct or support data collection on the racial,  
22 ethnic, and other demographic implications of COVID–19  
23 in the United States and its territories, including support  
24 to assist in the capacity building for State and local public  
25 health departments to collect and transmit racial, ethnic,



1 and other demographic data to the relevant Department  
2 of Health and Human Services agencies, there is author-  
3 ized to be appropriated—

4 (1) to the Centers for Disease Control and Pre-  
5 vention, \$12,000,000;

6 (2) to State, territorial , and Tribal public  
7 health agencies, distributed proportionally based on  
8 the total population of their residents who are en-  
9 rolled in Medicaid or who have no health insurance,  
10 \$15,000,000;

11 (3) to the Indian Health Service, Indian Tribes  
12 and Tribal organizations (as defined in section 4 of  
13 Indian Self-Determination and Education Assistance  
14 Act), and urban Indian organizations (as defined in  
15 section 4 of Indian Health Care Improvement Act),  
16 \$3,000,000;

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

19 (5) to the Food and Drug Administration,  
20 \$5,000,000;

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

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

1 **SEC. 4. COVID-19 DATA COLLECTION AND DISCLOSURE.**

2 (a) DATA COLLECTION.—The Secretary of Health  
3 and Human Services (referred to in this Act as the “Sec-  
4 retary”), acting through the Director of the Centers for  
5 Disease Control and Prevention and the Administrator of  
6 the Centers for Medicare & Medicaid Services, shall make  
7 publicly available on the website of the Centers for Disease  
8 Control and Prevention data collected across all surveil-  
9 lance systems relating to COVID-19, disaggregated by  
10 race, ethnicity, sex, age, primary language, socioeconomic  
11 status, disability status, and county, including the fol-  
12 lowing:

13 (1) Data related to all COVID-19 testing, in-  
14 cluding the number of individuals tested and the  
15 number of tests that were positive.

16 (2) Data related to treatment for COVID-19,  
17 including hospitalizations and intensive care unit ad-  
18 missions.

19 (3) Data related to COVID-19 outcomes, in-  
20 cluding total fatalities and case fatality rates (ex-  
21 pressed as the proportion of individuals who were in-  
22 fected with COVID-19 and died from the virus).

23 (b) APPLICATION OF STANDARDS.—To the extent  
24 practicable, data collection under this section shall follow  
25 standards developed by the Department of Health and  
26 Human Services Office of Minority Health and be col-

1 lected, analyzed, and reported in accordance with the  
2 standards promulgated by the Assistant Secretary for  
3 Planning and Evaluation under title XXXI of the Public  
4 Health Service Act (42 U.S.C. 300kk et seq.).

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

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

12 (1) complying with privacy protections provided  
13 under the regulations promulgated under section  
14 264(c) of the Health Insurance Portability and Ac-  
15 countability Act of 1996; and

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

21 (e) **CONSULTATION WITH TRIBES.**—The Indian  
22 Health Service shall consult with Indian Tribes and confer  
23 with urban Indian organizations on data collection and re-  
24 porting.

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

6 (g) REPORT.—Not later than 60 days after the date  
7 on which the Secretary certifies that the public health  
8 emergency related to COVID–19 has ended, the Depart-  
9 ment of Health and Human Services shall compile and  
10 submit to the Committee on Health, Education, Labor,  
11 and Pensions and the Committee on Finance of the Senate  
12 and the Committee on Energy and Commerce and the  
13 Committee on Ways and Means of the House of Rep-  
14 resentatives a preliminary report—

15 (1) describing the testing, hospitalization, mor-  
16 tality rates, and preferred language of patients asso-  
17 ciated with COVID–19 by race and ethnicity; and

18 (2) proposing evidenced-based response strate-  
19 gies to safeguard the health of these communities in  
20 future pandemics.

21 **SEC. 5. COMMISSION ON ENSURING HEATH EQUITY DUR-**  
22 **ING THE COVID–19 PUBLIC HEALTH EMER-**  
23 **GENCY.**

24 (a) IN GENERAL.—Not later than 30 days after the  
25 date of enactment of this Act, the Secretary shall establish

1 a commission, to be known as the “Commission on Ensuring  
2 ing Heath Equity During the COVID–19 Public Health  
3 Emergency” (referred to in this section as the “Commis-  
4 sion”) to provide clear and robust guidance on how to im-  
5 prove the collection, analysis, and use of demographic data  
6 in responding to future waves of the coronavirus.

