

116TH CONGRESS
2D SESSION

H. R. 8080

To amend the Public Health Service Act to encourage the development of certain public health data standards, authorize epidemiological surveillance grants, and authorize a data linkage demonstration project, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

AUGUST 21, 2020

Mr. PETERS (for himself, Ms. ESHOO, Mrs. MCBATH, and Mr. FITZPATRICK) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to encourage the development of certain public health data standards, authorize epidemiological surveillance grants, and authorize a data linkage demonstration project, 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 “Health Standards To
5 Advance Transparency, Integrity, Science, Technology In-
6 frastructure, and Confidential Statistics Act of 2020” or
7 the “Health STATISTICS Act of 2020”.

1 **SEC. 2. IMPROVING PUBLIC HEALTH DATA.**

2 Title XXXI of the Public Health Service Act (42
3 U.S.C. 300kk) is amended—

4 (1) by inserting before section 3101 the fol-
5 lowing subtitle designation and heading:

6 **“Subtitle A—In General”;**

7 and

8 (2) by adding at the end the following new sub-
9 title:

10 **“Subtitle B—Public Health**
11 **Common Data Standards**

12 **“SEC. 3111. TREATMENT OF PUBLIC HEALTH DATA.**

13 **“(a) STANDARDIZED REPORTING.—**

14 **“(1) IN GENERAL.—**The Secretary, acting
15 through the Director of the Centers for Disease
16 Control and Prevention, shall—

17 **“(A)** adopt and update as necessary uni-
18 form standards for State and local health de-
19 partments to report data to the Centers; and

20 **“(B)** in adopting and updating standards
21 under this subsection, give deference to—

22 **“(i)** corresponding standards devel-
23 oped by standards development organiza-
24 tions and voluntary consensus-based stand-
25 ards bodies; and

1 “(ii) the recommendations of the
2 working group established under para-
3 graph (3).

4 “(2) REQUIREMENTS.—The standards under
5 paragraph (1) shall—

6 “(A) be consistent with—

7 “(i) standards for the interoperability
8 of health information technology under
9 subtitle A;

10 “(ii) Office of Management and Budg-
11 et Circular A–119 (or any successor there-
12 to);

13 “(iii) Office of Management and
14 Budget standards for race and ethnicity
15 and other relevant measures; and

16 “(B) provide for the use of interoperable
17 systems, consistent with the application pro-
18 gramming interface standards and associated
19 implementation specifications under section
20 170.215 of title 45 (or any successor regula-
21 tions).

22 “(3) WORKING GROUP.—

23 “(A) ESTABLISHMENT.—The Secretary
24 shall establish a permanent technical working
25 group (in this paragraph referred to as the

1 ‘working group’) to make recommendations on
2 an ongoing basis and as needed to establish
3 more comprehensive common standards across
4 appropriate health care, public health, environ-
5 mental, and public assistance data systems.

6 “(B) DUTIES.—In making the recommen-
7 dations required by subparagraph (A), the
8 working group shall—

9 “(i) coordinate, and consult with the
10 Interagency Council on Statistical Policy
11 established under section 3504 of title 44,
12 United States Code, and any other relevant
13 interagency or intra-agency committee;

14 “(ii) include recommendations for—

15 “(I) efficiencies to reduce redun-
16 dancy and the public reporting burden
17 in Federal health data reporting re-
18 quirements and data collections; and

19 “(II) methods to facilitate evi-
20 dence-building through standardized
21 local and State reporting and cross-
22 agency, linkable data sharing between
23 and among local, State, and Federal
24 agencies to collect, acquire, and com-
25 pile complete statistics; and

1 “(iii) build on existing efforts of pub-
2 lic multistakeholder initiatives seeking to
3 standardize key data elements necessary
4 for documenting clinical and other activi-
5 ties related to the social determinants of
6 health in order to improve interoperability,
7 exchange, and use of social determinants
8 of health data across the health and
9 human services sectors.

10 “(C) ADDITIONAL CONSULTATION.—The
11 working group may consult with outside ex-
12 perts, including State, local, Tribal, and terri-
13 torial public health officials, public health re-
14 searchers, and health care providers rep-
15 resenting communities most affected by health
16 disparities.

17 “(D) TIMING.—Not later than 6 months
18 after the date of enactment of this subtitle, the
19 working group shall provide initial recommenda-
20 tions under subsection (a) to the Secretary and
21 the Director of the Centers for Disease Control
22 and Prevention.

