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117TH CONGRESS
2D SESSION

H. R. 8481

To amend the Public Health Service Act with respect to public health data accessibility, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JULY 21, 2022

Ms. UNDERWOOD (for herself, Mr. BERA, Ms. CASTOR of Florida, and Ms. DELAURO) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To amend the Public Health Service Act with respect to public health data accessibility, 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 ''Improving Data Accessibility Through Advancements in Public Health Act'' or the ''Improving DATA in Public Health Act''.

SEC. 2. SUPPORTING PUBLIC HEALTH DATA AVAILABILITY AND ACCESS.

(a) DESIGNATION OF PUBLIC HEALTH DATA STANDARDS.—Section 2823(a)(2) of the Public Health Service Act (42 U.S.C. 300hh–33(a)(2)) is amended—

(1) by striking ''In carrying out'' and inserting the following:

''(A) IN GENERAL.—In carrying out'';

(2) by striking ''shall, as appropriate and'' and inserting ''shall, not later than 2 years after the date of enactment of the Improving DATA in Public Health Act,''; and

(3) by adding at the end the following:

''(B) SELECTION OF DATA AND TECHNOLOGY STANDARDS.—The standards designated as described in subparagraph (A) may include standards to improve—

''(i) the exchange of electronic health information for—

''(I) electronic case reporting;

''(II) syndromic surveillance;

''(III) reporting of vital statistics; and

''(IV) reporting test orders and results electronically, including from laboratories;

''(ii) automated electronic reporting to relevant public health data systems of the Centers for Disease Control and Prevention; and

''(iii) such other uses as the Secretary determines appropriate.

''(C) NO DUPLICATIVE EFFORTS.—

''(i) IN GENERAL.—In carrying out the requirements of this paragraph, the Secretary, in consultation with the Office of the National Coordinator for Health Information Technology, may use input gathered (including input and recommendations gathered from the Health Information Technology Advisory Committee), and materials developed, prior to the date of enactment of the Improving DATA in Public Health Act.

''(ii) DESIGNATION OF STANDARDS.—Consistent with sections 13111 and 13112 of the HITECH Act, the data and technology standards designated pursuant to this paragraph shall align with the standards and implementation specifications

adopted by the Secretary pursuant to section 3004, as applicable.

''(D) PRIVACY AND SECURITY.—Nothing in this paragraph shall be construed as modifying applicable Federal or State information privacy or security law.

''(E) CONSIDERATIONS.—Standards designated under this paragraph shall include standards and implementation specifications necessary to ensure the appropriate capture, exchange, access, and use of information regarding race, ethnicity, sex (including sexual orientation and gender identity), disability status, veteran status, housing status, age, functional status, and other elements.''.

(b) STUDY ON LABORATORY INFORMATION STANDARDS.—

(1) IN GENERAL.—Not later than 1 year after the date of enactment of this Act, the Office of the National Coordinator for Health Information Technology shall conduct a study to review the use of standards for electronic ordering and reporting of laboratory test results.

(2) AREAS OF CONCENTRATION.—In conducting the study under paragraph (1), the Office of the Na-

tional Coordinator for Health Information Technology shall—

(A) determine the extent to which clinical laboratories are using standards for electronic ordering and reporting of laboratory test results;

(B) assess trends in laboratory compliance with standards for ordering and reporting laboratory test results and the effect of such trends on the interoperability of laboratory data with public health data systems;

(C) identify challenges related to collection and reporting of demographic and other data elements with respect to laboratory test results;

(D) identify any challenges associated with using or complying with standards and reporting laboratory test results with data elements identified in standards for electronic ordering and reporting of such results; and

(E) review other relevant areas determined appropriate by the Office of the National Coordinator for Health Information Technology.

(3) REPORT.—Not later than 2 years after the date of enactment of this Act, the Office of the National Coordinator for Health Information Tech-

nology shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report concerning the findings of the study conducted under paragraph (1).

