

117TH CONGRESS
1ST SESSION

S. 512

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

IN THE SENATE OF THE UNITED STATES

MARCH 1, 2021

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 Health, Education, Labor, and Pensions

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, mor-
 13 tality 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.

○