23 “(E) COMPOSITION.—

1 “(i) IN GENERAL.—The working
2 group shall, at a minimum, include rep-
3 resentation from—

4 “(I) all relevant Department of
5 Health and Human Services units, in-
6 cluding—

7 “(aa) the National Center
8 for Health Statistics;

9 “(bb) the Centers for Dis-
10 ease Control and Prevention;

11 “(cc) the Office of the Chief
12 Technology Officer in the Office
13 of the Secretary;

14 “(dd) the Office of the Na-
15 tional Coordinator for Health In-
16 formation Technology; and

17 “(ee) the Health and
18 Human Services Data Council;

19 “(II) the Office of Information
20 and Regulatory Affairs of the Office
21 of Management and Budget;

22 “(III) the National Institute of
23 Standards and Technology;

24 “(IV) the Veterans Health Ad-
25 ministration;

1 “(V) the Military Health System;

2 and

3 “(VI) the Indian Health Service.

4 “(ii) CHAIR.—The chair of the work-
5 ing group shall be the Director of the Na-
6 tional Center for Health Statistics (or the
7 Director’s designee).

8 “(b) INCREASING EFFICIENCY AND ADVANCING EVI-
9 DENCE BUILDING.—Consistent with the standards in ef-
10 fect under subsection (a), the Chief Statistician of the
11 United States in the Office of Management and Budget,
12 in accordance with section 3504(e) of title 44, United
13 States Code, shall issue and update on an ongoing basis
14 as needed, directives guiding Federal health data informa-
15 tion collection to reduce public reporting burden, ensure
16 information quality, improve use of determinants of health
17 data, and enhance access to health data for evidence-build-
18 ing activities.

19 “(c) COVID–19 HIGH-PRIORITY STANDARDS.—Not
20 later than 30 days after the date of enactment of this sub-
21 title, the Secretary, acting through the Director of the
22 Centers for Disease Control and Prevention, and in con-
23 sultation with the Director of the National Institutes of
24 Health, shall—

1 “(1) establish standards under subsection (a)
2 with respect to COVID–19, including for therapeutic
3 interventions, treatment settings, and associated out-
4 comes; and

5 “(2) in carrying out paragraph (1), adopt or
6 build upon existing standards.

7 “(d) SHARING DATA RELATED TO COVID–19.—
8 Subject to applicable law on the privacy and confiden-
9 tiality of individually identifiable information, the Sec-
10 retary shall—

11 “(1) share up-to-date data related to COVID–
12 19 data collected by the Department of Health and
13 Human Services with—

14 “(A) the Centers for Disease Control and
15 Prevention; and

16 “(B) Federal, State, and local public
17 health agencies outside of the Department of
18 Health and Human Services; and

19 “(2) make such data (including metadata as de-
20 fined in section 3502 of title 44, United States
21 Code) publicly available using standardized, ma-
22 chine-readable formats—

23 “(A) on the website of the Department of
24 Health and Human Services; and

1 “(B) in the Federal data catalogue main-
2 tained under section 3511(c) of title 44, United
3 States Code.

4 **“SEC. 3112. EPIDEMIOLOGICAL SURVEILLANCE GRANTS.**

5 “(a) GRANT AUTHORITY.—The Secretary, in con-
6 sultation with the Director of the National Center for
7 Health Statistics, may award grants or cooperative agree-
8 ments to public health reporting entities—

9 “(1) to establish protocols and acquire tech-
10 nologies to implement the standards under section
11 3111 for reporting, directly or indirectly, to the Fed-
12 eral Government, including by—

13 “(A) supporting expansion and moderniza-
14 tion of electronic case reporting, laboratory re-
15 porting, and mortality reporting;

16 “(B) making data sharing with the Na-
17 tional Center for Health Statistics bidirectional;

18 “(C) improving interoperability standards
19 and implementation specifications for industry
20 use to fulfill specific clinical health information
21 technology interoperability needs;

22 “(D) developing and implementing protec-
23 tions required by subsection (b); and

24 “(E) conducting real-world testing of data
25 sharing to ensure viability, scalability, and

1 adaptability of data collection and reporting ac-
2 tivities; and

3 “(2) to carry out such reporting using such pro-
4 tocols and technologies.

5 “(b) ADOPTION OF STANDARDS AND DATA PROTEC-
6 TIONS.—The Secretary may not award a grant or coopera-
7 tive agreement under subsection (a) unless the applicant
8 develops an implementation plan to develop and implement
9 policies, practices, procedures, and controls related to—

10 “(1) improving data quality and reporting time-
11 liness;

12 “(2) data security, in accordance with the most
13 recent versions of the Cybersecurity Framework and
14 Privacy Framework (or successor frameworks) of the
15 National Institute of Standards and Technology; and

16 “(3) confidentiality and privacy of any informa-
17 tion that pertains to an individual and from which,
18 either alone or in combination with other reasonably
19 available information, the individual’s identity can be
20 determined, including policies, practices, procedures,
21 and controls for—

22 “(A) minimizing collection, processing,
23 maintenance, retention, and disclosure of such
24 information to what is necessary, proportionate,
25 and limited for a good faith public health pur-

pose that is clearly described and limited in an agreement between the Federal Government and the recipient;

“(B) prohibiting disclosure of such information to persons, including government entities, absent legal safeguards included in Federal or State laws or regulations, for protecting the security and privacy of such information; and

“(C) making the data available to the National Center for Health Statistics for statistical purposes under subchapter III of chapter 35 of title 44, United States Code.