(c) SUPPORTING INFORMATION SHARING THROUGH DATA USE AGREEMENTS.—

(1) INTERAGENCY DATA USE AGREEMENTS WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES FOR PUBLIC HEALTH EMERGENCIES.—

(A) IN GENERAL.—The Secretary of Health and Human Services (referred to in this subsection as the ''Secretary'') shall, as appropriate, facilitate the development of, or updates to, memoranda of understanding, data use agreements, or other applicable interagency agreements regarding appropriate access, exchange, and use of public health data among the Centers for Disease Control and Prevention, the Office of the Assistant Secretary for Preparedness and Response, other relevant agencies or offices within the Department of Health and Human Services, and other relevant Federal agencies, in order to prepare for, identify,

monitor, and respond to declared or potential public health emergencies.

(B) REQUIREMENTS.—In carrying out activities pursuant to subparagraph (A), the Secretary shall—

(i) ensure that the agreements and memoranda of understanding described in such subparagraph—

(I) address the methods of granting access to data held by one agency or office with another to support the respective missions of such agencies or offices;

(II) consider minimum necessary principles of data sharing for appropriate use;

(III) include appropriate privacy and cybersecurity protections; and

(IV) are subject to regular updates, as appropriate;

(ii) collaborate with the Centers for Disease Control and Prevention, the Office of the Assistant Secretary for Preparedness and Response, the Office of the Chief Information Officer, and, as appropriate,

the Office of the National Coordinator for Health Information Technology, and other entities within the Department of Health and Human Services; and

(iii) consider the terms and conditions of any existing data use agreements with other public or private entities and any need for updates to such existing agreements, consistent with paragraph (2).

(2) DATA USE AGREEMENTS WITH EXTERNAL ENTITIES.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and the Assistant Secretary for Preparedness and Response, may update memoranda of understanding, data use agreements, or other applicable agreements and contracts to improve appropriate access, exchange, and use of public health data among the Centers for Disease Control and Prevention, the Office of the Assistant Secretary for Preparedness and Response, and external entities, including State, Tribal, local, and territorial health departments, laboratories, hospitals and other health care providers, electronic health records vendors, and other entities, as applicable and appropriate, in

order to prepare for, identify, monitor, and respond to declared or potential public health emergencies.

(3) REPORT.—Not later than 90 days after the date of enactment of this Act, the Secretary shall report to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives on the status of the memoranda of understanding and other agreements under this subsection.

(d) IMPROVING INFORMATION SHARING AND AVAILABILITY OF PUBLIC HEALTH DATA.—Part A of title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following:

"SEC. 310B. IMPROVING INFORMATION SHARING AND AVAILABILITY OF PUBLIC HEALTH DATA.

''(a) IN GENERAL.—The Secretary acting through the Director of the Centers for Disease Control and Prevention (in this section referred to as the 'Secretary') may require the reporting of public health and health care data and information to the Centers for Disease Control and Prevention by—

''(1) health care providers and facilities, including pharmacies;

''(2) public health, clinical, and other laboratories and diagnostic testing entities;

''(3) State, local, and Tribal health departments; and

''(4) other entities, as determined appropriate by the Secretary.

''(b) CONTENT, FORM, MANNER, AND FREQUENCY.—

''(1) COLLABORATION.—The Secretary shall collaborate with representatives of State, local, and Tribal health departments and other entities on determining the content, form, manner, and frequency of the reporting of public health and health care data and information required pursuant to subsection (a).

''(2) SIMULTANEOUS REPORTING.—In determining the content, form, manner, and frequency of the reporting of public health and health care data and information pursuant to subsection (a), where a disease, condition, or related event is reportable under applicable State or local law, the Secretary shall require the data and information to be reported first or simultaneously to the appropriate State or local jurisdiction.

