

117TH CONGRESS
2D SESSION

S. _____

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

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

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”.

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

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

6 (1) by striking “In carrying out” and inserting
7 the following:

8 “(A) IN GENERAL.—In carrying out”; and

9 (2) by striking “shall, as appropriate and” and
10 inserting “shall, not later than 2 years after the date
11 of enactment of the Improving DATA in Public
12 Health Act,”; and

13 (3) by adding at the end the following:

14 “(B) SELECTION OF DATA AND TECH-
15 NOLOGY STANDARDS.—The standards des-
16 igned as described in subparagraph (A) may
17 include standards to improve—

18 “(i) the exchange of electronic health
19 information for—

20 “(I) electronic case reporting;

21 “(II) syndromic surveillance;

22 “(III) reporting of vital statistics;

23 and

24 “(IV) reporting test orders and
25 results electronically, including from
26 laboratories;

1 “(ii) automated electronic reporting to
2 relevant public health data systems of the
3 Centers for Disease Control and Preven-
4 tion; and

5 “(iii) such other use cases as the Sec-
6 retary determines appropriate.

7 “(C) NO DUPLICATIVE EFFORTS.—

8 “(i) IN GENERAL.—In carrying out
9 the requirements of this paragraph, the
10 Secretary, in consultation with the Office
11 of the National Coordinator for Health In-
12 formation Technology, may use input gath-
13 ered (including input and recommendations
14 gathered from the Health Information
15 Technology Advisory Committee), and ma-
16 terials developed, prior to the date of en-
17 actment of the Improving DATA in Public
18 Health Act.

19 “(ii) DESIGNATION OF STANDARDS.—
20 Consistent with sections 13111 and 13112
21 of the HITECH Act, the data and tech-
22 nology standards designated pursuant to
23 this paragraph shall align with the stand-
24 ards and implementation specifications

1 previously adopted by the Secretary pursu-
2 ant to section 3004, as applicable.

3 “(D) PRIVACY AND SECURITY.—Nothing
4 in this paragraph shall be construed as modi-
5 fying applicable Federal or State information
6 privacy or security law.

7 “(E) CONSIDERATIONS.—Standards des-
8 ignated under this paragraph shall include
9 standards and implementation specifications
10 necessary to ensure the appropriate capture, ex-
11 change, access, and use, of information regard-
12 ing race, ethnicity, sex (including sexual ori-
13 entation and gender identity), disability status,
14 veteran status, housing status, age, functional
15 status, and other elements.”.

16 (b) STUDY ON LABORATORY INFORMATION STAND-
17 ARDS.—

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

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

1 tional Coordinator for Health Information Tech-
2 nology shall—

3 (A) determine the extent to which clinical
4 laboratories are using standards for electronic
5 ordering and reporting of laboratory test re-
6 sults;

7 (B) assess trends in laboratory compliance
8 with standards for ordering and reporting lab-
9 oratory test results and the effect of such
10 trends on the interoperability of laboratory data
11 with public health data systems;

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

15 (D) identify any challenges associated with
16 using or complying with standards and report-
17 ing laboratory test results with data elements
18 identified in standards for electronic ordering
19 and reporting of such results; and

20 (E) review other relevant areas determined
21 appropriate by the Office of the National Coor-
22 dinator for Health Information Technology.

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

1 nology shall submit to the Committee on Health,
2 Education, Labor, and Pensions of the Senate and
3 the Committee on Energy and Commerce of the
4 House of Representatives a report concerning the
5 findings of the study conducted under paragraph
6 (1).

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

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

12 (A) IN GENERAL.—The Secretary of
13 Health and Human Services (referred to in this
14 subsection as the “Secretary”) shall, as appro-
15 priate, facilitate the development of, or updates
16 to, memoranda of understanding, data use
17 agreements, or other applicable interagency
18 agreements regarding appropriate access, ex-
19 change, and use of public health data between
20 the Centers for Disease Control and Prevention,
21 the Office of the Assistant Secretary for Pre-
22 paredness and Response, other relevant agen-
23 cies or offices within the Department of Health
24 and Human Services, and other relevant Fed-
25 eral agencies, in order to prepare for, identify,

