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(Original Signature of Member)

117TH CONGRESS  
1ST SESSION

# H. R.

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To amend the Public Health Service Act to expand, enhance, and improve applicable public health data systems used by the Centers for Disease Control and Prevention, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

Ms. CASTOR of Florida introduced the following bill; which was referred to the Committee on \_\_\_\_\_

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# A BILL

To amend the Public Health Service Act to expand, enhance, and improve applicable public health data systems used by the Centers for Disease Control and Prevention, and for other purposes.

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 “Ensuring Transparent  
5 Honest Information on COVID–19 Act” or the “ETHIC  
6 Act”.

1 **SEC. 2. REQUIRED REPORTING BY STATE, LOCAL, TRIBAL,**  
2 **OR TERRITORIAL GOVERNMENTS REGARD-**  
3 **ING COVID-19.**

4 (a) IN GENERAL.—As a condition on receipt of funds  
5 through a covered grant or cooperative agreement, a  
6 State, local, Tribal, or Territorial government shall agree  
7 to direct the appropriate State, local, Tribal, or Territorial  
8 governmental entity (including any public health depart-  
9 ment thereof) to report to the Centers for Disease Control  
10 and Prevention, with respect to the jurisdiction involved  
11 and COVID-19—

12 (1) on a daily basis, the information listed in  
13 subsection (d); and

14 (2) on a weekly basis, the information listed in  
15 subsection (e).

16 (b) TRIBAL WAIVER.—

17 (1) REVIEW AND DISPOSITION.—Upon the re-  
18 ceipt of a written request from a Tribal government,  
19 or consortia thereof, for a waiver of the conditions  
20 specified in paragraphs (1) and (2) of subsection  
21 (a), the Director of the Centers for Disease Control  
22 and Prevention shall, not later than 30 days after  
23 receipt of such request, approve or deny it.

24 (2) DENIALS.—In the case of a denial of a re-  
25 quest under paragraph (1), the Director of the Cen-  
26 ters for Disease Control and Prevention shall—

1 (A) provide to the requestor a written ex-  
2 planation of the reasons for the denial; and

3 (B) provide the requestor with an oppor-  
4 tunity to correct any deficiencies in the request.

5 (c) COVERED GRANT OR COOPERATIVE AGREE-  
6 MENT.—For purposes of this section, a covered grant or  
7 cooperative agreement is any grant or cooperative agree-  
8 ment awarded under any of the following laws (including  
9 any amendment made thereby):

10 (1) The Coronavirus Preparedness and Re-  
11 sponse Supplemental Appropriations Act, 2020  
12 (Public Law 116–123).

13 (2) The Families First Coronavirus Response  
14 Act (Public Law 116–127).

15 (3) The CARES Act (Public Law 116–136).

16 (4) The Paycheck Protection Program and  
17 Health Care Enhancement Act (Public Law 116–  
18 139).

19 (5) The Consolidated Appropriations Act, 2021  
20 (Public Law 116–260).

21 (d) DAILY REPORTING.—The information to be re-  
22 ported daily pursuant to subsection (a)(1) consists of the  
23 following, disaggregated to the county level if applicable:

24 (1) Demographic characteristics, including, in a  
25 de-identified, disaggregated, and stratified manner,

1 race, ethnicity, age, sex, geographic region, and  
2 other relevant factors of individuals tested for or di-  
3 agnosed with COVID–19, to the extent such infor-  
4 mation is available.

5 (2) The number of adults with a confirmed case  
6 of COVID–19 who are hospitalized in an intensive  
7 care bed.

8 (3) The number of adults with a suspected case  
9 of COVID–19 who are hospitalized in an intensive  
10 care bed.

11 (4) The number of adults with a confirmed case  
12 of COVID–19 who are hospitalized in an inpatient  
13 care bed.

14 (5) The number of adults with a suspected case  
15 of COVID–19 who are hospitalized in an inpatient  
16 care bed.

17 (6) The number of children with a confirmed  
18 case of COVID–19 who are hospitalized in an inten-  
19 sive care bed.

