

April 22, 2023

The Honorable Mariannette Miller-Meeks  
House Energy & Commerce Committee  
1034 Longworth House Office Building  
Washington, DC 20515

## **RE: Centers for Disease Control and Prevention (CDC) Request for Information (RFI)**

Dear Representative Miller-Meeks:

[Civitas Networks for Health \(Civitas\)](#) appreciates the opportunity to provide input on the Centers for Disease Control and Prevention (CDC) Request for Information (RFI). Civitas Networks for Health is a national nonprofit collaborative comprised of more than 160 member organizations working to use health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health. We educate, promote, and influence both the private sector and policy makers on matters of interoperability, quality, coordination, health equity and cost-effectiveness of healthcare, and support multi-site grant-funded programs and projects. We are proud to support local health innovators by amplifying their voices at the national level and increasing the exchange of valuable resources, tools, and ideas. Recently, Civitas developed an Issue Brief describing the emerging Health Data Utility model and published a Framework for Health Data Utility, in partnership with the Maryland Health Care Commission. These documents are available on the Civitas Networks for Health website on the [Resources](#) page.

The RFI seeks information from stakeholders on what Congress should consider to reform and improve the CDC. We encourage Congress to build upon existing state health data networks and public-private initiatives by incorporating existing health data capabilities into important CDC programs. Specifically, we urge Congress to encourage the Department of Health and Human Services (HHS) to work with states to designate existing neutral, trusted, and nonprofit health information exchange(s) and health data collaboratives (HIEs) to serve as the state's health data utility (HDU). HDU models are designed and implemented in alignment with states' policies and priorities to address the needs of a broader health and healthcare ecosystem. An HDU can be defined as one or more entities, guided by a diverse stakeholder governance structure, that combine, enhance, and exchange disparate electronic health data sets for treatment, care coordination, quality improvement, population health, public health emergencies, and other public and community health purposes.

### **3. Good Guidance Practices**

Civitas members uphold multistakeholder governance models, which allow for an inclusive process where key stakeholders participate in the consideration, development, dissemination, and updates of public health guidance. Many of Civitas' members are Regional Health Improvement Collaboratives (RHICs). RHICs provide a neutral, trusted convening mechanism through which the community can plan, facilitate, and coordinate different activities required for the necessary transformation of the health care system. Consequently, RHICs are tightly tied to the communities they work with providing trusted information, supporting health literacy efforts,

and offering important guidance to their constituents. RHICs help ensure reliable information is easily accessible and comprehensible for the communities and populations they serve. Civitas' nonprofit and community-centric members, including RHICs, HIEs, HDUs, and All Payer Claims Databases (APCDs) all provide important data points to develop accurate health information and guidance and should be consulted as the CDC develops and disseminates public health guidance.

## **6. State Block Grant Programs**

Civitas recognizes that grant funding from the CDC plays an essential role in sustaining state, local, and territorial public health programs across the country. As noted in the RFI, applying for these grants requires a large amount of time and resources that could otherwise be spent on state public health programs. A state block grant program has the potential to alleviate some of these burdens. Additionally, a block grant program would allow for states to direct funding with more flexibility, directing it to the state public health programs where it is needed most. Every state has different needs and varying degrees of modernized public health infrastructure. Block grants can help states focus funding on specific areas where they may be lagging. For example, several states already have emerging HDUs, but a lack of long-term financial support has prevented other states from establishing HDUs. If the CDC changes to a block grant funding model, it should clearly allow states to utilize the funding for building and modernization of public health infrastructure, including establishing HDUs. The benefits of HDUs are discussed more broadly in the sections below.

## **7. Data and Surveillance**

Despite significant investment in data systems modernization, there continues to be insufficient connectivity and information sharing between state public health agencies, state health care agencies, local governments, the federal government, health care providers and health care payers to address health care matters of national importance. 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. Without integration, we cannot assess rehospitalization rates, infection rates for vaccinated patients, and the health status and health care use of patients with a prior COVID-19 infection, for example. Congress can play a critical role in improving data sharing between federal, state, and local agency partners, as well as across the private sector, by authorizing an "HDU Cooperative Agreement Program," explained in more detail under the ***CDC Authorization*** section below.

