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 
4 SECTION 1. SHORT TITLE.
5 This Act may be cited as the “Health Standards to
6 Advance Transparency, Integrity, Science, Technology In-
SEC. 2. IMPROVING PUBLIC HEALTH DATA.

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

(1) by inserting before section 3101 the following subtitle designation and heading:

“Subtitle A—In General”; and

(2) by adding at the end the following new subtitle:

“Subtitle B—Public Health Common Data Standards

“SEC. 3111. TREATMENT OF PUBLIC HEALTH DATA.

“(a) STANDARDIZED REPORTING.—

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

“(A) adopt and update as necessary uniform standards for State and local health departments to report data to the Centers; and

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

“(i) corresponding standards developed by standards development organiza-
tions and voluntary consensus-based standards bodies; and

“(ii) the recommendations of the working group established under paragraph (3)

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

“(A) be consistent with—

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

“(ii) Office of Management and Budget Circular A–119 (or any successor thereto);

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

“(B) provide for the use of interoperable systems, consistent with the application programming interface standards and associated implementation specifications under section 170.215 of title 45 (or any successor regulations).

“(3) WORKING GROUP.—
“(A) E STABLISHMENT.—The Secretary shall establish a permanent technical working group (in this paragraph referred to as the ‘working group’) to make recommendations on an ongoing basis and as needed to establish more comprehensive common standards across appropriate health care, public health, environmental, and public assistance data systems.

“(B) D UTIES.—In making the recommendations required by subparagraph (A), the working group shall—

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

“(ii) include recommendations for—

“(I) efficiencies to reduce redundancy and the public reporting burden in Federal health data reporting requirements and data collections; and

“(II) methods to facilitate evidence-building through standardized local and State reporting and cross-agency, linkable data sharing between
and among local, State, and Federal agencies to collect, acquire, and compile complete statistics; and

“(iii) build on existing efforts of public multistakeholder initiatives seeking to standardize key data elements necessary for documenting clinical and other activities related to the social determinants of health in order to improve interoperability, exchange, and use of social determinants of health data across the health and human services sectors.

“(C) ADDITIONAL CONSULTATION.—The working group may consult with outside experts, including State, local, Tribal, and territorial public health officials, public health researchers, and health care providers representing communities most affected by health disparities.

“(D) TIMING.—Not later than 6 months after the date of enactment of this subtitle, the working group shall provide initial recommendations under subsection (a) to the Secretary and the Director of the Centers for Disease Control and Prevention.
“(E) COMPOSITION.—

“(i) IN GENERAL.—The working group shall, at a minimum, include representation from—

“(I) all relevant Department of Health and Human Services units, including—

“(aa) the National Center for Health Statistics;

“(bb) the Centers for Disease Control and Prevention;

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

“(dd) the Office of the National Coordinator for Health Information Technology; and

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

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

“(III) the National Institute of Standards and Technology;
“(IV) the Veterans Health Administration;

“(V) the Military Health System;

and

“(VI) the Indian Health Service.

“(ii) CHAIR.—The chair of the working group shall be the Director of the National Center for Health Statistics (or the Director’s designee).

“(b) INCREASING EFFICIENCY AND ADVANCING EVIDENCE BUILDING.—Consistent with the standards in effect under subsection (a), the Chief Statistician of the United States in the Office of Management and Budget, in accordance with section 3504(e) of title 44, United States Code, shall issue and update on an ongoing basis as needed, directives guiding Federal health data information collection to reduce public reporting burden, ensure information quality, improve use of determinants of health data, and enhance access to health data for evidence-building activities.

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

“(1) establish standards under subsection (a) with respect to COVID–19, including for therapeutic interventions, treatment settings, and associated outcomes; and

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

“(d) SHarinG DaTa relatEd to COVID–19.—Subject to applicable law on the privacy and confidentiality of individually identifiable information, the Secretary shall—

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

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

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

“(2) make such data (including metadata as defined in section 3502 of title 44, United States Code) publicly available using standardized, machine-readable formats—
“(A) on the website of the Department of Health and Human Services; and

“(B) in the Federal data catalogue maintained under section 3511(c) of title 44, United States Code.

“SEC. 3112. EPIDEMIOLOGICAL SURVEILLANCE GRANTS.

“(a) Grant Authority.—The Secretary, in consultation with the Director of the National Center for Health Statistics, may award grants or cooperative agreements to public health reporting entities—

“(1) to establish protocols and acquire technologies to implement the standards under section 3111 for reporting, directly or indirectly, to the Federal Government, including by—

“(A) supporting expansion and modernization of electronic case reporting, laboratory reporting, and mortality reporting;

“(B) making data sharing with the National Center for Health Statistics bidirectional;

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

“(D) developing and implementing protections required by subsection (b); and
“(E) conducting real-world testing of data sharing to ensure viability, scalability, and adaptability of data collection and reporting activities; and

“(2) to carry out such reporting using such protocols and technologies.