20 (7) The number of children with a suspected  
21 case of COVID–19 who are hospitalized in an inten-  
22 sive care bed.

23 (8) The number of children with a confirmed  
24 case of COVID–19 who are hospitalized in an inpa-  
25 tient care bed.

1           (9) The number of children with a suspected  
2 case of COVID-19 who are hospitalized in an inpa-  
3 tient care bed.

4           (10) Out of the maximum number of beds for  
5 which hospitals are licensed to operate, the percent-  
6 age occupied by confirmed or suspected COVID-19  
7 patients.

8           (11) Total staffed hospital beds.

9           (12) The numbers of diagnostic and serological  
10 tests administered for COVID-19, disaggregated  
11 and stratified by—

12                 (A) the type of test (molecular and anti-  
13 gen); and

14                 (B) the testing positivity rate of each type  
15 of test.

16           (13) The median turnaround time for diag-  
17 nostic tests stratified by molecular and antigen tests.

18           (14) The percentage of new cases of COVID-  
19 19 linked to at least one other case and, if such new  
20 cases are part of a known outbreak, identification of  
21 such outbreak.

22           (15) The rate of transmission of COVID-19.

23           (16) The number of confirmed and probable  
24 deaths as a result of COVID-19, de-identified and

1 stratified by race, ethnicity, age, sex, geographic re-  
2 gion, and other relevant factors.

3 (17) The number of residents in nursing homes  
4 and assisted living facilities with a suspected or con-  
5 firmed case of COVID-19.

6 (18) The number of residents in nursing homes  
7 and assisted living facilities who have died from  
8 COVID-19.

9 (19) The number of staff in nursing homes and  
10 assisted living facilities with a suspected or con-  
11 firmed case of COVID-19.

12 (20) Such other information as the Director of  
13 the Centers for Disease Control and Prevention  
14 deems to be relevant.

15 (e) WEEKLY REPORTING.—The information to be re-  
16 ported weekly pursuant to subsection (a)(2) consists of the  
17 following, disaggregated to the county level if applicable:

18 (1) New infections of health care workers not  
19 confirmed to have contracted COVID-19 outside of  
20 the workplace.

21 (2) The median time between collection of  
22 specimens for diagnostic tests for COVID-19 and  
23 isolation of cases.

24 (3) The percentage of new cases of COVID-19  
25 among quarantined contacts.

1           (4) The following information, in a manner that  
2           is de-identified, and is disaggregated and stratified  
3           by race, ethnicity, age, sex, geographic region, and  
4           other relevant factors, to the extent such informa-  
5           tion is available:

6                   (A) New suspected and confirmed cases of  
7                   COVID-19 per 100,000 individuals.

8                   (B) The percent change in new suspected  
9                   and confirmed cases of COVID-19 per 100,000  
10                  individuals.

11                  (C) The number of COVID-19 vaccine  
12                  doses administered.

13                  (D) The number of individuals receiving a  
14                  first dose of COVID-19 vaccine.

15                  (E) The number of individuals completing  
16                  a vaccination course for COVID-19.

17           (5) The number of COVID-19 vaccine doses re-  
18           ceived by the reporting State, local, Tribal, or Terri-  
19           torial government, disaggregated by supplier.

20           (6) The number of nursing home and assisted  
21           living residents who have received a first dose of  
22           COVID-19 vaccine.

23           (7) The number of nursing home and assisted  
24           living residents who have completed a vaccination  
25           course for COVID-19.

1           (8) Such other information as the Director of  
2           the Centers for Disease Control and Prevention  
3           deems to be relevant.

4           (f) PUBLIC POSTING OF REPORTED DATA.—On a  
5           daily basis, the Director of the Centers for Disease Control  
6           and Prevention shall make the information reported pur-  
7           suant to this section, excluding personally identifiable in-  
8           formation, publicly available on the website of the Centers  
9           for Disease Control and Prevention.

10          (g) APPLICABILITY.—The condition on funding in  
11          subsection (a) applies with respect to the obligation and  
12          expenditure by the Federal Government of funds through  
13          a covered grant or cooperative agreement on or after the  
14          date of enactment of this Act, including with respect to  
15          covered grants and cooperative agreements awarded before  
16          such date.

