October 20, 2023

Senator Bill Cassidy, M.D.
Ranking Member
Senate HELP Committee
428 Senate Dirksen Office Building
Washington, DC 20510
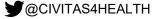
RE: Request for Information from Stakeholders on CDC Modernization

Dear Ranking Member Cassidy:

[Civitas Networks for Health (Civitas)](#) appreciates the opportunity to provide feedback on the September 26, 2023, request for information (RFI) from stakeholders on how to improve the CDC's core public health activities, including stakeholder coordination and public health data infrastructure. Civitas is a national nonprofit collaborative comprised of more than 170 member organizations—health information exchanges (HIEs), regional health improvement collaboratives (RHICs), and providers of services to meet their needs—working to use data frameworks, information infrastructure, and multi-stakeholder, cross-sector approaches to improve health for individuals and communities. We educate, promote, and influence both the private sector and policymakers on matters of interoperability, quality, coordination, and cost-effectiveness within the health system, while also supporting multi-site, grant-funded programs and projects around the country.

Civitas members have become leaders in the development of a new and innovative paradigm known as the Health Data Utility Model (HDU) that holds great promise for effectively managing the demands of this new landscape. The HDUs emerging around the country represent an evolution rather than a revolution in the structure of health information networks and value-added capabilities, combining the multi-directional data transmission infrastructure of incumbent statewide and regional HIEs with a wider array of quality improvement, analytics, community health and social service functions that in many areas have been advanced by RHICs and related quality improvement organizations of varying sizes.

The resulting nonprofit organizations—or partnerships of nonprofit organizations—which comprise an HDU can take advantage of scaling efficiencies across well-defined geographies to better serve their communities as information networks, secure data stewards, platforms for the integration of new technologies, and public health assets. HDUs' nonprofit status, local stakeholder governance (typically overseen by boards with representatives of different providers, patient advocates, and community organizations) and official recognition by public authorities (in state laws, regulations, or contracts) have positioned them as neutral system arbiters vis-à-vis corporate electronic health record platforms (EHRs) and other technology vendors, whose products are "plugged in" to the HIE architecture to perform specific functions at different sites, but who do not own or control the HDU at large. The service territory structure of HDUs also enables the participating organizations to achieve greater levels of financial self-sufficiency through payer and provider fee schedules, as well as through the use of public formula funds (e.g., Medicaid, block grants) and larger contracts. Analogies from outside the health space are

long-established models of nonprofit, public-serving utilities like electric cooperatives and water authorities that are thoroughly connected to wider infrastructure networks while maintaining sufficient autonomy to respond to their customers' needs, or the role of state and local roads in the national surface transportation network.

While many of the questions and topic areas included in your RFI overlap with Civitas' work and the activities of our members, we want to highlight the following key points which underscore the priorities for public-interest health data infrastructure and the value of the emerging HDU model in particular in any future CDC reform legislation:

Making Data Work for Everyone—How does electronic health record (EHR) data currently factor into CDC's data modernization efforts? Are there instances in which partnerships with integrated health care organizations or EHR vendors could provide data directly to CDC to conduct sentinel surveillance and generate insights, rather than relying solely upon data collected through health departments?

The HDUs developing around the country are in many cases the foremost examples of independent health data integration and multi-purpose functionality within their respective statewide and regional service areas—and in all cases, they are the leading independent nonprofit, public-serving systems. The most advanced Civitas member HDU organizations have successfully incorporated the vast majority (typically, over 90%) of clinical providers within their geographies into their information-sharing networks, from small primary care offices and rural health clinics to the largest hospital complexes and academic medical centers. Most of the larger hospital systems also make use of proprietary EHR vendor platforms, software, and associated data flows, which are interoperable with HDUs on the "back end" of data transfer and compliment, rather than compete with them in the current configuration of the national health information landscape (in the same way that manufacturers of electrical equipment do not "compete" with public electric utilities). In addition to connecting clinical providers to each-other, HDUs have assumed a unique and increasingly valuable role as social care data exchanges to integrate metrics associated with social determinants of health (SDOH) into the clinical workstream, enabling more effective patient-centered care and better long-term outcomes. Civitas members have been pioneers on this front from Arkansas (where Arkansas SHARE's statewide network connects patients who are homeless or at risk of homelessness to community housing organizations) to San Francisco (where the regional Serving Communities Health Information Exchange has built a WIC beneficiary referral system for local FQHCs).