For example, HDUs will ensure consistent and seamless reporting of public health data streams through trusted data connections with health care providers – relieving these providers of administrative burden and supporting the needs of public health. HIEs typically specialize in developing technical interfaces to enable interoperability and improve workflows. By combining multiple reporting requirements through a single connection, states can reduce the reporting burden on the delivery system.

Additionally, HDUs will allow for bidirectional information flow – ensuring that crucial data needed to respond to pandemics and other emergencies is available to clinicians as well as public health.

Finally, HDUs can also protect privacy by segmenting data to ensure only necessary information is shared with public health and policymakers.

Finally, the COVID-19 pandemic has revealed the need for significant modernization of and investment in our nation's public health infrastructure. We believe that HIEs' and emerging HDUs' knowledge gained during this public health crisis has and will continue to transform the ability to support public health departments and provider organizations for the current pandemic and future pandemics. HIEs and health data collaboratives played a critical role in responding to the pandemic. Civitas assisted with state and local surveillance and data collection efforts including precision focus on health equity, delivering alerts on test results and immunization status, as well as coordinating resource allocation such as hospital beds and ventilators across the country. In many states, HIEs and emerging HDUs were the backbone of strategic, coordinated, and efficient pandemic response. These networks rapidly deployed solutions to share data on the spread of the virus and enabled some states to catalyze on enormous insights for public health. HIEs and emerging HDUs have the trust of their community partners and can quickly identify solutions to complex problems.

## **8. CDC Authorization**

Congress should authorize an "HDU Cooperative Agreement Program" through the CDC to help states designate existing neutral, trusted, and nonprofit HIEs and or other nonprofit health data organizations to be the state's HDU. Additionally, an HDU Cooperative Agreement Program should be authorized for \$165 million per year to accommodate the new objectives of HDUs and to support regional multi-stakeholder collaboration to better respond to disasters and emergencies through health information sharing.

Given HDUs' ability to support public health departments and provider organizations for the current pandemic and future pandemics, we believe HDUs could fit under several CDC programs, such as:

- ***The Public Health Emergency Preparedness (PHEP) Cooperative Agreement Program***  
The PHEP Cooperative Agreement Program, which helps health departments build and strengthen their abilities to effectively respond to a range of public health threats, including infectious diseases, aligns with the support HDUs have provided health departments with standardizing data during the COVID-19 pandemic. We believe that in states where HDU capabilities exist, CDC should require state, local and public health departments to partner with public-private HDUs in their states instead of duplicating existing health data capabilities.
- ***The Public Health Situational Awareness and Bio Surveillance Network Program***  
The Public Health Situational Awareness and Bio surveillance Network Programs is intended to provide a real-time electronic nationwide public health situational awareness capability through an interoperable network to share data to improve the nation's ability to prepare for and respond to health emergencies. Congress should require CDC to leverage all existing resources that could strengthen this work, including clinical HDUs. We believe

this process must be transparent, requiring both state and federal stakeholders to be invited to participate in public meetings to discuss and provide input on the network.

Furthermore, HDUs will improve the efficiency and effectiveness of current HHS programs and activities and provide methods for states to designate existing neutral, trusted, and nonprofit HIEs or other nonprofit collaborative health data organization to be the HDU. State-based HDUs can build out and deploy a robust and highly collaborative digital health public utility infrastructure to facilitate state-wide electronic health data sharing across the health and healthcare ecosystem while protecting privacy and ensuring security. The state designated HDU should ensure that the state's health equity initiatives are tied to digital health data inputs from across the ecosystem to drive better health outcomes and more informed population health management programs and payment models. Each state designated HDU is essential in establishing a national framework that fulfills a current gap in health care by implementing a comprehensive digital health infrastructure as a public utility that will support data sharing between public and private health data stakeholders.