“(b) ADOPTION OF STANDARDS AND DATA PROTECTIONS.—The Secretary may not award a grant or cooperative agreement under subsection (a) unless the applicant develops an implementation plan to develop and implement policies, practices, procedures, and controls related to—

“(1) improving data quality and reporting timeliness;

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

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

“(A) minimizing collection, processing, maintenance, retention, and disclosure of such
information to what is necessary, proportionate, and limited for a good faith public health purpose 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;

“(E) new cases among quarantined contacts; and

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

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

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

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

“SEC. 3113. EVIDENCE-BUILDING DEMONSTRATION PROGRAM.

“(a) IN GENERAL.—The Secretary acting through the Director of the National Center for Health Statistics (in this section referred to as the ‘Secretary’) shall expand
the data linkage program of the Department of Health and Human Services consisting of Federal statistical and programmatic datasets from specified Federal entities, as authorized by subchapter III of chapter 35 of title 44, United States Code, for the purpose of facilitating statistical public health research on trends and patterns across specifically defined, statistically relevant populations, with a particular focus on linking social determinants of health data, including with respect to—

“(1) food insecurity;
“(2) housing instability;
“(3) transportation access;
“(4) safety;
“(5) social connection and isolation;
“(6) financial resource strain; and
“(7) stress.

“(b) ACTIVITIES.—The activities of the demonstration program under this section shall include:

“(1) Assessing the availability of identified and deidentified data sets held by Federal, State, local, and non-Federal entities that may be useful for research described in subsection (a).
“(2) Using existing authorities and linkages of data in accordance with subchapter III of chapter 35 of title 44, United States Code, when relevant to re-
request the submission of datasets to the National Center for Health Statistics for linking.

“(c) LIMITATION.—The Secretary shall limit access to data under the demonstration program under this section—

“(1) to Federal statistical agencies and qualified public and private researchers, as determined by the Director of the National Center for Health Statistics;

“(2) for a period to be specified by the Secretary; and

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

“(d) PROCESS FOR MAKING DATA AVAILABLE.—

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

“(2) REQUIREMENTS.—Before any data is made available pursuant to the demonstration program under this section by an entity described in subsection (b)(1) to another entity described in subsection (b)(1)—

“(A) the receiving entity shall submit to the Director of the National Center for Health
Statistics an application for data for the purpose described in subsection (a); and

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

“(e) RULEMAKING.—

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

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

“(B) shall not delay such implementation for purposes of promulgating the regulations required by paragraph (2).

“(2) PROMULGATION.—The Secretary shall—

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

“(B) specify in such regulations the allowed and disallowed purposes for sharing and linking data through the program, including areas of potential research.

“(f) WEBSITE.—The Secretary shall maintain a publicly accessible website—
“(1) providing information about demonstration
program under this section;

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

“(3) facilitating oversight of such demonstration
program;

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

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

“(6) identifying linked datasets;

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

“(8) identifying sources of the datasets; and

“(9) delineating categories of personal data.

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

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

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

“(h) CONTRACTED ENTITIES.—
“(1) IN GENERAL.—Subject to the availability of appropriations, the Secretary may enter into contracts with eligible entities, as appropriate, for infrastructure and support services in carrying out the demonstration program under this section.

“(2) ELIGIBILITY.—To be eligible for a contract under paragraph (1), an entity shall—

“(A) demonstrate core capabilities for data sharing, data linkage, and compliance with subchapter III of chapter 35 of title 44, United States Code; and

“(B) adhere to security standards in accordance with the Federal Risk and Authorization Management Program (or any successor program).

“(i) RULE OF CONSTRUCTION.—Nothing in this section shall be construed to authorize the availability or use of data for—

“(1) law enforcement; or

“(2) any determination of the eligibility of an individual for any direct or indirect payment, benefit, or service.

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

“(1) identification of best States practices for—

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

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

“(2) recommendations to improve—

“(A) such sharing and reporting; and

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

“SEC. 3114. BUILDING STATISTICAL PUBLIC HEALTH RESEARCH CAPACITY.

“(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall provide financial assistance to research entities and public health departments to establish, expand, or enhance capacity for conducting statistical public health research—

“(1) in connection with the programs and activities under this subtitle; and

“(2) in accordance with subchapter III of chapter 35 of title 44, United States Code.

“(b) CAPACITY FOR SHARING AND LINKING.—The capacity referred to in subsection (a) may include sharing
and linking information and accessing and utilizing linked
health data files in accordance with established data use
agreements with data holders (including electronic case re-
porting, electronic health records, and electronic test or-
ders and results) with public health agencies and related
systems, including the National Death Index, immuniza-
tion information systems, syndromic surveillance systems,
laboratory information management systems, electronic
case reporting systems, medical examiner case manage-
ment systems, and Patient Unified Look-up Systems for
Emergencies.

"SEC. 3115. RULE OF CONSTRUCTION.

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

"SEC. 3116. AUTHORIZATION OF APPROPRIATIONS.

"There are authorized to be appropriated—

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

"(2) to carry out section 3113, $100,000,000
for the period of fiscal years 2020 through 2025."