

117TH CONGRESS  
1ST SESSION

# H. R. 1370

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

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## IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 25, 2021

Ms. PRESSLEY (for herself, Ms. LEE of California, Ms. BASS, Ms. KELLY of Illinois, Mrs. LAWRENCE, Mr. MEEKS, Mr. ESPAILLAT, Ms. OCASIO-CORTEZ, Mr. EVANS, Ms. TLAIB, Mrs. WATSON COLEMAN, Ms. MENG, Ms. BLUNT ROCHESTER, Mr. MFUME, Mr. JOHNSON of Georgia, Ms. CLARKE of New York, Ms. DEGETTE, Ms. NORTON, Ms. JAYAPAL, and Mrs. DEMINGS) 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

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## 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 of 2021”.

1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) The World Health Organization (WHO) de-  
4 clared COVID–19 a “Public Health Emergency of  
5 International Concern” on January 30, 2020. By  
6 late January 2021, there have been over 22,000,000  
7 confirmed cases of, and 383,351 deaths associated  
8 with, COVID–19 in the United States.

9 (2) From the beginning of this pandemic,  
10 Black, Brown, and American Indian/Alaska Native  
11 (in this section referred to as “AI/AN”) people in  
12 the United States have suffered the largest burden  
13 of illness, hospitalization, and death from COVID–  
14 19. The Centers for Disease Control and Prevention  
15 (CDC) reports that AI/AN people are 4 times as  
16 likely as White people to be hospitalized for COVID–  
17 19, and that Black and Hispanic/Latino people are  
18 2.8 times as likely to die of COVID–19 as White  
19 people.

20 (3) Historically, structures and systems such as  
21 racism, ableism, and class oppression have rendered  
22 affected Black and Brown communities more vulner-  
23 able to inequities and have prevented people from  
24 achieving optimal health even when there is not a  
25 crisis of pandemic proportions, highlighting that rac-

1       ism and not race presents as a risk factor driving  
2       inequities in illness and death.

3           (4) Significant differences in access to health  
4       care, specifically to primary health care providers,  
5       health care information, and greater perceived dis-  
6       crimination in health care place Black, Brown, and  
7       AI/AN communities, individuals with disabilities,  
8       and Limited English Proficient individuals at great-  
9       er risk of receiving delayed, and perhaps poorer,  
10      health care.

11          (5) Stark racial inequities across the United  
12      States, including unequal access to stable housing,  
13      quality education, and decent employment, signifi-  
14      cantly impact the ability of Black, Hispanic/Latinx,  
15      and AI/AN individuals to take care of their most  
16      basic health needs. Black and Brown communities  
17      are more likely to experience homelessness and  
18      struggle with low-paying jobs or unemployment. An  
19      analysis by the University of New Hampshire found  
20      that in every month between March and August  
21      2020, Black and Latino workers had significantly  
22      higher unemployment rates than White workers,  
23      even after adjusting for age and education status.

24          (6) Black, Hispanic/Latinx, and AI/AN commu-  
25      nities experience higher rates of chronic disease and

1 disabilities, such as diabetes, hypertension, and asth-  
2 ma, than non-Hispanic White communities, which  
3 predisposes them to greater risk of complications  
4 and mortality should they contract COVID–19.

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

11 (8) Language barriers are highly correlated  
12 with medication noncompliance and inconsistent en-  
13 gagement with health systems. Without language ac-  
14 cessibility data and research around COVID–19,  
15 communities with limited English proficiency are  
16 less likely to receive critical testing and preventive  
17 health services. Yet, to date, the Centers for Disease  
18 Control and Prevention does not disseminate  
19 COVID–19 messaging in critical languages, includ-  
20 ing Mandarin Chinese, Spanish, and Korean within  
21 the same timeframe as information in English de-  
22 spite requirements to ensure limited English pro-  
23 ficient populations are not discriminated against  
24 under title VI of the Civil Rights Act of 1964 and  
25 subsequent laws and Federal policies.

