

116TH CONGRESS
2D SESSION

H. R. 6585

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

IN THE HOUSE OF REPRESENTATIVES

APRIL 21, 2020

Ms. KELLY of Illinois (for herself, Ms. PRESSLEY, Ms. BASS, Ms. LEE of California, Ms. CLARKE of New York, Mr. RICHMOND, Mr. BUTTERFIELD, Ms. BARRAGÁN, Mrs. BEATTY, Ms. ADAMS, Mr. BEYER, Mr. BISHOP of Georgia, Mr. BLUMENAUER, Ms. BLUNT ROCHESTER, Mr. BROWN of Maryland, Mr. CÁRDENAS, Mr. CARSON of Indiana, Ms. CASTOR of Florida, Mr. CASTRO of Texas, Ms. JUDY CHU of California, Mr. CLAY, Mr. CORREA, Mr. CROW, Mr. DANNY K. DAVIS of Illinois, Ms. DEGETTE, Mrs. DEMINGS, Mrs. DINGELL, Mr. ENGEL, Mr. ESPAILLAT, Mr. EVANS, Ms. FUDGE, Mr. GARCÍA of Illinois, Mr. GOMEZ, Mr. GRIJALVA, Ms. HAALAND, Mr. HASTINGS, Mrs. HAYES, Mr. HORSFORD, Mr. JEFFRIES, Ms. JOHNSON of Texas, Mr. JOHNSON of Georgia, Ms. KAPTUR, Mr. KENNEDY, Mr. KILDEE, Mr. KILMER, Mr. LARSON of Connecticut, Mrs. LAWRENCE, Mr. LEVIN of Michigan, Mr. LEWIS, Mr. LOWENTHAL, Mr. LYNCH, Mr. McEACHIN, Mr. MCGOVERN, Mr. MEEKS, Ms. MENG, Ms. MOORE, Mr. MOULTON, Mr. NADLER, Mrs. NAPOLITANO, Mr. NEGUSE, Ms. NORTON, Ms. OCASIO-CORTEZ, Ms. OMAR, Mr. PAYNE, Ms. PLASKETT, Mr. POCAN, Mr. RASKIN, Mr. RUSH, Ms. SÁNCHEZ, Ms. SCANLON, Ms. SCHAKOWSKY, Mr. DAVID SCOTT of Georgia, Mr. SCOTT of Virginia, Mr. SERRANO, Ms. SEWELL of Alabama, Ms. SHALALA, Mr. SMITH of Washington, Mr. SOTO, Ms. SPEIER, Mr. THOMPSON of Mississippi, Ms. TLAIB, Mr. TONKO, Mrs. TORRES of California, Mrs. TRAHAN, Ms. UNDERWOOD, Ms. VELÁZQUEZ, Ms. WASSERMAN SCHULTZ, Ms. WATERS, Ms. WILD, Ms. WILSON of Florida, Mr. DEFazio, and Ms. SPANBERGER) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Natural Resources, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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

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

19 (3) Early reporting on racial inequities in
20 COVID–19 testing and treatment have renewed calls
21 for the Centers for Disease Control and Prevention
22 and other relevant subagencies within the Depart-

1 ment of Health and Human Services to publicly re-
2 lease racial and demographic information to better
3 inform the pandemic response, specifically in com-
4 munities of color and in Limited English Proficient
5 (LEP) communities.

6 (4) The burden of morbidity and mortality in
7 the United States has historically fallen dispropor-
8 tionately on marginalized communities (those who
9 suffer the most from great public health needs and
10 are the most medically underserved).

11 (5) Historically, structures and systems, such
12 as racism, ableism and class oppression, have ren-
13 dered affected individuals more vulnerable to inequi-
14 ties and have prevented people from achieving their
15 optimal health even when there is not a crisis of
16 pandemic proportions.

17 (6) Significant differences in access to health
18 care, specifically to primary health care providers,
19 health care information, and greater perceived dis-
20 crimination in health care place communities of
21 color, individuals with disabilities, and LEP individ-
22 uals at greater risk of receiving delayed, and per-
23 haps poorer, health care.

24 (7) Stark racial inequities across the United
25 States, including unequal access to stable housing,

1 quality education, and decent employment signifi-
2 cantly impact the ability of individuals to take care
3 of their most basic health needs. Communities of
4 color are more likely to experience homelessness and
5 struggle with low-paying jobs or unemployment. To
6 date, experts have cited that 2 in 5 Latino residents
7 in New York City, the current epicenter of the
8 COVID–19 pandemic, are recently unemployed as a
9 direct consequence of COVID–19. And at a time
10 when sheltering in place will save lives, less than 1
11 in 5 Black workers and roughly 1 in 6 Latino work-
12 ers are able to work from home.

