

118TH CONGRESS
1ST SESSION

S. 3545

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

IN THE SENATE OF THE UNITED STATES

DECEMBER 14, 2023

Mr. KAINE (for himself, Mr. MURPHY, and Ms. SMITH) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act with respect to public health data accessibility, 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 “Improving Data Acces-
5 sibility Through Advancements in Public Health Act” or
6 the “Improving DATA in Public Health Act”.

7 **SEC. 2. SUPPORTING PUBLIC HEALTH DATA AVAILABILITY**
8 **AND ACCESS.**

9 (a) DESIGNATION OF PUBLIC HEALTH DATA STAND-
10 ARDS.—Section 2823(a)(2) of the Public Health Service

1 Act (42 U.S.C. 300hh–33(a)(2)) is amended by adding at
2 the end the following:

3 “(D) SELECTION OF DATA AND TECH-
4 NOLOGY STANDARDS.—The standards des-
5 ignated as described in subparagraph (A) may
6 include standards to improve—

7 “(i) the exchange of electronic health
8 information for—

9 “(I) electronic case reporting;

10 “(II) syndromic surveillance;

11 “(III) reporting of vital statistics;

12 and

13 “(IV) reporting test orders and
14 results electronically, including from
15 laboratories;

16 “(ii) automated electronic reporting to
17 relevant public health data systems of the
18 Centers for Disease Control and Preven-
19 tion; and

20 “(iii) such other uses as the Secretary
21 determines appropriate.

22 “(E) CONSIDERATIONS.—Standards des-
23 ignated under this paragraph shall include
24 standards and implementation specifications
25 necessary to ensure the appropriate capture, ex-

1 change, access, and use of information regard-
 2 ing race, ethnicity, sex (including sexual ori-
 3 entation and gender identity), disability status,
 4 veteran status, housing status, age, functional
 5 status, and other elements.”.

6 (b) IMPROVING INFORMATION SHARING AND AVAIL-
 7 ABILITY OF PUBLIC HEALTH DATA.—Section 310B of the
 8 Public Health Service Act (42 U.S.C. 242u) is amended
 9 to read as follows:

10 **“SEC. 310B. IMPROVING INFORMATION SHARING AND**
 11 **AVAILABILITY OF PUBLIC HEALTH DATA.**

12 “(a) IN GENERAL.—The Secretary acting through
 13 the Director of the Centers for Disease Control and Pre-
 14 vention (in this section referred to as the ‘Secretary’) may
 15 require the reporting of public health and health care data
 16 and information to the Centers for Disease Control and
 17 Prevention by—

18 “(1) health care providers and facilities, includ-
 19 ing pharmacies;

20 “(2) public health, clinical, and other labora-
 21 tories and diagnostic testing entities;

22 “(3) State, local, and Tribal health depart-
 23 ments; and

24 “(4) other entities, as determined appropriate
 25 by the Secretary.

1 “(b) CONTENT, FORM, MANNER, AND FRE-
2 QUENCY.—

3 “(1) COLLABORATION.—The Secretary shall
4 collaborate with representatives of State, local, and
5 Tribal health departments and other entities on de-
6 termining the content, form, manner, and frequency
7 of the reporting of public health and health care
8 data and information required pursuant to sub-
9 section (a).

10 “(2) SIMULTANEOUS REPORTING.—In deter-
11 mining the content, form, manner, and frequency of
12 the reporting of public health and health care data
13 and information pursuant to subsection (a), where a
14 disease, condition, or related event is reportable
15 under applicable State or local law, the Secretary
16 shall require the data and information to be reported
17 first or simultaneously to the appropriate State or
18 local jurisdiction.

19 “(3) ALIGNMENT WITH STANDARDS AND IM-
20 PLEMENTATION SPECIFICATIONS.—The content,
21 form, manner, and frequency requirements required
22 pursuant to this section shall align with the stand-
23 ards and implementation specifications adopted by
24 the Secretary under section 3004, where applicable.

1 “(4) REASONABLE EFFORTS TO LIMIT REPORT-
2 ING.—The Secretary shall make reasonable efforts
3 to limit the public health and health care data and
4 information required to be reported under this sec-
5 tion to the minimum necessary to accomplish the in-
6 tended public health purpose.