7 (b) MEMBERSHIP AND CHAIRPERSON.—

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

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

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

14 (C) the Commissioner of Food and Drugs;

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

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

19 (F) the Director of the Indian Health  
20 Service;

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

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

25 (I) the Surgeon General;

1 (J) the Administrator of the Health Re-  
2 sources and Services Administration;

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

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

7 (M) the Chairperson of the National Coun-  
8 cil on Disability;

9 (N) at least 4 State, local, territorial, and  
10 Tribal public health officials representing de-  
11 partments of public health, who shall represent  
12 jurisdictions from different regions of the  
13 United States with relatively high concentra-  
14 tions of historically marginalized populations, to  
15 be appointed by the Secretary; and

16 (O) racially and ethnically diverse rep-  
17 resentation from at least 3 independent experts  
18 with knowledge or field experience with racial  
19 and ethnic disparities in public health appointed  
20 by the Secretary.

21 (2) CHAIRPERSON.—The President of the Na-  
22 tional Academies of Sciences, Engineering, and Med-  
23 icine, or designee, shall serve as the chairperson of  
24 the Commission.

25 (c) DUTIES.—The Commission shall—

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

3           (2) determine how to best use such data to pro-  
4           mote health equity across the United States and re-  
5           duce racial, Tribal, and other demographic dispari-  
6           ties in COVID–19 prevalence and outcomes;

7           (3) gather available data related to COVID–19  
8           treatment of individuals with disabilities, including  
9           denial of treatment for pre-existing conditions, re-  
10          moval or denial of disability related equipment (in-  
11          cluding ventilators and CPAP), and data on comple-  
12          tion of DNR orders, and identify barriers to obtain-  
13          ing accurate and timely data related to COVID–19  
14          treatment of such individuals;

15          (4) solicit input from public health officials,  
16          community-connected organizations, health care pro-  
17          viders, State and local agency officials, and other ex-  
18          perts on barriers to, and best practices for, collecting  
19          demographic data; and

20          (5) recommend policy changes that the data in-  
21          dicates are necessary to reduce disparities.

22          (d) REPORT.—Not later than 60 days after the date  
23          of enactment of this Act, and every 180 days thereafter  
24          until the Secretary certifies that the public health emer-  
25          gency related to COVID–19 has ended, the Commission

1 shall submit a written report of its findings and rec-  
2 ommendations to Congress and post such report on a  
3 website of the Department of Health and Human Services.

4 Such reports shall contain information concerning—

5           (1) how to enhance State, local, territorial, and  
6           Tribal capacity to conduct public health research on  
7           COVID–19, with a focus on expanded capacity to  
8           analyze data on disparities correlated with race, eth-  
9           nicity, income, sex, age, disability status, specific ge-  
10          ographic areas, and other relevant demographic  
11          characteristics, and an analysis of what demographic  
12          data is currently being collected about COVID–19,  
13          the accuracy of that data and any gaps, how this  
14          data is currently being used to inform efforts to  
15          combat COVID–19, and what resources are needed  
16          to supplement existing public health data collection;

17           (2) how to collect, process, and disclose to the  
18          public the data described in paragraph (1) in a way  
19          that maintains individual privacy while helping di-  
20          rect the State and local response to the virus;

21           (3) how to improve demographic data collection  
22          related to COVID–19 in the short- and long-term,  
23          including how to continue to grow and value the  
24          Tribal sovereignty of data and information con-  
25          cerning Tribal communities;



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

5           (5) to the extent possible, a preliminary anal-  
6           ysis of sex, gender, sexual orientation, and gender  
7           identity disparities in COVID–19 treatment and  
8           mortality;

9           (6) an analysis of COVID–19 treatment of indi-  
10          viduals with disabilities, including equity of access to  
11          treatment and equipment and intersections of dis-  
12          ability status with other demographic factors, includ-  
13          ing race, and recommendations for how to improve  
14          transparency and equity of treatment for such indi-  
15          viduals during the COVID–19 public health emer-  
16          gency and future emergencies;

17          (7) how to support State, local, and Tribal ca-  
18          pacity to eliminate barriers to COVID–19 testing  
19          and treatment; and

20          (8) to the extent possible, a preliminary anal-  
21          ysis of Federal Government policies that disparately  
22          exacerbate the COVID–19 impact, and recommenda-  
23          tions to improve racial and other demographic dis-  
24          parities in health outcomes.

1           (e) AUTHORIZATION OF APPROPRIATIONS.—There is  
2 authorized to be appropriated such sums as may be nec-  
3 essary to carry out this section.