At the same time, emerging HDU networks have expanded to include public health authorities at the state and local level, which partner with the HDUs to extract data for area disease surveillance and population health purposes. Among the 65 Civitas HIE member organizations that are most readily characterized as HDU models by virtue of their scope, structure, and capabilities, the vast majority (94%) have an information sharing partnership with at least one public health department. Many of these HDUs are connected to more than one health department, including the largest urban centers in their states and regions. As one example, Louisiana's PelEx/Health Care Quality Forum exchange partnership directly connects to the Louisiana Department of Health as well as the public health and behavioral health agencies of Orleans and Jefferson parishes. Most emerging HDUs also still have room to grow—particularly in rural counties, where resources for

onboarding and staff who have the time and ability to train are often in much shorter supply. Examples of Civitas members that have nonetheless successfully networked public health departments across the urban-rural divide include Kentucky Health Information Exchange (KHIE), Indiana Health Information Exchange (IHIE), and HEALTHeLINK in western New York.

The practical importance of Civitas members' integration of both provider EHRs and public health departments into their networks (alongside payers, social care providers, and other community-based organizations) was demonstrated to an unprecedented degree during the COVID-19 pandemic. HIE/RHIC partnerships and emerging HDUs were the backbone of strategic, coordinated, and efficient pandemic response in many states and regions, rapidly deploying cross-cutting solutions to share lifesaving data on the localized spread of the virus, bed availability, and community impact from different participants' datasets that allowed for the necessary prioritization of resources—and generated substantial new insights for public health authorities in many states. The experience of the pandemic shows not only the extent to which expanding HIEs and emerging HDUs have become essential public health infrastructure in their service areas, but the value that these organizations bring to the table as potential partners for the CDC's health information sharing enterprise. To date, a few Civitas member HDUs have collaborated directly with the CDC on specific projects, such as the work of Maryland's Chesapeake Regional Information System for our Patients (CRISP) with the CDC Division Global Migration and Quarantine to help flag COVID cases among international travelers. However, the potential for much more expansive CDC-HDU data sharing partnerships is vast and largely untapped relative to the localized insights and efficiencies that the agency could gain.

Making Data Work for Everyone—Do you see any opportunities to improve CDC's public health data modernization initiative and related efforts to implement public health data standards?

The centrality of emerging HDU frameworks to health data infrastructure and to public health data in particular is a relatively new development, but one that will only further cement itself in the coming years amidst ongoing EHR adoption, the growing imperative for interoperability to drive transition to value-based care, and the structural need for neutral, independent, and accountable arbiters of the whole digitized health data system. The CDC's Data Modernization Initiative (DMI) launched in 2020 recognizes systemic digitization and the public sector's slow progress relative to other stakeholders, and has committed much-needed and much-appreciated resources to solve the problem by providing large formula allocations to state and local health authorities. The most recent tranches of DMI funding through the 5-year, $3.9 billion "Strengthening US Public Health Infrastructure, Workforce, and Data Systems" grant program have been split into three categories for each of the 116 state and local health department awardees: workforce (hiring, retraining, and related human capital development); "foundational capabilities" (organizational competencies like planning, communications, partnership development, governance, and performance evaluation); and data modernization (most of the technology-related functions, including data infrastructure, interoperability, and analytical capabilities).

Health department awardees' partnerships with their state and regional HDUs already cover a wide range of technical, training, and programmatic activities that fall well within the scope of each of these three activity categories. For purposes of improving the impact and efficiency of DMI

formula grants and the CDC's effort as a whole, the priority should be ensuring that HDU partnerships are recognized under the relevant category designations as eligible for funding support. Particularly at the local level, Civitas member HIEs and emerging HDUs report that public health departments are unsure as to the scope of activities, partners, and functions that their DMI allocations can be used for, and that in the absence of very clear guidance from the CDC they risk using taxpayer dollars to create redundant service lines or miss opportunities for network integration. Given how far even relatively modest amounts of money can go toward successfully onboarding rural county health authorities and staff, the lack of an explicit HIE/HDU acknowledgement in DMI allocations to date is a shortcoming that can and should be addressed. CDC has the authority to target meaningful portions of its already-authorized and appropriated DMI resources to HDUs and public-service health information organizations, and Congress can also exercise its own power to prioritize this funding within the CDC budget through the annual appropriations process of separate reform legislation.