The state and local need for HDUs is growing and federal investment is essential to improve the efficiency and effectiveness of current HHS programs and activities related to the advancement of health equity, data modernization, data interoperability, and value-based care. HDUs can be sustained through public and private revenue sources by delivering value-add services based on local, regional, and state needs. HDUs can thrive not only on federal funding but through state dollars, cooperative agreements, grants, private partnerships, and other investments in promoting HDU. We believe our proposed investment in HDUs will help CDC accomplish the goal of better responding to disasters and emergencies.

Many states, HIEs, and health data collaboratives are well-positioned to evolve into the HDU model. HDUs have more advanced technical infrastructures, greater interoperability, and provide public health with valuable information obtained from multiple sources and policy support. Existing technical and relationship infrastructure for health data exchange needs strengthening; states and HIEs are building on more than a decade of health IT investments and learnings to expand the role of health data to improve care delivery and support public health priorities. The following drivers contribute to the greater need for common health data infrastructure and governance models:

- (1) Multistakeholder data needs: Health care, public health, and community health data are often siloed, managed by different entities, and have different data sharing policies that can be restrictive and create challenges in matching or combining data to further shared interests and goals. A data-centered collaborative approach to enhancing health data collection, sharing, and analysis are critical to advancing the health of communities.
- (2) Statewide health data interoperability infrastructure: Disparate information systems often serve as a barrier to patients/individuals/families/caregivers and delivery system providers (e.g., hospitals, care providers, community organizations) as well as coordination with data organizations, community partners, and state agencies. Ubiquitous data sharing and use across all geographies, serving all settings, providers, and populations is crucial in addressing health priorities.

- (3) Social data needs: Many states also lack infrastructure to support standardized social data capture, interoperability of data across sectors, and integrated data aggregation and advanced analytics. Social data and community-level coordination are critical in addressing individuals' social needs and health inequities. Emerging Community Care Hubs, community-centered entities that organize and support networks of community-based organizations (CBOs) through centralized administrative and operational infrastructure, and social health platform vendors should be considered.
- (4) Data-informed public health preparedness, readiness, response, and recovery: Public health jurisdictions have broad data and technology needs to analyze determinants of health and health indicators and track disease burden and equity considerations. Integrating data sources and leveraging data and infrastructure modernization investments improve data availability and insights among the health care, social, and public health sectors.
- (5) Standards for data privacy and security: Federal and state privacy rules vary. Ensuring alignment of data privacy and security controls that keep pace with a rapidly evolving health-data and technology landscape addresses gaps and ambiguities in consent, protection, and access.

HDU design considerations and implementation approaches vary and may evolve as implementers progress to an ideal future state. The following table denotes aspects of HIEs and HDUs to guide planning, design, and implementation of an HDU model. An HIE may provide some but not all services described under HDU. We recommend the HDU designations include the elements of HDUs noted in the table below.

Component	HIE	HDU
<b>Scope of Technical Capabilities and Infrastructure</b>	<ul style="list-style-type: none"> <li>• Facilitates access to clinical data for treatment and care coordination across participating health care organizations.</li> <li>• May report clinical data for public health uses (e.g., vaccines, syndromic surveillance, notifiable conditions).</li> </ul>	<ul style="list-style-type: none"> <li>• Utilizes policy levers to advance data sharing and infrastructure for the aggregation and integration of the multiple data sets (see examples in Appendix B) in ways that expand analytics, quality reporting, data visualization, and other services beyond traditional clinical data exchange.</li> <li>• Serves as a designated data source (e.g., public health registries, controlled and non-controlled medications, and social determinants of health data).</li> <li>• Expansive network connections directly or through other data networks to payers, providers, and community support services.</li> </ul>
<b>Relationship with State(s) and Authority</b>	<ul style="list-style-type: none"> <li>• May have a cooperative partnership with one or more states to align strategy, objectives, and funding.</li> </ul>	<ul style="list-style-type: none"> <li>• Designated authority defines roles and responsibilities and is formalized via a method of the state's choosing (e.g.,</li> </ul>

