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117TH CONGRESS
1ST SESSION

H. R. 976

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.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 11, 2021

Ms. CASTOR of Florida (for herself and Ms. UNDERWOOD) introduced the following bill; which was referred to the Committee on Oversight and Reform, and in addition to the Committee on Energy and Commerce, 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 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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Ensuring Transparent Honest Information on COVID–19 Act'' or the ''ETHIC Act''.

SEC. 2. REQUIRED REPORTING BY STATE, LOCAL, TRIBAL, OR TERRITORIAL GOVERNMENTS REGARDING COVID–19.

(a) IN GENERAL.—As a condition on receipt of funds through a covered grant or cooperative agreement, a State, local, Tribal, or Territorial government shall agree to direct the appropriate State, local, Tribal, or Territorial governmental entity (including any public health department thereof) to report to the Centers for Disease Control and Prevention, with respect to the jurisdiction involved and COVID–19—

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

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

(b) TRIBAL WAIVER.—

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

(2) DENIALS.—In the case of a denial of a request under paragraph (1), the Director of the Centers for Disease Control and Prevention shall—

(A) provide to the requestor a written explanation of the reasons for the denial; and

(B) provide the requestor with an opportunity to correct any deficiencies in the request.

(c) COVERED GRANT OR COOPERATIVE AGREEMENT.—For purposes of this section, a covered grant or cooperative agreement is any grant or cooperative agreement awarded under any of the following laws (including any amendment made thereby):

(1) The Coronavirus Preparedness and Response Supplemental Appropriations Act, 2020 (Public Law 116–123).

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

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

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

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

(d) DAILY REPORTING.—The information to be reported daily pursuant to subsection (a)(1) consists of the following, disaggregated to the county level if applicable:

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

race, ethnicity, age, sex, geographic region, and other relevant factors of individuals tested for or diagnosed with COVID–19, to the extent such information is available.

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

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

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

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

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

(7) The number of children with a suspected case of COVID–19 who are hospitalized in an intensive care bed.

(8) The number of children with a confirmed case of COVID–19 who are hospitalized in an inpatient care bed.

(9) The number of children with a suspected case of COVID–19 who are hospitalized in an inpatient care bed.

(10) Out of the maximum number of beds for which hospitals are licensed to operate, the percentage occupied by confirmed or suspected COVID–19 patients.

(11) Total staffed hospital beds.

(12) The numbers of diagnostic and serological tests administered for COVID–19, disaggregated and stratified by—

(A) the type of test (molecular and antigen); and

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

(13) The median turnaround time for diagnostic tests stratified by molecular and antigen tests.

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

(15) The rate of transmission of COVID–19.

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

stratified by race, ethnicity, age, sex, geographic region, and other relevant factors.

(17) The number of residents in nursing homes and assisted living facilities with a suspected or confirmed case of COVID–19.

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

(19) The number of staff in nursing homes and assisted living facilities with a suspected or confirmed case of COVID–19.

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

(e) WEEKLY REPORTING.—The information to be reported weekly pursuant to subsection (a)(2) consists of the following, disaggregated to the county level if applicable:

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

(2) The median time between collection of specimens for diagnostic tests for COVID–19 and isolation of cases.

(3) The percentage of new cases of COVID–19 among quarantined contacts.

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

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

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

(C) The number of COVID–19 vaccine doses administered.

(D) The number of individuals receiving a first dose of COVID–19 vaccine.

(E) The number of individuals completing a vaccination course for COVID–19.

(5) The number of COVID–19 vaccine doses received by the reporting State, local, Tribal, or Territorial government, disaggregated by supplier.

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

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

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

(f) PUBLIC POSTING OF REPORTED DATA.—On a daily basis, the Director of the Centers for Disease Control and Prevention shall make the information reported pursuant to this section, excluding personally identifiable information, publicly available on the website of the Centers for Disease Control and Prevention.

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

SEC. 3. STUDY EXAMINING PUBLIC HEALTH DATA AND INFRASTRUCTURE NECESSARY DURING AND AFTER THE COVID–19 PUBLIC HEALTH EMERGENCY.

(a) IN GENERAL.—The Secretary of Health and Human Services (in this section referred to as the ''Secretary'') shall seek to enter into a contract with the National Academies of Sciences, Engineering, and Medicine (referred to in this section as the ''National Academies'')

not later than 30 days after the date of enactment of this Act, under which the National Academies agree to conduct a study with stakeholders from Federal agencies, State, Tribal, Territorial, and local governments, research institutions, industry, and nonprofit organizations that would review the current system for public health data infrastructure and reporting and provide recommendations on needed data and system improvements for future pandemics and ongoing public health needs.

(b) SUBMISSION OF REPORT.—The contract under subsection (a) shall require that the study under such subsection be completed, and a report on the resulting recommendations be submitted to the Secretary, the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, not later than 12 months after the date the contract was executed.

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

(1) review the current public health data systems and the reporting structure for Federal, State, Tribal, Territorial, and local public health information, including vital records;

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

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

(4) examine how systems can be accessed and used by a wide range of users, including external researchers;

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

(6) examine nontraditional data sources or alternative data gathering methods that could be used to complement traditionally collected data;

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

(8) identify core elements of a ''minimum data set'' that might be used for State population surveillance, including demographic components that are necessary to ensure health equity in public health decision making;

(9) examine how surveillance systems can be explicitly designed to ensure underserved populations (which may include racial and ethnic minorities, immigrants, individuals in nursing homes, other institutionalized populations, and individuals experiencing homelessness) are included in reporting;

(10) consider how traditional and nontraditional data might be used to promote health equity across the United States and reduce racial, Tribal, and other demographic disparities;

(11) examine data gaps and barriers to collecting, analyzing, and using demographic data to characterize the COVID–19 pandemic for public health action and research to improve public health actions and identify ways to fill those gaps; and

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

(d) DISAGGREGATION OF DATA.—To the extent feasible, the contract under subsection (a) shall require data to be disaggregated by race, ethnicity, age, gender, disability, geography, language, socioeconomic status, and other factors.

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

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