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

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

22           (11) Without clear understanding of how  
23 COVID–19 impacts marginalized racial and ethnic  
24 communities, there will be exacerbated risk of en-  
25 dangering the most historically vulnerable of our

1 Nation. A recent national study found that Amer-  
2 ican Indian/Alaska Natives were 3.5 times more like-  
3 ly to be infected with COVID–19, however that data  
4 excluded 27 States as they had reported less than 70  
5 percent of race/ethnicity data to the Centers for Dis-  
6 ease Control and Prevention making it impossible to  
7 include them in the analysis thus creating a signifi-  
8 cant data gap for understanding the impact of  
9 COVID–19 on this vulnerable population.

10 (12) The consequences of misunderstanding the  
11 racial and ethnic impact of COVID–19 expound be-  
12 yond communities of color such that it would impact  
13 all.

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

22 (14) To date, race and ethnicity data on  
23 COVID–19 cases, test, hospitalizations, deaths, and  
24 vaccinations is incomplete and lacking. The incon-  
25 sistency of data collection by Federal, State, and

1 local health authorities poses a threat to analysis  
2 and synthesis of the pandemic impact on Black, His-  
3 panic/Latinx, and AI/AN communities. However, re-  
4 search and medical experts of Historically Black  
5 Colleges and Universities and Tribal Colleges and  
6 Universities, academic health care institutions which  
7 are historically and geographically embedded in  
8 minoritized and marginalized communities, generally  
9 also possess rapport with the communities they  
10 serve. They are well-positioned, as trusted thought  
11 leaders and health care service providers, to collect  
12 data and conduct research toward creating holistic  
13 solutions to remedy the inequitable impact of this  
14 and future public health crises.

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

22 (16) The dearth of racially and ethnically  
23 disaggregated data reflecting the health of Black,  
24 Hispanic/Latinx, and AI/AN communities underlies

1 the challenges of a fully informed public health re-  
2 sponse.

3 (17) Without collecting race and ethnicity data  
4 associated with COVID–19 vaccinations, testing,  
5 hospitalizations, morbidities, and mortalities, as well  
6 as publicly disclosing it, Black, Hispanic/Latinx, and  
7 AI/AN communities will remain at greater risk of  
8 disease and death.

9 **SEC. 3. EMERGENCY FUNDING FOR FEDERAL DATA COL-**  
10 **LECTION ON THE RACIAL, ETHNIC, AND**  
11 **OTHER DEMOGRAPHIC DISPARITIES OF**  
12 **COVID–19.**

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

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

23 (2) to State and territorial public health agen-  
24 cies, distributed proportionally based on the total  
25 population of their residents who are enrolled in



1 Medicaid or who have no health insurance,  
2 \$15,000,000;

3 (3) to the Indian Health Service, Indian Tribes  
4 and Tribal organizations (as defined in section 4 of  
5 the Indian Self-Determination and Education Assist-  
6 ance Act), and urban Indian organizations (as de-  
7 fined in section 4 of the Indian Health Care Im-  
8 provement Act), \$3,000,000;

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

11 (5) to the Food and Drug Administration,  
12 \$5,000,000;

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

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

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

18 (a) DATA COLLECTION.—The Secretary of Health  
19 and Human Services (referred to in this Act as the “Sec-  
20 retary”), acting through the Director of the Centers for  
21 Disease Control and Prevention and the Administrator of  
22 the Centers for Medicare & Medicaid Services, shall make  
23 publicly available on the website of the Centers for Disease  
24 Control and Prevention data collected across all surveil-  
25 lance systems relating to COVID-19, disaggregated by

1 race, ethnicity, sex, age, primary language, socioeconomic  
2 status, disability status, and county, including the fol-  
3 lowing:

4 (1) Data related to all COVID–19 testing, in-  
5 cluding the number of individuals tested and the  
6 number of tests that were positive.

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

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

14 (4) Data related to COVID–19 vaccinations, in-  
15 cluding—

16 (A) the number of vaccines administered;

17 (B) the number of vaccinations offered, ac-  
18 cepted, and refused;

19 (C) the most common reasons for refusal;  
20 and

21 (D) the percentage of vaccine doses allo-  
22 cated and administered to each priority group.

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

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

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

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

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

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

22 (e) INDIAN HEALTH SERVICE.—The Indian Health  
23 Service shall consult with Indian Tribes and confer with  
24 urban Indian organizations on data collection and report-  
25 ing for purposes of this Act.