Component	HIE	HDU
	<ul style="list-style-type: none"> <li>May enter into a state or regional designation agreement, which outlines terms and conditions and is periodically reviewed and updated, as needed.</li> <li>State participation in developing programs and services.</li> </ul>	<p>legislation, executive order, rulemaking).</p> <ul style="list-style-type: none"> <li>Uses policy levers to increase efficient and appropriate data exchange and removes restrictions or barriers to electronic health data exchange.</li> <li>Partners with state and local government to align public health goals and secure necessary funding.</li> </ul>
<b>Governance</b>	<ul style="list-style-type: none"> <li>Multi-stakeholder structure for participating organizations and consumers.</li> <li>May prioritize services internally or with a limited group of stakeholders, perhaps with a focus on sustainability.</li> </ul>	<ul style="list-style-type: none"> <li>Establishes expansive multi-stakeholder, cross-sector governance model with state and community partners.</li> <li>Prioritizes services through shared governance ensuring responsiveness to community health initiatives.</li> <li>Ensures a neutral and transparent approach to decision-making.</li> </ul>
<b>Stakeholder Engagement and Community Partnership</b>	<ul style="list-style-type: none"> <li>Works in parallel with other health data networks.</li> <li>May share data sets with community partners.</li> </ul>	<ul style="list-style-type: none"> <li>Collaborates with data networks and community collaboratives to share and exchange data (e.g., emerging community care hubs,<sup>1</sup> community information exchanges, or All-Payer Claims Databases).</li> <li>Houses or integrates with an existing community directory to offer information on community resources, locations, and services available for individuals, specific populations, or the community (e.g., food banks, homeless shelters, crisis intervention support, or behavioral health services).</li> </ul>
<b>Financing</b>	<ul style="list-style-type: none"> <li>Time-limited funding for technical or implementation services; may receive Medicaid funding.</li> </ul>	<ul style="list-style-type: none"> <li>Long-term, braided, and blended funding strategy that encompasses local, state, federal, and private investments for value-add technical services, reusable infrastructure, and community engagement and support.</li> </ul>

<sup>1</sup> ACL Administration for Community Living, *ACL Announces Selected Participants of the Community Care Hub National Learning Community*, November 2022. Available at: <https://acl.gov/news-and-events/announcements/acl-announces-selected-participants-community-care-hub-national>.

Component	HIE	HDU
<b>Privacy and Security</b>	<ul style="list-style-type: none"> <li>May codify in statute, regulation, or other agreements required privacy and security policies above the minimum required in federal law.</li> </ul>	<ul style="list-style-type: none"> <li>Continuous learning and implementation of cybersecurity and privacy frameworks and standards to ensure rigorous protections that provide appropriate assurances to federal, state, and regional authorities and build stakeholder confidence. Includes frameworks and standards for health and relevant industries outside of health care.</li> </ul>
<b>Accountability and Measurement</b>	<ul style="list-style-type: none"> <li>Reports information to assess performance, quality, and value of services to participating organizations.</li> </ul>	<ul style="list-style-type: none"> <li>Increased accountability through oversight, performance measurement, and evaluation to monitor return on investment and guide strategy for clinical and public health purposes.</li> </ul>

**9. CDC Foundation Mission and Purpose**

Private philanthropy is critically important to non-profit entities that rely on diversified revenue streams. CDC Foundation (CDCF) grants are necessary to help bolster public health infrastructure. An inconsistent financing model creates challenges in sustaining health technology investments. CDCF grants can play a critical role in ensuring access to funds to strengthen public health infrastructure. Additionally, Civitas acts as strategic partner on CDCF’s strategic priority of data modernization. These partnerships help clear pathways for technology, people, and policies to enable cutting-edge intelligence that practitioners and policy makers can leverage to improve public health.

Thank you for the opportunity to comment. Please do not hesitate to reach out to me and my colleagues at Civitas or our member organizations with any questions regarding this response. We want to be a resource to you and the Energy & Commerce Committee as we work together to achieve a community-governed, interoperable health data system to improve public health and health care outcomes.

Sincerely,



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