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

3 (B) REQUIREMENTS.—In carrying out ac-
4 tivities pursuant to subparagraph (A), the Sec-
5 retary shall—

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

9 (I) address the methods of grant-
10 ing access to data held by one agency
11 or office with another to support the
12 respective missions of such agencies
13 or offices;

14 (II) consider minimum necessary
15 principles of data sharing for appro-
16 priate use;

17 (III) include appropriate privacy
18 and cybersecurity protections; and

19 (IV) are subject to regular up-
20 dates, as appropriate;

21 (ii) collaborate with the Centers for
22 Disease Control and Prevention, the Office
23 of the Assistant Secretary for Prepared-
24 ness and Response, the Office of the Chief
25 Information Officer, and, as appropriate,

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

5 (iii) consider the terms and conditions
6 of any existing data use agreements with
7 other public or private entities and any
8 need for updates to such existing agree-
9 ments, consistent with paragraph (2).

10 (2) DATA USE AGREEMENTS WITH EXTERNAL
11 ENTITIES.—The Secretary, acting through the Di-
12 rector of the Centers for Disease Control and Pre-
13 vention and the Assistant Secretary for Prepared-
14 ness and Response, may update memoranda of un-
15 derstanding, data use agreements, or other applica-
16 ble agreements and contracts to improve appropriate
17 access, exchange, and use of public health data be-
18 tween the Centers for Disease Control and Preven-
19 tion and the Office of the Assistant Secretary for
20 Preparedness and Response and external entities, in-
21 cluding State, Tribal, and territorial health depart-
22 ments, laboratories, hospitals and other health care
23 providers, electronic health records vendors, and
24 other entities, as applicable and appropriate, in

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

3 (3) REPORT.—Not later than 90 days after the
4 date of enactment of this Act, the Secretary shall re-
5 port to the Committee on Health, Education, Labor,
6 and Pensions of the Senate and the Committee on
7 Energy and Commerce of the House of Representa-
8 tives on the status of the agreements under this sub-
9 section.

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

14 **“SEC. 310B. IMPROVING INFORMATION SHARING AND**
15 **AVAILABILITY OF PUBLIC HEALTH DATA.**

16 “(a) IN GENERAL.—The Secretary, acting through
17 the Director of the Centers for Disease Control and Pre-
18 vention, may require the reporting of public health and
19 health care data and information to the Centers for Dis-
20 ease Control and Prevention by—

21 “(1) health care providers and facilities, includ-
22 ing pharmacies;

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

1 “(3) State, local, and Tribal health depart-
2 ments;

3 “(4) health information exchanges and health
4 information networks; and

5 “(5) other entities, as determined by the Sec-
6 retary.

7 “(b) CONTENT, FORM, AND MANNER.—The Sec-
8 retary shall prescribe the content, form, manner, and fre-
9 quency of the reporting of public health and health care
10 data and information required by subsection (a), including
11 necessary demographic data or other data elements that
12 the Secretary determines is necessary for public health
13 surveillance under this section. The Secretary may collabo-
14 rate with representatives of State, local, and Tribal health
15 departments and other entities, in developing the content,
16 form, manner, and frequency requirement under this sub-
17 section. Such requirements shall align with the standards
18 and implementation specifications adopted by the Sec-
19 retary under section 3004, as applicable.

20 “(c) DECREASED BURDEN.—The Secretary shall
21 make reasonable efforts to limit public health and health
22 care data and information reported under this section to
23 the minimum necessary information needed to accomplish
24 the intended public health purpose.

1 “(d) ACCESS BY RELEVANT PUBLIC HEALTH AU-
2 THORITIES.—The Secretary shall collaborate with rep-
3 resentatives of State, local, and Tribal health depart-
4 ments, and entities representing such departments to en-
5 sure data collected under this section is accessible, as ap-
6 propriate, to State, local, or Tribal health authorities.
7 Nothing in this section shall be construed to limit the au-
8 thority to share public health surveillance data with State,
9 local, or Tribal health authorities.

