

117TH CONGRESS  
1ST SESSION

**S.** \_\_\_\_\_

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

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IN THE SENATE OF THE UNITED STATES

Ms. WARREN (for herself, Ms. BALDWIN, Mr. BLUMENTHAL, Mr. BOOKER, Mr. KAINE, Ms. KLOBUCHAR, Mr. MARKEY, Mr. MERKLEY, Ms. ROSEN, Ms. STABENOW, Mr. VAN HOLLEN, and Mr. WYDEN) introduced the following bill; which was read twice and referred to the Committee on

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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”.

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

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

16 (3) Historically, structures and systems such as  
17 racism, ableism, and class oppression have rendered  
18 affected Black and Brown communities more vulner-  
19 able to inequities and have prevented people from  
20 achieving optimal health even when there is not a  
21 crisis of pandemic proportions, highlighting that rac-  
22 ism and not race presents as a risk factor driving  
23 inequities in illness and death.

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

1 health care information, and greater perceived dis-  
2 crimination in health care place Black, Brown, and  
3 AI/AN communities, individuals with disabilities,  
4 and Limited English Proficient individuals at great-  
5 er risk of receiving delayed, and perhaps poorer,  
6 health care.

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

20 (6) Black, Hispanic/Latinx, and AI/AN commu-  
21 nities experience higher rates of chronic disease and  
22 disabilities, such as diabetes, hypertension, and asth-  
23 ma, than non-Hispanic White communities, which  
24 predisposes them to greater risk of complications  
25 and mortality should they contract COVID-19.

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

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

22           (9) Further, it is critical to disaggregate data  
23 further by ancestry to address disparities among  
24 Asian American, Native Hawaiian, and Pacific Is-  
25 lander groups. According to the National Equity

1 Atlas, while 13 percent of the Asian population over-  
2 all lived in poverty in 2015, 39 percent of Burmese  
3 people, 29 percent of Hmong people, and 21 percent  
4 of Pacific Islanders lived in poverty.

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

18 (11) Without clear understanding of how  
19 COVID-19 impacts marginalized racial and ethnic  
20 communities, there will be exacerbated risk of en-  
21 dangering the most historically vulnerable of our  
22 Nation. A recent national study found that Amer-  
23 ican Indian/Alaska Natives were 3.5 times more like-  
24 ly to be infected with COVID-19, however that data  
25 excluded 27 States as they had reported less than 70

1       percent of race/ethnicity data to the Centers for Dis-  
2       ease Control and Prevention making it impossible to  
3       include them in the analysis thus creating a signifi-  
4       cant data gap for understanding the impact of  
5       COVID–19 on this vulnerable population.

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

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

18          (14) To date, race and ethnicity data on  
19       COVID–19 cases, test, hospitalizations, deaths, and  
20       vaccinations is incomplete and lacking. The incon-  
21       sistency of data collection by Federal, State, and  
22       local health authorities poses a threat to analysis  
23       and synthesis of the pandemic impact on Black, His-  
24       panic/Latinx, and AI/AN communities. However, re-  
25       search and medical experts of Historically Black

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

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

18 (16) The dearth of racially and ethnically  
19 disaggregated data reflecting the health of Black,  
20 Hispanic/Latinx, and AI/AN communities underlies  
21 the challenges of a fully informed public health re-  
22 sponse.

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

1 as publicly disclosing it, Black, Hispanic/Latinx, and  
2 AI/AN communities will remain at greater risk of  
3 disease and death.

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

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

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

18 (2) to State and territorial public health agen-  
19 cies, distributed proportionally based on the total  
20 population of their residents who are enrolled in  
21 Medicaid or who have no health insurance,  
22 \$15,000,000;

23 (3) to the Indian Health Service, Indian Tribes  
24 and Tribal organizations (as defined in section 4 of  
25 the Indian Self-Determination and Education Assist-

1           ance Act), and urban Indian organizations (as de-  
2           fined in section 4 of the Indian Health Care Im-  
3           provement Act), \$3,000,000;

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

6           (5) to the Food and Drug Administration,  
7           \$5,000,000;

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

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

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

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

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

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

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

11          (4) Data related to COVID–19 vaccinations, in-  
12          cluding—

13                 (A) the number of vaccines administered;

14                 (B) the number of vaccinations offered, ac-  
15                 cepted, and refused;

16                 (C) the most common reasons for refusal;

17                 and

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

20          (b) APPLICATION OF STANDARDS.—To the extent  
21          practicable, data collection under this section shall follow  
22          standards developed by the Department of Health and  
23          Human Services Office of Minority Health and be col-  
24          lected, analyzed, and reported in accordance with the  
25          standards promulgated by the Assistant Secretary for

1 Planning and Evaluation under title XXXI of the Public  
2 Health Service Act (42 U.S.C. 300kk et seq.).

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

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

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

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

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

23 (f) SUMMARY.—Not later than 60 days after the date  
24 on which the Secretary certifies that the public health  
25 emergency related to COVID–19 has ended, the Secretary

1 shall make publicly available a summary of the final statis-  
2 tics related to COVID–19.

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

12 (1) describing the testing, hospitalization, mortal-  
13 ity rates, vaccination rates, and preferred lan-  
14 guage of patients associated with COVID–19 by race  
15 and ethnicity; and

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

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

21 **SEC. 5. COMMISSION ON ENSURING DATA FOR HEATH EQ-**  
22 **UITY.**

23 (a) IN GENERAL.—Not later than 30 days after the  
24 date of enactment of this Act, the Secretary shall establish  
25 a commission, to be known as the “Commission on Ensuring

1 ing Data for Health Equity” (referred to in this section  
2 as the “Commission”) to provide clear and robust guid-  
3 ance on how to improve the collection, analysis, and use  
4 of demographic data in responding to future public health  
5 emergencies.

6 (b) MEMBERSHIP AND CHAIRPERSON.—

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

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

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

13 (C) the Commissioner of Food and Drugs;

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

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

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

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

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

24 (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, or an urban Indian  
12 health representative, who shall represent juris-  
13 dictions from different regions of the United  
14 States with relatively high concentrations of  
15 historically marginalized populations, to be ap-  
16 pointed by the Secretary; and

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

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

1 (c) DUTIES.—The Commission shall—

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

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

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

18 (4) solicit input from public health officials,  
19 community-connected organizations, health care pro-  
20 viders, State and local agency officials, Tribal offi-  
21 cials, and other experts on barriers to, and best  
22 practices for, collecting demographic data; and

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

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

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

20 (2) how to collect, process, and disclose to the  
21 public the data described in paragraph (1) in a way  
22 that maintains individual privacy while helping di-  
23 rect the State, local, and Tribal response to public  
24 health emergencies;

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

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

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

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

22           (7) how to support State, local, and Tribal ca-  
23 pacity to eliminate barriers to vaccinations, testing,  
24 and treatment during the COVID–19 pandemic and  
25 future public health emergencies; and

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

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