Civitas Networks for Health
Comments to Pandemic and All-Hazards Preparedness Act (PAHPA) Request for Information (RFI)

Note: The RFI was submitted through a Google form; a formal letter was not required. The PAHPA RFI is available here.

Suggestions for the program(s) listed below.

- Assistant Secretary for Preparedness and Response (ASPR)

BACKGROUND: Civitas Networks for Health (Civitas) appreciates the opportunity to provide input on the Pandemic and All-Hazards Preparedness Act (PAHPA) Request for Information (RFI). Civitas Networks for Health is a national 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 will soon publish a framework for Health Data Utility, in partnership with the Maryland Health Care Commission. These documents are or will be available on the Civitas Networks for Health website on the Resources page.

REQUEST FOR PAHPA/ASPR: Authorize funding through the Hospital Preparedness Program (HPP) for states to designate existing neutral, trusted, and nonprofit health information exchanges (HIEs) or other health data sharing entity to be the state’s health data utility (HDU). Additionally, funding levels for cooperative agreement through the HPP must be increased over existing authorizations by $165 million per fiscal year to accommodate the new objectives of HDUs: to support regional collaboration to better respond to disasters and emergencies through health information sharing.

REQUEST JUSTIFICATION:

We believe HDUs can fall under the following programs in PAHPA:

- Hospital Preparedness Program (HPP) [ASPR]
- Regional Health Care Emergency Preparedness and Response Systems (RHCEPRS) Program [ASPR]
- National Health Security Strategy (NHSS) [ASPR]
- Public Health Emergency Preparedness (PHEP) Cooperative Agreement Program [CDC]
- Public Health Situational Awareness and Bio surveillance Network Programs [CDC]

Funding for HDUs can be authorized through the HPP at the Department of Health and Human Services (HHS) under the Assistant Secretary for Preparedness and Response (ASPR). HPP is already the primary source of federal funding for health care system preparedness and response
and supports regional collaboration and health care preparedness and response by encouraging the development and sustainment of health care coalitions (HCC). HDUs can play a critical role in improving HPP given HDUs’ regional collaboration to better respond to disasters and emergencies through health information sharing.

However, funding for HDUs may not be limited to one sub-agency given HDUs’ applicability to a number of programs within ASPR. Given HDUs’ ability to support public health departments and provider organizations for the current pandemic and future pandemics, we believe HDUs could also fit under a number of other APRS programs as determined by the Secretary or Assistant Secretary of HHS. For example, another program HDUs fit into is the Regional Health Care Emergency Preparedness and Response Systems (RHCEPRS) Program under ASPR. The RHCEPRS Program builds upon and unifies existing assets within states and across regions to support a more coherent, comprehensive, and capable health care disaster response system able to respond to health security threats. Given HDUs are the health data source of truth to facilitate strategic, coordinated, and efficient pandemic response in many states, they can play an active role in supporting the goal of the RHCEPRS Program to ensure a unified response in future disasters. Further, HDUs could fit into the National Health Security Strategy (NHSS) within ASPR, which establishes a framework for strengthening the U.S.’s national capability to prevent, detect, assess, prepare for, mitigate, respond to, and recover from disasters and emergencies.

In addition, HDUs must be able to function across agencies. While HDUs can be authorized by ASPR, HDUs are not limited to any single program. For example, the Public Health Emergency Preparedness (PHEP) Cooperative Agreement Program within CDC, 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. HDUs may also fit into Public Health Situational Awareness and Bio surveillance Network Programs within CDC, which are 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.

Many states and HIEs 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.

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.
- Allow bidirectional information flow – ensuring that crucial data needed to respond to pandemics and other emergencies is available to clinicians as well as public health.
- Protect privacy by segmenting data to ensure only necessary information is shared with public health and policymakers.

HDUs will play a critical role in continuing to transform the ability to support public health departments and provider organizations for the current pandemic and future pandemics. In addition, HDUs will further PAHPA’s mission of improving the nation’s public health and medical preparedness and response capabilities for emergencies.

Furthermore, authorization of HDUs through ASPR is applicable given the critical role HIEs and RHICs play in responding to the pandemic. 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 RHICs’ 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. We 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 RHICs 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 RHICs have the trust of their community partners and can quickly identify solutions to complex problems.

These efforts were not without challenges, as we saw inconsistent information sharing and an inability to respond quickly and seamlessly when the underlying technical and trusted relationship infrastructure was missing. Health care data siloes 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. These challenges have been starkly illustrated during the pandemic and continue to hinder our ongoing response to COVID-19.

Despite significant investment, 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, 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.