“(c) COVID–19 REPORTING.—The Secretary may not award a grant or cooperative agreement under subsection (a) unless the applicant agrees—

“(1) to use the grant for activities under subsection (a) with respect to COVID–19, including with respect to—

“(A) testing results data;

“(B) testing results turnaround time;

“(C) hospitalization and intensive care unit data;

“(D) new infections among health care workers;

1 “(E) new cases among quarantined con-
2 tacts; and

3 “(F) long-term care facilities, prisons, and
4 other congregate settings; and

5 “(2) in carrying out such activities, to
6 disaggregate data by age, sex, race, ethnicity, and
7 ZIP Code, as appropriate and to the extent possible.

8 “(d) APPLICATION.—A public health reporting entity
9 applying for a grant or cooperative agreement under this
10 section shall submit an application to the Secretary at
11 such time and in such manner as the Secretary may re-
12 quire.

13 “(e) DEFINITION.—In this section, the term ‘public
14 health reporting entity’ means any entity that reports data
15 to the Centers for Disease Control and Prevention or an-
16 other public health authority, including a State or local
17 public health department, a public health laboratory, and
18 a health care provider.

19 **“SEC. 3113. EVIDENCE-BUILDING DEMONSTRATION PRO-**
20 **GRAM.**

21 “(a) IN GENERAL.—The Secretary acting through
22 the Director of the National Center for Health Statistics
23 (in this section referred to as the ‘Secretary’) shall expand
24 the data linkage program of the Department of Health
25 and Human Services consisting of Federal statistical and

1 programmatic datasets from specified Federal entities, as
2 authorized by subchapter III of chapter 35 of title 44,
3 United States Code, for the purpose of facilitating statis-
4 tical public health research on trends and patterns across
5 specifically defined, statistically relevant populations, with
6 a particular focus on linking social determinants of health
7 data, including with respect to—

8 “(1) food insecurity;

9 “(2) housing instability;

10 “(3) transportation access;

11 “(4) safety;

12 “(5) social connection and isolation;

13 “(6) financial resource strain; and

14 “(7) stress.

15 “(b) ACTIVITIES.—The activities of the demonstra-
16 tion program under this section shall include:

17 “(1) Assessing the availability of identified and
18 deidentified data sets held by Federal, State, local,
19 and non-Federal entities that may be useful for re-
20 search described in subsection (a).

21 “(2) Using existing authorities and linkages of
22 data in accordance with subchapter III of chapter 35
23 of title 44, United States Code, when relevant to re-
24 quest the submission of datasets to the National
25 Center for Health Statistics for linking.

1 “(c) LIMITATION.—The Secretary shall limit access
2 to data under the demonstration program under this sec-
3 tion—

4 “(1) to Federal statistical agencies and quali-
5 fied public and private researchers, as determined by
6 the Director of the National Center for Health Sta-
7 tistics;

8 “(2) for a period to be specified by the Sec-
9 retary; and

10 “(3) exclusively for the purpose described in
11 subsection (a).

12 “(d) PROCESS FOR MAKING DATA AVAILABLE.—

13 “(1) IN GENERAL.—Consistent with paragraph
14 (2), the Secretary shall establish a rigorous process
15 for making data available and usable pursuant to
16 the demonstration program under this section.

17 “(2) REQUIREMENTS.—Before any data is
18 made available pursuant to the demonstration pro-
19 gram under this section by an entity described in
20 subsection (b)(1) to another entity described in sub-
21 section (b)(1)—

22 “(A) the receiving entity shall submit to
23 the Director of the National Center for Health
24 Statistics an application for data for the pur-
25 pose described in subsection (a); and

1 “(B) the Director shall approve or deny
2 such request in writing, including in the case of
3 a denial an explanation of the reasons for the
4 denial.

5 “(e) RULEMAKING.—

6 “(1) NO DELAY ON IMPLEMENTATION.—The
7 Secretary—

8 “(A) shall begin implementation of the
9 demonstration program under this section upon
10 the date of enactment of this subtitle; and

11 “(B) shall not delay such implementation
12 for purposes of promulgating the regulations re-
13 quired by paragraph (2).

