Title: To strengthen the public health infrastructure of the United States, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Building Exchange Together to Expand Real-time Health Data Networks Act" or the "BETTER Health Data Networks Act".

SEC. 2. SENSE OF CONGRESS.

It is the Sense of Congress that—

(1) health care data silos, duplication of effort, and a lack of interoperability between and among Federal, State, local, and territorial governments, as well as across the private sector, have hampered our national ability to address and respond to health care's most intractable problems, including chronic and infectious disease, capacity management, and better coordination of community services. This results in unnecessary administrative burden, inconsistent interpretation of data, and delayed response;

(2) a series of reports from the Government Accountability Office in 2020, 2021, and 2022 highlighted pervasive challenges with pandemic response, including that—

(A) Department of Health and Human Services data sources are not accessible in a consistent manner from States, and States are not centralizing health data effectively or as efficiently as needed to support real-time utilization and accuracy;

(B) quality health data relating to race and ethnicity is lacking for several 9 health indicators, including testing, cases, hospitalizations, deaths, and vaccinations;

(C) low-quality health data makes it difficult to track hospitalizations and compare the impact of infectious disease from one area to another in a timely manner; and

(D) incomplete health data in public health systems makes it difficult to allocate necessary resources to hospitals and other front line providers in need of supplies;

(3) there is insufficient connectivity and information sharing between State public health agencies, State health care agencies, local governments, the Federal Government, health care providers, community-based organizations, and health care payers to address health care matters of national importance without proper investments to implement a health data infrastructure to solve these challenges;

(4) there is a lack of capacity to merge and integrate data from public health systems with real-time clinical and laboratory data to permit longitudinal tracking, for instance to assess rehospitalization rates, infection rates for vaccinated patients, and the health status and health care use of patients;

(5) without additional action and investment at the State level, health data silos will hinder our national ability to respond to future public health crises and to achieve other critical priorities, such as eliminating health disparities, integrating medical and behavioral

health care, and addressing social needs;

(6) to improve and facilitate the secure, real time, interoperable movement of health data between and among stakeholders, every State needs a neutral, trusted nonprofit health data utility—

(A) to securely bridge and connect the data silos; and

(B) to rapidly provide data and data insights to meet individual, public, and population health use cases;

[(7) it is necessary to ensure that each State has the flexibility and opportunity to implement its health data utility to accommodate its unique needs while also demonstrating core capabilities; and]

[(8) State health data utilities that are public-private partnerships are a necessary and critical component of a national framework for a health data infrastructure.]

SEC. 3. DEFINITIONS.

In this Act:

[(1) STATE.—The term "State" means those defined in 7 U.S. Code § 349.]

(2) SECRETARY.—The term "Secretary" means the Secretary of Health and Human Services, acting through their designee.

SEC. 4. PROMOTION OF HEALTH DATA UTILITIES.

(a) In General.—The Secretary shall establish criteria for a recognition program under which the Secretary shall encourage states to designate a Health Data Utility for purposes of—

(1) strengthening the public health infrastructure at the state level;

(2) generating public and population health insights; and

(4) providing shared services to manage and use health data to improve—

(A) public health and pandemic response;

(B) health care quality;

(C) care coordination;

(D) health outcomes; and

(E) other purposes as deemed appropriate by the State.

(b) Recognition program.—The Secretary shall recognize not more than 1 state-designated entity per State for purposes of strengthening the public health infrastructure by aggregating data from across health care entities and public health agencies to generate public and population health insights, and to provide shared services to manage and use such health data to improve public health and pandemic response, health care quality, care coordination and health outcomes.

(c) Eligibility.—

(1) STATE DESIGNATION.—

(A) IN GENERAL.—A State may designate an eligible entity that meets the criteria described in paragraph (3) for recognition by the Secretary under this section.

(B) FORM OF DESIGNATION.—A designation under subparagraph (A) may be made in the form of legislation, an Executive order, a contract, or any other mechanism determined appropriate by the State. A state may redesignate eligibility as needed.

(2) CRITERIA.—To be a federally recognized Health Data Utility, an entity shall—

(A) be a state-designated entity under subsection (c)(1)(A);

(B) be a nonprofit statewide health data sharing entity or State agency that operates an existing health information exchange network that—

(i) facilitates the exchange of clinical and other types of health data; and

(ii) creates unified health records for patients;

(C)(i) have technical connections to a significant percentage of the health care providers in the State; or

(ii) operate in a State that has established a statewide clinical health information exchange requirement;

(D) be held to a high level of patient privacy protections, such as advanced identity management, patient consent management, and patient matching capabilities, through its technology or governance structure;

(E) be held to a high level of cybersecurity standards, such as credentialing by a national health information security certifying entity;

(F) be governed by a multi-stakeholder, vendor-neutral oversight body that includes, at a minimum, health care provider and public health representation;

(G) adhere to data-sharing policies and quality standards that are aligned with Federal policy and standards as applicable;

(H) be capable of inter- and intra-State information exchange via multiple modalities, such as query and push notifications; and

(I) adhere to health information exchange industry standards with respect to network performance requirements.

(d) Recognition; Selection.—

(1) IN GENERAL.—An eligible entity desiring federal recognition, in addition to state recognition, shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

(2) SELECTION.—In selecting eligible entities for recognition under this section, the Secretary shall—

(A) consider the existing infrastructure for exchanging health data in the applicable State, as well as the ability of the State-based applicant to collaborate with other non-profit information sharing organizations in their State and local jurisdictions including those serving a particular region;

(B) leverage existing health data infrastructure to ensure past Federal investments are fully utilized;

(C) consider the ability of the state-based applicant to support federal public health agencies in—

(i) improving public health reporting and data sharing to address health disparities at the State and local levels;

(ii) integrating data from public health systems with real-time clinical, laboratory, and other data to permit longitudinal tracking and data aggregation for analysis and other purposes, as appropriate;

(iii) carrying out data sharing to support the coordination of health care to meet key data needs, including public health emergencies, ongoing public health issues, chronic disease surveillance, and addressing social needs, as appropriate;

(iv) carrying out data analysis to support quality reporting and outcomes research and improvement in Federal health care programs and State-funded health care programs; and

(v) carrying out other related functions, as determined appropriate by the Secretary.

(e) Leveraging of Health Data Utilities for Public Health and Emergency Preparedness – In states where HHS has recognized a Health Data Utility, it shall incorporate, to the extent appropriate, the resources and capabilities of this entity in implementing programs under 42 USC Part B section. 247c – 247d-6f.

(f) NONPREEMPTION. – Nothing in this section shall preempt any State law.