17       **SEC. 3. STUDY EXAMINING PUBLIC HEALTH DATA AND IN-**  
18                               **FRASTRUCTURE NECESSARY DURING AND**  
19                               **AFTER THE COVID-19 PUBLIC HEALTH EMER-**  
20                               **GENCY.**

21          (a) IN GENERAL.—The Secretary of Health and  
22          Human Services (in this section referred to as the “Sec-  
23          retary”) shall seek to enter into a contract with the Na-  
24          tional Academies of Sciences, Engineering, and Medicine  
25          (referred to in this section as the “National Academies”)

1 not later than 30 days after the date of enactment of this  
2 Act, under which the National Academies agree to conduct  
3 a study with stakeholders from Federal agencies, State,  
4 Tribal, Territorial, and local governments, research insti-  
5 tutions, industry, and nonprofit organizations that would  
6 review the current system for public health data infra-  
7 structure and reporting and provide recommendations on  
8 needed data and system improvements for future  
9 pandemics and ongoing public health needs.

10 (b) SUBMISSION OF REPORT.—The contract under  
11 subsection (a) shall require that the study under such sub-  
12 section be completed, and a report on the resulting rec-  
13 ommendations be submitted to the Secretary, the Com-  
14 mittee on Health, Education, Labor, and Pensions of the  
15 Senate and the Committee on Energy and Commerce of  
16 the House of Representatives, not later than 12 months  
17 after the date the contract was executed.

18 (c) STUDY TOPICS.—The contract under subsection  
19 (a) shall require the study under such subsection to—

20 (1) review the current public health data sys-  
21 tems and the reporting structure for Federal, State,  
22 Tribal, Territorial, and local public health informa-  
23 tion, including vital records;

24 (2) review current standards for reporting,  
25 quality controls, and transparency of the data;

1           (3) examine data gaps and barriers to timely  
2           and accurate reporting and identify ways to fill  
3           those gaps;

4           (4) examine how systems can be accessed and  
5           used by a wide range of users, including external re-  
6           searchers;

7           (5) examine how different data systems interact  
8           and how different data sources can be integrated;

9           (6) examine nontraditional data sources or al-  
10          ternative data gathering methods that could be used  
11          to complement traditionally collected data;

12          (7) identify needed improvements to the public  
13          health data systems and structure, especially with  
14          regard to the needs of Tribal systems;

15          (8) identify core elements of a “minimum data  
16          set” that might be used for State population surveil-  
17          lance, including demographic components that are  
18          necessary to ensure health equity in public health  
19          decision making;

20          (9) examine how surveillance systems can be ex-  
21          plicitly designed to ensure underserved populations  
22          (which may include racial and ethnic minorities, im-  
23          migrants, individuals in nursing homes, other insti-  
24          tutionalized populations, and individuals experi-  
25          encing homelessness) are included in reporting;

1           (10) consider how traditional and nontradi-  
2           tional data might be used to promote health equity  
3           across the United States and reduce racial, Tribal,  
4           and other demographic disparities;

5           (11) examine data gaps and barriers to col-  
6           lecting, analyzing, and using demographic data to  
7           characterize the COVID–19 pandemic for public  
8           health action and research to improve public health  
9           actions and identify ways to fill those gaps; and

10          (12) report on what is known based on existing  
11          data about how COVID–19 is impacting subgroups  
12          of the population with respect to access to testing,  
13          treatment, and vaccination (hospitalization and ac-  
14          cess to drugs and medical equipment), and health  
15          outcomes (morbidity and mortality).

16          (d) DISAGGREGATION OF DATA.—To the extent fea-  
17          sible, the contract under subsection (a) shall require data  
18          to be disaggregated by race, ethnicity, age, gender, dis-  
19          ability, geography, language, socioeconomic status, and  
20          other factors.

21          (e) AUTHORIZATION OF APPROPRIATIONS.—To carry  
22          out this section, there is authorized to be appropriated  
23          \$1,000,000, to remain available until expended.