''(3) ALIGNMENT WITH STANDARDS AND IMPLEMENTATION SPECIFICATIONS.—The content, form, manner, and frequency requirements required pursuant to this section shall align with the standards and implementation specifications adopted by the Secretary under section 3004, where applicable.

''(4) REASONABLE EFFORTS TO LIMIT REPORTING.—The Secretary shall make reasonable efforts to limit the public health and health care data and information required to be reported under this section to the minimum necessary to accomplish the intended public health purpose.

''(5) IMPLEMENTATION AND REGULATIONS.—The Secretary—

''(A) may promulgate by regulation the content, form, manner, and frequency in which public health and health care data and information is required to be reported under this section; and

''(B) in the event of a public health emergency declared under section 319, or where the Secretary determines there is a significant potential for such an emergency to exist, may issue such requirements—

"(i) by guidance in accordance with this section; and

"(ii) without regard to the procedures otherwise required by section 553 of title 5, United States Code.

"(c) ENSURING THAT DATA IS ACCESSIBLE IN A TIMELY MANNER TO STATE, LOCAL, AND TRIBAL HEALTH AUTHORITIES.—

"(1) COLLABORATION.—The Secretary shall collaborate with representatives of State, local, and Tribal health departments, and entities representing such departments, to ensure that data and information that is collected by the Centers for Disease Control and Prevention pursuant to this section are accessible, as appropriate, in a timely manner, to State, local, and Tribal health authorities.

"(2) RULES OF CONSTRUCTION.—Nothing in this section shall be construed—

"(A) to prevent any Federal agency, State, local, or Tribal health department, or other entity from collecting data or information under other applicable law; or

"(B) to limit the authority of the Centers for Disease Control and Prevention to share

public health surveillance data with State, local, or Tribal health authorities.

''(3) REASONABLE EFFORTS TO REDUCE REPORTING BURDENS AND POTENTIAL DUPLICATION.—The Secretary shall make reasonable efforts to collaborate with representatives of Federal agencies and State, local, and Tribal health departments to reduce reporting burdens and potential duplication of reporting requirements. Such efforts may include ensuring simultaneous sharing of data and information described in subsection (b) with State, local, and Tribal public health agencies.

''(d) CONFIDENTIALITY AND PROTECTION OF DATA.—Any identifiable, sensitive information (as defined in section 301(d)) reported to the Centers for Disease Control and Prevention pursuant to this section shall not be further disclosed or provided to any other individual or party, including any party involved in civil, criminal, or administrative litigation, except—

''(1) as necessary for public health purposes, including with relevant Federal, State, local, or tribal public health authorities;

''(2) as required under section 552a(d)(1) of title 5, United States Code;

''(3) as required by applicable Federal laws, excluding instances of disclosure in any Federal, State, or local civil, criminal, administrative, legislative, or other proceeding; or

''(4) with the consent of each individual to whom the information pertains.

''(e) EXEMPTION OF CERTAIN PUBLIC HEALTH DATA FROM DISCLOSURE.—The Secretary may exempt from disclosure under section 552(b)(3) of title 5, United States Code, public health and health care data and information collected by the Centers for Disease Control and Prevention pursuant to this section or any other authority under which the Centers collects public health or health care data and information if—

''(1) an individual is identified through such data or information; or

''(2) there is at least a very small risk, as determined by current scientific practices or statistical methods, that some combination of the data or information, the request for disclosure under such section 552(b)(3), and other available data sources or the application of technology could be used to deduce the identity of the individuals to which such data or information pertains.

"SEC. 310C. PUBLIC HEALTH INFORMATION SHARING AND AVAILABILITY ADVISORY COMMITTEE.

''(a) ESTABLISHMENT.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall establish an advisory committee, to be known as the Public Health Information Sharing and Availability Advisory Committee, to advise, and make recommendations to, the Director with respect to the implementation of public health and health care data and information reporting and sharing under section 310B.