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

19 (9) Such communities are made even more vul-
20 nerable to the uncertainty of the preparation, re-
21 sponse, and events surrounding the pandemic public
22 health crisis, COVID–19. For instance, in the recent
23 past, multiple epidemiologic studies and reviews have
24 reported higher rates of hospitalization due to the
25 2009 H1N1 pandemic among the poor, individuals

1 with disabilities and preexisting conditions, those liv-
2 ing in impoverished neighborhoods, and individuals
3 of color and ethnic backgrounds in the United
4 States. These findings highlight the urgency to
5 adapt the COVID–19 response to monitor and act
6 on these inequities via data collection and research
7 by race and ethnicity.

8 (10) Research experts recognize that there are
9 underlying differences in illness and death when
10 each of these factors are examined through socio-
11 economic and racial or ethnic lenses. These socially
12 determinant factors of health accelerate disease and
13 degradation.

14 (11) Language barriers are highly correlated
15 with medication noncompliance and inconsistent en-
16 gagement with health systems. Without language ac-
17 cessibility data and research around COVID–19,
18 these communities are less likely to receive critical
19 testing and preventive health services. Yet, to date,
20 the Centers for Disease Control and Prevention do
21 not disseminate COVID–19 messaging in critical
22 languages, including Mandarin Chinese, Spanish,
23 and Korean within the same timeframe as informa-
24 tion in English despite requirements to ensure lim-
25 ited English proficient populations are not discrimi-

1 nated against under title VI of the Civil Rights Act
2 of 1964 and subsequent laws and Federal policies.

3 (12) Further, it is critical to disaggregate data
4 further by ancestry to address disparities among
5 Asian American, Native Hawaiian, and Pacific Is-
6 lander groups. According to the National Equity
7 Atlas, while 13 percent of the Asian population over-
8 all lived in poverty in 2015, 39 percent of Burmese
9 people, 29 percent of Hmong people, and 21 percent
10 of Pacific Islanders lived in poverty.

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

24 (14) Without clear understanding of how
25 COVID–19 impacts marginalized racial and ethnic

1 communities, there will be exacerbated risk of en-
2 dangering the most historically vulnerable of our
3 Nation.

4 (15) The consequences of misunderstanding the
5 racial and ethnic impact of COVID–19 expound be-
6 yond communities of color such that it would impact
7 all.

8 (16) Race and ethnicity are valuable research
9 and practice variables when used and interpreted ap-
10 propriately. Health data collected on patients by
11 race and ethnicity will boost and more efficiently di-
12 rect critical resources and inform risk communica-
13 tion development in languages and at appropriate
14 health literacy levels, which resonate with historically
15 vulnerable communities of color.

16 (17) To date, there is no public standardized
17 and comprehensive race and ethnicity data reposi-
18 tory of COVID–19 testing, hospitalizations, or mor-
19 tality. The inconsistency of data collection by Fed-
20 eral, State, and local health authorities, and the in-
21 ability to access data by public research institutions
22 and academic organizations, poses a threat to anal-
23 ysis and synthesis of the pandemic impact on com-
24 munities of color. However, research and medical ex-
25 perts of Historically Black Colleges and Universities,

1 academic health care institutions which are histori-
2 cally and geographically embedded in minoritized
3 and marginalized communities, generally also pos-
4 sess rapport with the communities they serve. They
5 are well-positioned, as trusted thought leaders and
6 health care service providers, to collect data and con-
7 duct research toward creating holistic solutions to
8 remedy the inequitable impact of this and future
9 public health crises.

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

17 (19) The dearth of racially and ethnically
18 disaggregated data reflecting the health of commu-
19 nities of color underlies the challenges of a fully in-
20 formed public health response.

21 (20) Without collecting race and ethnicity data
22 associated with COVID–19 testing, hospitalizations,
23 morbidities, and mortalities, as well as publicly dis-
24 closing it, communities of color will remain at great-
25 er risk of disease and death.

1 **SEC. 3. EMERGENCY FUNDING FOR FEDERAL DATA COL-**
2 **LECTION ON THE RACIAL, ETHNIC, AND**
3 **OTHER DEMOGRAPHIC DISPARITIES OF**
4 **COVID-19.**

5 To conduct or support data collection on the racial,
6 ethnic, and other demographic implications of COVID-19
7 in the United States and its territories, including support
8 to assist in the capacity building for State and local public
9 health departments to collect and transmit racial, ethnic,
10 and other demographic data to the relevant Department
11 of Health and Human Services agencies, there is author-
12 ized to be appropriated—

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

15 (2) to State, territorial, and Tribal public
16 health agencies, distributed proportionally based on
17 the total population of their residents who are en-
18 rolled in Medicaid or who have no health insurance,
19 \$15,000,000;

20 (3) to the Indian Health Service, Indian Tribes
21 and Tribal organizations (as defined in section 4 of
22 the Indian Self-Determination and Education Assist-
23 ance Act), and urban Indian organizations (as de-
24 fined in section 4 of the Indian Health Care Im-
25 provement Act), \$3,000,000;

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

3 (5) to the Food and Drug Administration,
4 \$5,000,000;

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

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

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

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

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

1 (2) Data related to treatment for COVID–19,
2 including hospitalizations and intensive care unit ad-
3 missions.