7 “(5) IMPLEMENTATION AND REGULATIONS.—
8 The Secretary—

9 “(A) may promulgate by regulation the
10 content, form, manner, and frequency in which
11 public health and health care data and informa-
12 tion is required to be reported under this sec-
13 tion; and

14 “(B) in the event of a public health emer-
15 gency declared under section 319, or where the
16 Secretary determines there is a significant po-
17 tential for such an emergency to exist, may
18 issue such requirements—

19 “(i) by guidance in accordance with
20 this section; and

21 “(ii) without regard to the procedures
22 otherwise required by section 553 of title
23 5, United States Code.

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

4 “(1) COLLABORATION.—The Secretary shall
5 collaborate with representatives of State, local, and
6 Tribal health departments, and entities representing
7 such departments, to ensure that data and informa-
8 tion that is collected by the Centers for Disease Con-
9 trol and Prevention pursuant to this section are ac-
10 cessible, as appropriate, in a timely manner, to
11 State, local, and Tribal health authorities.

12 “(2) RULES OF CONSTRUCTION.—Nothing in
13 this section shall be construed—

14 “(A) to prevent any Federal agency, State,
15 local, or Tribal health department, or other en-
16 tity from collecting data or information under
17 other applicable law; or

18 “(B) to limit the authority of the Centers
19 for Disease Control and Prevention to share
20 public health surveillance data with State, local,
21 or Tribal health authorities.

22 “(3) REASONABLE EFFORTS TO REDUCE RE-
23 PORTING BURDENS AND POTENTIAL DUPLICA-
24 TION.—The Secretary shall make reasonable efforts
25 to collaborate with representatives of Federal agen-

1 cies and State, local, and Tribal health departments
2 to reduce reporting burdens and potential duplica-
3 tion of reporting requirements. Such efforts may in-
4 clude ensuring simultaneous sharing of data and in-
5 formation described in subsection (b) with State,
6 local, and Tribal public health authorities.

7 “(d) CONFIDENTIALITY AND PROTECTION OF
8 DATA.—Any identifiable, sensitive information reported to
9 the Centers for Disease Control and Prevention pursuant
10 to this section shall not be further disclosed or provided
11 to any other individual or party, including any party in-
12 volved in civil, criminal, or administrative litigation, ex-
13 cept—

14 “(1) as necessary for public health purposes, in-
15 cluding with relevant Federal, State, local, or tribal
16 public health authorities;

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

19 “(3) as required by applicable Federal laws, ex-
20 cluding instances of disclosure in any Federal, State,
21 or local civil, criminal, administrative, legislative, or
22 other proceeding; or

23 “(4) with the consent of each individual to
24 whom the information pertains.

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

9 “(1) an individual is identified through such
 10 data or information; or

11 “(2) there is at least a very small risk, as deter-
 12 mined by current scientific practices or statistical
 13 methods, that some combination of the data or in-
 14 formation, the request for disclosure under such sec-
 15 tion 552(b)(3), and other available data sources or
 16 the application of technology could be used to de-
 17 duce the identity of the individuals to which such
 18 data or information pertains.”.

19 (c) PUBLIC HEALTH INFORMATION SHARING AND
 20 AVAILABILITY ADVISORY COMMITTEE.—Part A of title III
 21 of the Public Health Service Act (42 U.S.C. 241 et seq.)
 22 is amended by adding at the end the following:

1 **“SEC. 310C. PUBLIC HEALTH INFORMATION SHARING AND**
2 **AVAILABILITY ADVISORY COMMITTEE.**

3 “(a) ESTABLISHMENT.—The Secretary, acting
4 through the Director of the Centers for Disease Control
5 and Prevention, shall establish an advisory committee, to
6 be known as the Public Health Information Sharing and
7 Availability Advisory Committee, to advise, and make rec-
8 ommendations to, the Director with respect to the imple-
9 mentation of public health and health care data and infor-
10 mation reporting and sharing under section 310B.