''(b) MEMBERSHIP.—The membership of the advisory committee established pursuant to this section shall include—

''(1) individuals with subject matter expertise or experience in the following areas of public health and health care data and information, including—

''(A) State, territorial, local, and Tribal health department data systems or practices; and

''(B) health care data;

''(2) ex officio members, including from relevant Federal agencies such as the Office of the National Coordinator for Health Information Technology, the Centers for Medicare & Medicaid Services, the Centers for Disease Control and Prevention, and the Office of the Assistant Secretary for Health;

''(3) representatives of national organizations, including the Council of State and Territorial Epidemiologists, the Association of Public Health Laboratories, the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Big Cities Health Coalition; and

''(4) such additional members as the Secretary deems appropriate.

''(c) FACA APPLICABILITY.—The advisory committee established pursuant to this section is deemed to be an advisory committee subject to the Federal Advisory Committee Act.''.

(e) IMPROVING PUBLIC HEALTH DATA COLLECTION.—

(1) IN GENERAL.—The Secretary of Health and Human Services (referred to in this subsection as the ''Secretary'') shall award grants, contracts, or cooperative agreements to eligible entities for purposes of identifying, developing, or disseminating best practices in the collection of electronic health information and the use of designated data standards and implementation specifications—

(A) to improve the quality and completeness of data, including demographic data, col-

lected, accessed, or used for public health purposes; and

(B) to address health disparities and related health outcomes.

(2) ELIGIBLE ENTITIES.—To be eligible to receive an award under this subsection an entity shall—

(A) be a health care provider, academic medical center, community-based organization, State, local governmental entity, Indian Tribe or Tribal organization (as such terms are defined in section 4 of the Indian Self Determination and Education Assistance Act (25 U.S.C. 5304)), Urban Indian organization (as defined in section 4 of the Indian Health Care Improvement Act (25 U.S.C. 1603)), or other appropriate public or private nonprofit entity, or a consortia of any such entities; and

(B) submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require.

(3) ACTIVITIES.—Entities receiving awards under this subsection shall use such award to develop and test best practices for training health care providers to use standards and implementation spec-

ifications that assist in the capture, access, exchange, and use of electronic health information, including demographic information, disability status, veteran status, housing status, functional status, and other data elements. Such activities shall, at a minimum, include—

(A) improving, understanding, and using data standards and implementation specifications;

(B) developing or identifying methods to improve communication with patients in a culturally and linguistically appropriate manner, including to better capture information related to demographics of such individuals;

(C) developing methods for accurately categorizing and recording patient responses using available data standards;

(D) educating providers regarding the utility of such information for public health purposes and the importance of accurate collection and recording of such data; and

(E) other activities, as the Secretary determines appropriate.

(4) REPORTING.—

(A) REPORTING BY AWARD RECIPIENTS.—Each recipient of an award under this subsection shall submit to the Secretary a report on the results of best practices identified, developed, or disseminated through such award.

(B) REPORT TO CONGRESS.—Not later than 1 year after the completion of the program under this subsection, the Secretary shall submit a report to Congress on the success of the best practices developed under such program, opportunities for further dissemination of such best practices, and recommendations for improving the capture, access, exchange, and use of information to improve public health and reduce health disparities.

(5) NONDUPLICATION OF EFFORTS.—The Secretary shall ensure that the activities and programs carried out under this subsection are free of unnecessary duplication of effort.

(6) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated $10,000,000 for each of fiscal years 2023 through 2025 to carry out this subsection.

(f) INFORMATION COLLECTION.—Section 319D(a) of the Public Health Service Act (42 U.S.C. 247d–4(a)) is amended by adding at the end the following:

"(5) INFORMATION COLLECTION.—Subchapter I of chapter 35 of title 44, United States Code, shall not apply to information collection by the Centers for Disease Control and Prevention, including the Agency for Toxic Substances and Disease Registry, that are part of investigations, research, surveillance, or evaluations undertaken for public health purposes.".

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