DRAFT Health Data Utility Legislative Language
As of February 1, 2022

WORKING TITLE:

Building Exchange Together To Expand Real-time (BETTER) Health Data Networks Act

Section 1. SENSE OF CONGRESS.

It is the Sense of Congress that:

(1) Health care data siloes, 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 the COVID-19 pandemic. This results in unnecessary administrative burden, inconsistent interpretation of data, and delayed response.

(2) A series of reports from the Government Accountability Office (GAO) in 2020 and 2021 highlighted pervasive challenges with the pandemic response, including that HHS 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; lack of quality data related to race and ethnicity for several COVID-19 health indicators, including testing, cases, hospitalizations, deaths, and vaccinations; low-quality data makes it difficult to track COVID-19 cases, hospitalizations, and compare the impact of COVID-19 from one area to another in a timely manner; and incomplete public health data 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 for these challenges.

(4) In addition, 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 with a prior COVID-19 infection.

(5) Without additional action and investment at the state and federal level, health care 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 care data between and among stakeholders, every state needs a neutral, trusted nonprofit health data utility to securely bridge and connect the data silos and to rapidly provide data and data insights to meet individual, public and population health use cases.

(7) To ensure that each state has the necessary guidance to implement its health data utility, Congress recognizes that health data utilities are necessary and critical component to enable a national framework for a health data infrastructure.

Section 2. GRANTS TO SUPPORT HEALTH DATA UTILITIES.

(1) IN GENERAL. —The Secretary of Health and Human Services, through the National Coordinator for Health Information Technology, shall award cooperative agreements to up to one eligible entity per State and territory for purposes of strengthening the public health infrastructure of the United States and

addressing health care inequities 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.

(2) IMPLEMENTATION GRANTS. —

(A) ELIGIBILITY CRITERIA. ---

(1) To be eligible to receive a health data utility cooperative agreement under this section, an entity shall —

(I) be a nonprofit, statewide health data sharing entity, or state agency operating an existing health information exchange network, facilitating the exchange of clinical and other types of health data and creating unified health records for patients;

(II) have technical connections to a significant percentage of the State's health care providers or operate in a State that has established a statewide clinical health information exchange requirement;

(III) 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;

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

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

(V) adhere to data sharing policies and quality standards that are aligned with Federal policy and standards;

(VI) be capable of exchanging information via multiple modalities such as query and push notifications; and

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

(2) Based on these criteria, a state shall designate an eligible entity to enter into such a cooperative agreement and to coordinate and share information with such state's healthcare agencies and public health agencies including state, local, territorial, and tribal public health agencies where applicable. Such designation may be made in the form of legislation, an executive order, a contract, or any other mechanism deemed appropriate by the state. Eligible entities may be designated to receive cooperative agreements by multiple states.

(3) If there is not an entity meeting criteria under (2)(A)(1)(I) in a given state, the Secretary shall have discretion to award a cooperative agreement to an entity or consortium of entities meeting the majority of the above criteria as deemed necessary given the unique circumstances in a particular State or apply for a planning grant as authorized under section 3.

(B) PROGRAM REQUIREMENTS. – In awarding cooperative agreements under section (2), the Secretary shall:

(1) Consider the existing infrastructure for exchanging health information in states and localities, and avoid duplicating past federal investments or systems able to meet current and future health

data needs;

(2) Encourage eligible entities to collaborate with other non-profit information sharing organizations in their state and local jurisdictions including those serving particular regions; and

(3) Consider the ability of the applicant to support public health agencies in the following:

(I) Improving public health reporting at the state, local and territorial level, including reporting data to the Department of Health and Human Services;

(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) 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) Data analysis to support quality reporting and outcomes research and improvement in federally and state funded health care programs;

(V) Other related functions, as deemed appropriate by the Secretary.

(C) PLANNING GRANTS. --

(1) Within 90 days of the effective date of this Act, the Secretary, through the National Coordinator, shall issue a Request for Information to identify entities that meet the criteria in subsection (2).

(2) If a state indicates that there are no entities in its state that meet the health data utility criteria set forth in section 2 and the Secretary, in collaboration with the state, is unable to identify any eligible entities based on the responses to the Request for Information in section (b)(1), a state may apply for a planning grant.

(3) Within 180 days of the effective date of this Act, the Secretary, through the Office of the National Coordinator, shall maintain a database and tracking system of health data utilities meeting the requirements in Section 2(A) so that states receiving a planning grant can match their needs with potential information exchange partners.

(4) When evaluating planning grant applications, ONC shall:

(I)Prioritize proposals that achieve economies of scale, such as by sharing infrastructures/operating capabilities among states, as appropriate; and

(II) Require a state receiving a planning grant to designate an entity meeting the criteria in section 2A as its health data utility no later than at the completion of the performance period of its grant.

(D) FUNDING. – For the programs authorized in sections (2)(A) and (2)(C), it is hereby authorized $165,000,000 per year from fiscal years 2023-2028. No more than $20,000,000 of these funds may be used for planning grant during the five-year period from fiscal years 2023-2028.

Section 3. LEVERAGING HEALTH DATA UTILITIES FOR FEDERAL-STATE INFORMATION SHARING.

Within one year of enactment of this Act, the Secretary, through the Office of the National Coordinator for Health Information Technology and in partnership with the Centers for Disease Control and Prevention, the Food and Drug Administration, and the National Institutes of Health as appropriate, shall develop a strategy for leveraging health data utilities funded by the grant program outlined in Section 2(A) to facilitate information sharing between the states and federal government across the public health and clinical health care records system to provide situational awareness and early warning during public health crises, to support public health reporting and infrastructure, to better understand and address chronic disease, and to better understand issues of health equity. This effort shall be aligned with the Centers for Disease Control and Prevention's Data Modernization Initiative as appropriate.