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(Original Signature of Member)

116TH CONGRESS
2D SESSION

H. R.

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

Mr. PETERS introduced the following bill; which was referred to the Committee on _____

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-

1 frastructure, and Confidential Statistics Act of 2020” or
2 the “Health STATISTICS Act of 2020”.

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

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

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

8 **“Subtitle A—In General”; and**

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

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

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

14 **“(a) STANDARDIZED REPORTING.—**

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

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

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

23 **“(i)** corresponding standards devel-
24 oped by standards development organiza-

1 tions and voluntary consensus-based stand-
2 ards bodies; and

3 “ (ii) the recommendations of the
4 working group established under para-
5 graph (3)

6 “(2) REQUIREMENTS.—The standards under
7 paragraph (1) shall—

8 “(A) be consistent with—

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

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

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

18 “(B) provide for the use of interoperable
19 systems, consistent with the application pro-
20 gramming interface standards and associated
21 implementation specifications under section
22 170.215 of title 45 (or any successor regula-
23 tions).

24 “(3) WORKING GROUP.—

1 “(A) ESTABLISHMENT.—The Secretary
2 shall establish a permanent technical working
3 group (in this paragraph referred to as the
4 ‘working group’) to make recommendations on
5 an ongoing basis and as needed to establish
6 more comprehensive common standards across
7 appropriate health care, public health, environ-
8 mental, and public assistance data systems.

9 “(B) DUTIES.—In making the rec-
10 ommendations required by subparagraph (A),
11 the working group shall—

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

17 “(ii) include recommendations for—

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

22 “(II) methods to facilitate evi-
23 dence-building through standardized
24 local and State reporting and cross-
25 agency, linkable data sharing between

1 and among local, State, and Federal
2 agencies to collect, acquire, and com-
3 pile complete statistics; and

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

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

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

1 “(E) COMPOSITION.—

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

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

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

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

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

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

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

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

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

1 “(IV) the Veterans Health Ad-
2 ministration;

3 “(V) the Military Health System;
4 and

5 “(VI) the Indian Health Service.

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

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

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

1 sultation with the Director of the National Institutes of
2 Health, shall—

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

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

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

13 “(1) share up-to-date data related to COVID–
14 19 data collected by the Department of Health and
15 Human Services with—

16 “(A) the Centers for Disease Control and
17 Prevention; and

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

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

1 “(A) on the website of the Department of
2 Health and Human Services; and

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

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

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

11 “(1) to establish protocols and acquire tech-
12 nologies to implement the standards under section
13 3111 for reporting, directly or indirectly, to the Fed-
14 eral Government, including by—

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

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

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

24 “(D) developing and implementing protec-
25 tions required by subsection (b); and

1 “(E) conducting real-world testing of data
2 sharing to ensure viability, scalability, and
3 adaptability of data collection and reporting ac-
4 tivities; and

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

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

12 “(1) improving data quality and reporting time-
13 liness;

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

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

24 “(A) minimizing collection, processing,
25 maintenance, retention, and disclosure of such

1 information to what is necessary, proportionate,
2 and limited for a good faith public health pur-
3 pose that is clearly described and limited in an
4 agreement between the Federal Government
5 and the recipient;

6 “(B) prohibiting disclosure of such infor-
7 mation to persons, including government enti-
8 ties, absent legal safeguards included in Federal
9 or State laws or regulations, for protecting the
10 security and privacy of such information; and

11 “(C) making the data available to the Na-
12 tional Center for Health Statistics for statistical
13 purposes under subchapter III of chapter 35 of
14 title 44, United States Code.

15 “(c) COVID–19 REPORTING.—The Secretary may
16 not award a grant or cooperative agreement under sub-
17 section (a) unless the applicant agrees—

18 “(1) to use the grant for activities under sub-
19 section (a) with respect to COVID–19, including
20 with respect to—

21 “(A) testing results data;

22 “(B) testing results turnaround time;

23 “(C) hospitalization and intensive care unit
24 data;

1 “(D) new infections among health care
2 workers;

3 “(E) new cases among quarantined con-
4 tacts; and

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

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

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

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

21 **“SEC. 3113. EVIDENCE-BUILDING DEMONSTRATION PRO-**
22 **GRAM.**

23 “(a) IN GENERAL.—The Secretary acting through
24 the Director of the National Center for Health Statistics
25 (in this section referred to as the ‘Secretary’) shall expand

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

10 “(1) food insecurity;

11 “(2) housing instability;

12 “(3) transportation access;

13 “(4) safety;

14 “(5) social connection and isolation;

15 “(6) financial resource strain; and

16 “(7) stress.

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

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

23 “(2) Using existing authorities and linkages of
24 data in accordance with subchapter III of chapter 35
25 of title 44, United States Code, when relevant to re-

1 quest the submission of datasets to the National
2 Center for Health Statistics for linking.

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

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

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

12 “(3) exclusively for the purpose described in
13 subsection (a).

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

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

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

24 “(A) the receiving entity shall submit to
25 the Director of the National Center for Health

1 Statistics an application for data for the pur-
2 pose described in subsection (a); and

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

7 “(e) RULEMAKING.—

8 “(1) NO DELAY ON IMPLEMENTATION.—The
9 Secretary—

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

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

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

17 “(A) issue regulations for carrying out this
18 section; and

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

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

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

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

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

7 “(4) providing lists of datasets from Federal
8 and nonfederal entities;

9 “(5) providing lists of identified and
10 deidentified datasets;

11 “(6) identifying linked datasets;

12 “(7) delineating a process to protect privacy
13 and confidentiality;

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

15 “(9) delineating categories of personal data.

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

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

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

25 “(h) CONTRACTED ENTITIES.—

1 “(1) IN GENERAL.—Subject to the availability
2 of appropriations, the Secretary may enter into con-
3 tracts with eligible entities, as appropriate, for infra-
4 structure and support services in carrying out the
5 demonstration program under this section.

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

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

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

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

19 “(1) law enforcement; or

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

23 “(j) REPORT TO CONGRESS.—Not later than 1 year
24 after the date of enactment of this Act, and annually

1 thereafter, the Secretary shall submit a report to the Con-
2 gress on the implementation of this section, including—

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

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

6 “(B) ensuring the quality of such data;
7 and

8 “(2) recommendations to improve—

9 “(A) such sharing and reporting; and

10 “(B) access to the National Death Index
11 by researchers.

12 **“SEC. 3114. BUILDING STATISTICAL PUBLIC HEALTH RE-**
13 **SEARCH CAPACITY.**

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

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

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

24 “(b) CAPACITY FOR SHARING AND LINKING.—The
25 capacity referred to in subsection (a) may include sharing

1 and linking information and accessing and utilizing linked
2 health data files in accordance with established data use
3 agreements with data holders (including electronic case re-
4 porting, electronic health records, and electronic test or-
5 ders and results) with public health agencies and related
6 systems, including the National Death Index, immuniza-
7 tion information systems, syndromic surveillance systems,
8 laboratory information management systems, electronic
9 case reporting systems, medical examiner case manage-
10 ment systems, and Patient Unified Look-up Systems for
11 Emergencies.

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

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

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

19 “There are authorized to be appropriated—

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

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