10 “(e) EXEMPTION OF CERTAIN PUBLIC HEALTH
11 DATA FROM DISCLOSURE.—The Secretary, acting
12 through the Director of the Centers for Disease Control
13 and Prevention, may exempt from disclosure under section
14 552(b)(3) of title 5, United States Code, public health
15 data that are collected by the Centers for Disease Control
16 and Prevention, if—

17 “(1) an individual is identified through such
18 data; or

19 “(2) there is at least a very small risk, as deter-
20 mined by current scientific practices or statistical
21 methods, that some combination of the information,
22 the request, and other available data sources or the
23 application of technology could be used to deduce
24 the identity of an individual.”.

1 (e) IMPROVING PUBLIC HEALTH DATA COLLEC-
2 TION.—

3 (1) IN GENERAL.—The Secretary of Health and
4 Human Services (referred to in this subsection as
5 the “Secretary”) shall award grants, contracts, or
6 cooperative agreements to eligible entities for pur-
7 poses of identifying, developing, or disseminating
8 best practices in the collection of electronic health
9 information and the use of designated data stand-
10 ards and implementation specifications to improve
11 the quality and completeness of data, including de-
12 mographic data, collected, accessed, or used for pub-
13 lic health purposes and to address health disparities
14 and related health outcomes.

15 (2) ELIGIBLE ENTITIES.—To be eligible to re-
16 ceive an award under this subsection an entity
17 shall—

18 (A) be a health care provider, academic
19 medical center, community-based organization,
20 State, local governmental entity, Indian Tribe
21 or Tribal organization (as such terms are de-
22 fined in section 4 of the Indian Self Determina-
23 tion and Education Assistance Act (25 U.S.C.
24 5304)), urban Indian organization (as defined
25 in section 4 of the Indian Health Care Improve-

1 ment Act (25 U.S.C. 1603)), or other appro-
2 priate public or private nonprofit entity, or a
3 consortia of any such entities; and

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

7 (3) ACTIVITIES.—Entities receiving awards
8 under this subsection shall use such award to de-
9 velop and test best practices for training health care
10 providers to use standards and implementation spec-
11 ifications that assist in the capture, access, ex-
12 change, and use of electronic health information, in-
13 cluding demographic information, disability status,
14 veteran status, housing status, functional status,
15 and other data elements. Such activities shall in-
16 clude, at a minimum—

17 (A) improving, understanding, and using
18 data standards and implementation specifica-
19 tions;

20 (B) developing or identifying methods to
21 improve communication with patients in a
22 culturally- and linguistically-appropriate man-
23 ner, including to better capture information re-
24 lated to demographics of such individuals;

1 (C) developing methods for accurately cat-
2 egorizing and recording patient responses using
3 available data standards;

4 (D) educating providers regarding the util-
5 ity of such information for public health pur-
6 poses and the importance of accurate collection
7 and recording of such data; and

8 (E) other activities, as the Secretary deter-
9 mines appropriate.

10 (4) REPORTING.—

11 (A) REPORTING BY AWARD RECIPIENTS.—
12 Each recipient of an award under this sub-
13 section shall submit to the Secretary a report
14 on the results of best practices identified, devel-
15 oped, or disseminated through such award.

16 (B) REPORT TO CONGRESS.—Not later
17 than 1 year after the completion of the program
18 under this subsection, the Secretary shall sub-
19 mit a report to Congress on the success of best
20 practices developed under such program, oppor-
21 tunities for further dissemination of such best
22 practices, and recommendations for improving
23 the capture, access, exchange, and use of infor-
24 mation to improve public health and reduce
25 health disparities.

1 (5) NON-DUPLICATION OF EFFORTS.—The Sec-
2 retary shall ensure that the activities and programs
3 carried out under this subsection are free of unnec-
4 essary duplication of effort.

5 (6) AUTHORIZATION OF APPROPRIATIONS.—
6 There are authorized to be appropriated
7 \$10,000,000 for each of fiscal years 2023 through
8 2025 to carry out this subsection.

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

12 “(5) INFORMATION COLLECTION.—Subchapter
13 I of chapter 35 of title 44, United States Code, shall
14 not apply to information collection by the Centers
15 for Disease Control and Prevention, including the
16 Agency for Toxic Substances and Disease Registry,
17 that are part of investigations, research, surveil-
18 lance, or evaluations undertaken for public health
19 purposes.”.