1 (f) SUMMARY.—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, vaccination rates, and preferred lan-  
17 guage of patients associated with COVID–19 by race  
18 and ethnicity; and

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

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

1 **SEC. 5. COMMISSION ON ENSURING DATA FOR HEATH EQ-**  
2 **UITY.**

3 (a) IN GENERAL.—Not later than 30 days after the  
4 date of enactment of this Act, the Secretary shall establish  
5 a commission, to be known as the “Commission on Ensuring  
6 Data for Heath Equity” (referred to in this section  
7 as the “Commission”) to provide clear and robust guidance  
8 on how to improve the collection, analysis, and use  
9 of demographic data in responding to future public health  
10 emergencies.

11 (b) MEMBERSHIP AND CHAIRPERSON.—

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

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

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

18 (C) the Commissioner of Food and Drugs;

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

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

23 (F) the Director of the Indian Health  
24 Service;

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

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

3 (I) the Surgeon General;

4 (J) the Administrator of the Health Re-  
5 sources and Services Administration;

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

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

10 (M) the Chairperson of the National Coun-  
11 cil on Disability;

12 (N) at least 4 State, local, territorial, and  
13 Tribal public health officials representing de-  
14 partments of public health, or an urban Indian  
15 health representative, who shall represent juris-  
16 dictions from different regions of the United  
17 States with relatively high concentrations of  
18 historically marginalized populations, to be ap-  
19 pointed by the Secretary; and

20 (O) at least 3 independent experts of ra-  
21 cially and ethnically diverse representation with  
22 knowledge or field experience with racial and  
23 ethnic disparities in public health appointed by  
24 the Secretary.

1           (2) CHAIRPERSON.—The President of the Na-  
2           tional Academies of Sciences, Engineering, and Med-  
3           icine, or designee, shall serve as the chairperson of  
4           the Commission.

5           (c) DUTIES.—The Commission shall—

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

8                 (2) determine how to best use such data to pro-  
9                 mote health equity across the United States and re-  
10                duce racial, Tribal, and other demographic dispari-  
11                ties in health outcomes;

12                (3) gather available data related to treatment of  
13                individuals with disabilities during the COVID–19  
14                pandemic and other public health emergencies, in-  
15                cluding access to vaccinations, denial of treatment  
16                for pre-existing conditions, removal or denial of dis-  
17                ability related equipment (including ventilators and  
18                CPAP machines), and data on completion of DNR  
19                orders, and identify barriers to obtaining accurate  
20                and timely data related to treatment of such individ-  
21                uals;

22                (4) solicit input from public health officials,  
23                community-connected organizations, health care pro-  
24                viders, State and local agency officials, Tribal offi-

1 cials, and other experts on barriers to, and best  
2 practices for, collecting demographic data; and

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

5 (d) REPORT.—Not later than 1 year after the date  
6 of enactment of this Act, the Commission shall submit a  
7 written report of its findings and recommendations to  
8 Congress and post such report on the website of the De-  
9 partment of Health and Human Services. Such reports  
10 shall contain information concerning—

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

24 (2) how to collect, process, and disclose to the  
25 public the data described in paragraph (1) in a way



1 that maintains individual privacy while helping di-  
2 rect the State, local, and Tribal response to public  
3 health emergencies;

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

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

14 (5) to the extent possible, an analysis of sex,  
15 gender, sexual orientation, and gender identity dis-  
16 parities in COVID–19 treatment and mortality;

17 (6) an analysis of COVID–19 treatment of indi-  
18 viduals with disabilities, including equity of access to  
19 treatment and equipment and intersections of dis-  
20 ability status with other demographic factors, includ-  
21 ing race, and recommendations for how to improve  
22 transparency and equity of treatment for such indi-  
23 viduals during the COVID–19 public health emer-  
24 gency and future emergencies;

1           (7) how to support State, local, and Tribal ca-  
2       capacity to eliminate barriers to vaccinations, testing,  
3       and treatment during the COVID–19 pandemic and  
4       future public health emergencies; and

5           (8) to the extent possible, an analysis of Fed-  
6       eral Government policies that disparately exacerbate  
7       the COVID–19 impact, and recommendations to im-  
8       prove racial and other demographic disparities in  
9       health outcomes.

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

○