Mechanisms to Modernize—What other policies should Congress consider, aside from those that have already been enacted?

The HDU model's reach, proven ability to support state and local public health departments, and potential to enhance the CDC's own surveillance and population health mission should factor into Congress' CDC reform considerations and into health data infrastructure proposals more broadly. Civitas Networks for Health has drafted a prospective legislative framework called the "Building Exchange Together to Expand Real-time Health Data Networks Act (BETTER Act) that consolidates a number of ideas to strengthen emerging HDUs across the country. The most important of these concepts is the creation of an official federal recognition process for "state-designated HDUs" within HHS (which would also apply to CDC programs). Such a process would further accelerate and institutionalize the trend towards HDU state designation—a majority of Civitas member HDUs already have some form of official state legislative, executive, or regulatory sanction in their service areas—while opening doors for further opportunities to partner with federal agencies and receive federal support. Critically, this process would exist as a mechanism for HHS to effectively ratify state decisions on the shape of their own HDU frameworks and allow federal resources to be targeted accordingly, rather than being a top-down "one size fits all" approach that risks duplicating investments already made and usurping local stakeholder governance.

While the BETTER Act itself has not been introduced in Congress, it inspired the report language below that has been approved by the Senate Appropriations Committee in its Fiscal Year 2024 Labor, Health and Human Services, Education, and related agencies appropriations bill (S. 2624, S Rept.118-84). In defining HDU models, endorsing state designation, and directing ONC and CDC to use existing resources (including DMI resources) to provide support, this language represents an important step towards strengthening the health data ecosystem:

The Committee recognizes the importance of electronic health data as a critical piece to address the health needs and care delivery challenges of diverse communities. The Committee strongly encourages HHS to work with States to designate existing neutral, trusted, and nonprofit HIEs to be 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. The Committee recognizes that each State designated HDU is essential in establishing a national framework that fulfills a current gap in healthcare by implementing a comprehensive digital health infrastructure as a public utility that will support data sharing between public and private health data stakeholders. The Committee directs HHS, through ONC and other relevant Federal agencies, to leverage existing authorities, funds, and other resources to construct policy and regulations that strengthen existing HIE infrastructure to facilitate their transition into HDUs. If necessary, the Committee encourages the Secretary to issue policy guidelines, or best practices, to encourage each State to designate an HIE or HIEs to be a State's HDU.

The Committee urges CDC to encourage States to coordinate with ONC to designate existing neutral, trusted, and nonprofit health information exchange(s) [HIEs] to be the State's HDU. HDUs will build upon CDC's current work to create modern, integrated, and real-time public health infrastructure by building out a highly collaborative public utility infrastructure to facilitate State-wide electronic health data sharing across the healthcare ecosystem. A State-designated HDU will drive better health outcomes and more informed population health management programs and payment models. The CDC may use appropriated funding through the Data Modernization Initiative to support the development of HDUs. The Committee urges CDC to issue policy guidelines or best practices to support the establishment of HDUs across the country.

Elsewhere, Congress can also work to further strengthen HDU frameworks by incorporating similar HDU-specific directives into other public health programs at the CDC. The Public Health Emergency Preparedness (PHEP) Cooperative Agreement Program is one example, which helps health departments build and strengthen their abilities to effectively respond to infectious disease and other public health threats consistent with the critical role played by HDUs during the COVID-19 pandemic. Where HDU capabilities exist, CDC can improve the integration and efficiency of the program by requiring state, local and public health departments to partner with HDUs instead of duplicating existing health data capabilities. The Public Health Situational Awareness and Bio surveillance Network Program is another example, intended to provide a real-time, nationwide, and interoperable electronic public health situational awareness capability to improve emergency preparation and response. 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.

Thank you again for the opportunity to comment. Please do not hesitate to reach out to Civitas if we can be a resource 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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