14 “(2) PROMULGATION.—The Secretary shall—

15 “(A) issue regulations for carrying out this
16 section; and

17 “(B) specify in such regulations the al-
18 lowed and disallowed purposes for sharing and
19 linking data through the program, including
20 areas of potential research.

21 “(f) WEBSITE.—The Secretary shall maintain a pub-
22 licly accessible website—

23 “(1) providing information about demonstration
24 program under this section;

1 “(2) facilitating stakeholder participation in
2 such demonstration program;

3 “(3) facilitating oversight of such demonstra-
4 tion program;

5 “(4) providing lists of datasets from Federal
6 and nonfederal entities;

7 “(5) providing lists of identified and deidenti-
8 fied datasets;

9 “(6) identifying linked datasets;

10 “(7) delineating a process to protect privacy
11 and confidentiality;

12 “(8) identifying sources of the datasets; and

13 “(9) delineating categories of personal data.

14 “(g) PROGRAM REQUIREMENTS.—The demonstration
15 program under this section shall be designed to—

16 “(1) support data matching services for agen-
17 cies and researchers using the National Death
18 Index; and

19 “(2) facilitate collaboration with States and pri-
20 vate entities to examine, update, and modernize the
21 fee structure of the National Death Index to support
22 a broad range of data queries.

23 “(h) CONTRACTED ENTITIES.—

24 “(1) IN GENERAL.—Subject to the availability
25 of appropriations, the Secretary may enter into con-

1 tracts with eligible entities, as appropriate, for infra-
2 structure and support services in carrying out the
3 demonstration program under this section.

4 “(2) ELIGIBILITY.—To be eligible for a con-
5 tract under paragraph (1), an entity shall—

6 “(A) demonstrate core capabilities for data
7 sharing, data linkage, and compliance with sub-
8 chapter III of chapter 35 of title 44, United
9 States Code; and

10 “(B) adhere to security standards in ac-
11 cordance with the Federal Risk and Authoriza-
12 tion Management Program (or any successor
13 program).

14 “(i) RULE OF CONSTRUCTION.—Nothing in this sec-
15 tion shall be construed to authorize the availability or use
16 of data for—

17 “(1) law enforcement; or

18 “(2) any determination of the eligibility of an
19 individual for any direct or indirect payment, ben-
20 efit, or service.

21 “(j) REPORT TO CONGRESS.—Not later than 1 year
22 after the date of enactment of this Act, and annually
23 thereafter, the Secretary shall submit a report to the Con-
24 gress on the implementation of this section, including—

25 “(1) identification of best States practices for—

1 “(A) sharing data with, and reporting data
2 to, the National Death Index; and

3 “(B) ensuring the quality of such data;
4 and

5 “(2) recommendations to improve—

6 “(A) such sharing and reporting; and

7 “(B) access to the National Death Index
8 by researchers.

9 **“SEC. 3114. BUILDING STATISTICAL PUBLIC HEALTH RE-**
10 **SEARCH CAPACITY.**

11 “(a) IN GENERAL.—The Secretary, acting through
12 the Director of the Centers for Disease Control and Pre-
13 vention, shall provide financial assistance to research enti-
14 ties and public health departments to establish, expand,
15 or enhance capacity for conducting statistical public health
16 research—

17 “(1) in connection with the programs and ac-
18 tivities under this subtitle; and

19 “(2) in accordance with subchapter III of chap-
20 ter 35 of title 44, United States Code.

21 “(b) CAPACITY FOR SHARING AND LINKING.—The
22 capacity referred to in subsection (a) may include sharing
23 and linking information and accessing and utilizing linked
24 health data files in accordance with established data use
25 agreements with data holders (including electronic case re-

1 porting, electronic health records, and electronic test or-
2 ders and results) with public health agencies and related
3 systems, including the National Death Index, immuniza-
4 tion information systems, syndromic surveillance systems,
5 laboratory information management systems, electronic
6 case reporting systems, medical examiner case manage-
7 ment systems, and Patient Unified Look-up Systems for
8 Emergencies.

9 **“SEC. 3115. RULE OF CONSTRUCTION.**

10 “Nothing in this subtitle shall be construed to super-
11 sede the authority of the Director of the Office of Manage-
12 ment and Budget under title 44, United States Code, to
13 determine and issue relevant standards for information
14 management.

15 **“SEC. 3116. AUTHORIZATION OF APPROPRIATIONS.**

16 “There are authorized to be appropriated—

17 “(1) to carry out this subtitle (other than sec-
18 tion 3113), \$450,000,000, to remain available until
19 expended; and

20 “(2) to carry out section 3113, \$100,000,000
21 for the period of fiscal years 2020 through 2025.”.

○