11 “(b) MEMBERSHIP.—The membership of the advisory
12 committee established pursuant to this section shall in-
13 clude—

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

17 “(A) State, territorial, local, and Tribal
18 health department data systems or practices;
19 and

20 “(B) health care data;

21 “(2) ex officio members, including from relevant
22 Federal agencies such as the Office of the National
23 Coordinator for Health Information Technology, the
24 Centers for Medicare & Medicaid Services, the Cen-
25 ters for Disease Control and Prevention, and the Of-
26 fice of the Assistant Secretary for Health;

1 “(3) representatives of national organizations,
2 including the Council of State and Territorial Epi-
3 demiologists, the Association of Public Health Lab-
4 oratories, the Association of State and Territorial
5 Health Officials, the National Association of County
6 and City Health Officials, and the Big Cities Health
7 Coalition; and

8 “(4) such additional members as the Secretary
9 determines appropriate.

10 “(c) FACA APPLICABILITY.—The advisory com-
11 mittee established pursuant to this section is deemed to
12 be an advisory committee subject to the Federal Advisory
13 Committee Act.”.

14 (d) IMPROVING PUBLIC HEALTH DATA COLLEC-
15 TION.—

16 (1) IN GENERAL.—The Secretary of Health and
17 Human Services (referred to in this subsection as
18 the “Secretary”) shall award grants, contracts, or
19 cooperative agreements to eligible entities for pur-
20 poses of identifying, developing, or disseminating
21 best practices in the collection of electronic health
22 information and the use of designated data stand-
23 ards and implementation specifications—

24 (A) to improve the quality and complete-
25 ness of data, including demographic data, col-

1 lected, accessed, or used for public health pur-
2 poses; and

3 (B) to address health disparities and re-
4 lated health outcomes.

5 (2) ELIGIBLE ENTITIES.—To be eligible to re-
6 ceive an award under this subsection an entity
7 shall—

8 (A) be a health care provider, academic
9 medical center, community-based organization,
10 State, local governmental entity, Indian Tribe
11 or Tribal organization (as such terms are de-
12 fined in section 4 of the Indian Self Determina-
13 tion and Education Assistance Act (25 U.S.C.
14 5304)), Urban Indian organization (as defined
15 in section 4 of the Indian Health Care Improve-
16 ment Act (25 U.S.C. 1603)), or other appro-
17 priate public or private nonprofit entity, or a
18 consortia of any such entities; and

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

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

1 ifications that assist in the capture, access, ex-
2 change, and use of electronic health information, in-
3 cluding demographic information, disability status,
4 veteran status, housing status, functional status,
5 and other data elements. Such activities shall, at a
6 minimum, include—

7 (A) improving, understanding, and using
8 data standards and implementation specifica-
9 tions;

10 (B) developing or identifying methods to
11 improve communication with patients in a cul-
12 turally and linguistically appropriate manner,
13 including to better capture information related
14 to demographics of such individuals;

15 (C) developing methods for accurately cat-
16 egorizing and recording patient responses using
17 available data standards;

18 (D) educating providers regarding the util-
19 ity of such information for public health pur-
20 poses and the importance of accurate collection
21 and recording of such data; and

22 (E) other activities, as the Secretary deter-
23 mines appropriate.

24 (4) REPORTING.—

1 (A) REPORTING BY AWARD RECIPIENTS.—

2 Each recipient of an award under this sub-
3 section shall submit to the Secretary a report
4 on the results of best practices identified, devel-
5 oped, or disseminated through such award.

6 (B) REPORT TO CONGRESS.—Not later
7 than 1 year after the completion of the program
8 under this subsection, the Secretary shall sub-
9 mit a report to Congress on the success of the
10 best practices developed under such program,
11 opportunities for further dissemination of such
12 best practices, and recommendations for im-
13 proving the capture, access, exchange, and use
14 of information to improve public health and re-
15 duce health disparities.

16 (5) NONDUPLICATION OF EFFORTS.—The Sec-
17 retary shall ensure that the activities and programs
18 carried out under this subsection are free of unnec-
19 essary duplication of effort.

20 (6) AUTHORIZATION OF APPROPRIATIONS.—

21 There is authorized to be appropriated \$10,000,000
22 for each of fiscal years 2024 through 2026 to carry
23 out this subsection.

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

4 “(5) INFORMATION COLLECTION.—Subchapter
5 I of chapter 35 of title 44, United States Code, shall
6 not apply to information collection by the Centers
7 for Disease Control and Prevention, including the
8 Agency for Toxic Substances and Disease Registry,
9 that are part of investigations, research, surveil-
10 lance, or evaluations undertaken for public health
11 purposes under any available authority.”.

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