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

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

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

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

23 (1) complying with privacy protections provided
24 under the regulations promulgated under section

1 264(c) of the Health Insurance Portability and Ac-
2 countability Act of 1996; and

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

8 (e) CONSULTATION WITH TRIBES.—The Indian
9 Health Service shall consult with Indian Tribes and confer
10 with urban Indian organizations on data collection and re-
11 porting.

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

17 (g) REPORT.—Not later than 60 days after the date
18 on which the Secretary certifies that the public health
19 emergency related to COVID–19 has ended, the Depart-
20 ment of Health and Human Services shall compile and
21 submit to the Committee on Health, Education, Labor,
22 and Pensions and the Committee on Finance of the Senate
23 and the Committee on Energy and Commerce and the
24 Committee on Ways and Means of the House of Rep-
25 resentatives a preliminary report—

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

4 (2) proposing evidenced-based response strate-
5 gies to safeguard the health of these communities in
6 future pandemics.

7 **SEC. 5. COMMISSION ON ENSURING HEALTH EQUITY DUR-**
8 **ING THE COVID–19 PUBLIC HEALTH EMER-**
9 **GENCY.**

10 (a) IN GENERAL.—Not later than 30 days after the
11 date of enactment of this Act, the Secretary shall establish
12 a commission, to be known as the “Commission on Ensuring
13 Health Equity During the COVID–19 Public Health
14 Emergency” (referred to in this section as the “Commis-
15 sion”) to provide clear and robust guidance on how to im-
16 prove the collection, analysis, and use of demographic data
17 in responding to future waves of the coronavirus.

18 (b) MEMBERSHIP AND CHAIRPERSON.—

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

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

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

25 (C) the Commissioner of Food and Drugs;

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

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

5 (F) the Director of the Indian Health
6 Service;

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

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

11 (I) the Surgeon General;

12 (J) the Administrator of the Health Re-
13 sources and Services Administration;

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

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

18 (M) the Chairperson of the National Coun-
19 cil on Disability;

20 (N) at least 4 State, local, territorial, and
21 Tribal public health officials representing de-
22 partments of public health, who shall represent
23 jurisdictions from different regions of the
24 United States with relatively high concentra-

1 tions of historically marginalized populations, to
2 be appointed by the Secretary; and

3 (O) racially and ethnically diverse rep-
4 resentation from at least 3 independent experts
5 with knowledge or field experience with racial
6 and ethnic disparities in public health appointed
7 by the Secretary.

8 (2) CHAIRPERSON.—The President of the Na-
9 tional Academies of Sciences, Engineering, and Med-
10 icine, or designee, shall serve as the chairperson of
11 the Commission.

12 (c) DUTIES.—The Commission shall—

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

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

19 (3) gather available data related to COVID–19
20 treatment of individuals with disabilities, including
21 denial of treatment for pre-existing conditions, re-
22 moval or denial of disability related equipment (in-
23 cluding ventilators and CPAP), and data on comple-
24 tion of DNR orders, and identify barriers to obtain-

1 ing accurate and timely data related to COVID–19
2 treatment of such individuals;

3 (4) solicit input from public health officials,
4 community-connected organizations, health care pro-
5 viders, State and local agency officials, and other ex-
6 perts on barriers to, and best practices for, collecting
7 demographic data; and

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

10 (d) REPORT.—Not later than 60 days after the date
11 of enactment of this Act, and every 180 days thereafter
12 until the Secretary certifies that the public health emer-
13 gency related to COVID–19 has ended, the Commission
14 shall submit a written report of its findings and rec-
15 ommendations to Congress and post such report on a
16 website of the Department of Health and Human Services.
17 Such reports shall contain information concerning—

18 (1) how to enhance State, local, territorial, and
19 Tribal capacity to conduct public health research on
20 COVID–19, with a focus on expanded capacity to
21 analyze data on disparities correlated with race, eth-
22 nicity, income, sex, age, disability status, specific ge-
23 ographic areas, and other relevant demographic
24 characteristics, and an analysis of what demographic
25 data is currently being collected about COVID–19,

1 the accuracy of that data and any gaps, how this
2 data is currently being used to inform efforts to
3 combat COVID–19, and what resources are needed
4 to supplement existing public health data collection;

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

9 (3) how to improve demographic data collection
10 related to COVID–19 in the short- and long-term,
11 including how to continue to grow and value the
12 Tribal sovereignty of data and information con-
13 cerning Tribal communities;

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

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

22 (6) an analysis of COVID–19 treatment of indi-
23 viduals with disabilities, including equity of access to
24 treatment and equipment and intersections of dis-
25 ability status with other demographic factors, includ-

1 ing race, and recommendations for how to improve
2 transparency and equity of treatment for such indi-
3 viduals during the COVID–19 public health emer-
4 gency and future emergencies;

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

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

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

○