

July 10, 2023

Bernard Sanders
Chair
Senate HELP Committee
428 Senate Dirksen Office Building
Washington, DC 20510

Robert P. Casey, Jr.
Member
Senate HELP Committee
393 Russell Senate Office Building
Washington, DC 20510

Bill Cassidy, M.D.
Ranking Member
Senate HELP Committee
428 Senate Dirksen Office Building
Washington, DC 20510

Mitt Romney
Member
Senate HELP Committee
354 Russell Senate Office Building
Washington, DC 20510

RE: Comments on Pandemic and All-Hazards Preparedness Act (PAHPA) Discussion Draft

Dear Chair Sanders, Ranking Member Cassidy, Senator Casey, and Senator Romney:

[Civitas Networks for Health \(Civitas\)](#) appreciates the opportunity to provide feedback on the Pandemic and All-Hazards Preparedness Act (PAHPA) discussion draft prepared by the Senate Health, Education, Labor, and Pensions (HELP) Committee. Civitas Networks for Health is a national nonprofit collaborative comprised of more than 165 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 emergence of Health Data Utilities (HDUs) from earlier Health Information Exchange (HIE) structures and published an HDU framework detailing their advantages in partnership with the Maryland Health Care Commission. These documents are available on the Civitas Networks for Health website on the [Resources](#) page. In short, HDUs are nonprofits characterized by cooperative leadership, publicly designated authority, and advanced technical capabilities to combine, enhance, and exchange electronic health data across care and service settings for treatment, care coordination, quality improvement, and community and public health purposes while maintaining the highest standards of privacy and security. If HIEs in their original form represent a “pre-pandemic” standard for operationalizing health data for public and community benefit, then HDUs represent the evolving “post-pandemic” framework that is broader, deeper, more self-sustaining, and better positioned for future health challenges.

FEEDBACK ON PAHPA DISCUSSION DRAFT

First Priority: Include HIEs and HDUs in PAHPA provisions for “State and Regional Systems to Enhance Situational Awareness in Public Health Emergencies” (Section 319D of the Public Health Service Act)

We urge the Senate HELP Committee to explicitly include HIEs and HDUs as entities that States, or consortia of States, must collaborate with as part of the existing grant provisions under PHSA SEC. 319D, Subsection (d), and by extension the new Public Health Data Pilot Program envisioned by the discussion draft (the proposed PHSA SEC. 319D-2). Below is the suggested language:

Under SEC. 205. PILOT PROGRAM FOR PUBLIC HEALTH DATA AVAILABILITY

(Line 1 of page 28), insert

(iii) By inserting “health information exchanges, health data utilities,” after “public health agencies,”

OR

Section 319D of the Public Health Service Act (42 U.S.C. 247d–4) is amended—

(1) In subsection (d) –

(A) In paragraph (1) –

(i) By inserting “health information exchanges, health data utilities,” after “public health agencies,”

Rationale: Since the last PAHPA reauthorization in 2019, HIEs and the HDUs that have developed from them have become even more central components of health infrastructure for public authorities around the country. HIEs and HDUs’ role in interoperable networks has expanded beyond clinical health data exchange use cases to cover a wide range of operational, financial and logistical functions, and their value as critical infrastructure for public health departments and provider organizations will only increase over the coming years.

In many states, HIEs and emerging HDUs were the backbone of strategic, coordinated, and efficient pandemic response during the COVID-19 pandemic. These networks rapidly deployed cross-cutting solutions to share critical lifesaving data on the spread of the virus, bed availability, and demographic impact that allowed for necessary prioritization of resources—generating substantial new insights for public health authorities in many states. HIEs and emerging HDUs have a strong commitment to community governance as well as security and privacy that builds trust and facilitates long-term local partnerships, allowing them to quickly identify solutions to complex problems. HIEs and HDUs exchange millions of pieces of public health information on a daily—even hourly—basis to create and maintain more comprehensive accounts of provider, payor, patient, and population needs than has ever previously existed. As such, they are critical partners for the long-term success of the federal government’s data modernization enterprise.

Accordingly, the next iteration of PAHPA needs to reflect the integral role that HIEs and HDUs currently play in public health information systems if Congress wants to maximize the effectiveness of its legislative effort and taxpayers’ return on investment. The lessons of COVID-

19 can be incorporated into a wide range of PAHPA readiness and response programs; with these comments, Civitas has attempted to highlight the sections of the discussion draft and corresponding PHSA provisions where the most concise changes to accommodate HIEs and HDUs can have the greatest potential impact.

Of these changes, Civitas' top priority is the explicit inclusion of HIEs and HDUs in PAHPA's grant authorization for "State and Regional Systems to Enhance Situational Awareness in Public Health Emergencies" as part of "modernizing public health situational awareness and biosurveillance" in PHSA Section 319D. This part of the text is notable because the 2019 PAHPA language already includes some elements of HIE and HDU structure and function in its description of "an interoperable network of systems to share data and information that is de-identified...and built on existing State situational awareness systems" (Subsection c), which HHS has the authority to help "implement" through "grants to States or consortia of states" (Subsection d). Civitas and its members appreciate that the discussion draft doubles down on the importance of the grants by mandating that the Department of Health and Human Services actually issue them (changing "Secretary may" to "Secretary shall" in line 17, page 27 of the draft) and by enhancing this part of PAHPA with a new "Public Health Data Pilot Program."

Civitas' proposed language would make HIEs and HDUs a required part of the state-level "interoperable networks" to be funded—because they are already key parts of these networks on the state and regional levels—and part of the new Public Health Data Pilot. The funding authorized would allow states to make capital investments in HIE and HDU-enabled surveillance capabilities, and to rapidly bring those capabilities online alongside other data collection, sharing, and analysis functions that were refined during the COVID-19 pandemic and continue to develop. While many HIEs and (especially) HDUs do have their own regular sources of operational revenue via provider and payor fees, the resources to make larger-scale investments on an accelerated timeframe have been more difficult to find since the end of HITECH Act incentive payments in 2021, coupled with regulatory limits on how states can fund their Medicaid Management Information Systems (MMIS) that continue to be imposed by CMS and OMB.

Second Priority: Include HIEs and HDUs in PAHPA provisions for "State and Regional Hospital Preparedness to Improve Surge Capacity" (Section 319C-2 of the Public Health Service Act)

We encourage the Senate HELP Committee to update the existing community and hospital preparedness grant program under PHSA SEC 319C-2 by including HIEs and HDUs as coalition members and coordinating stakeholders. Below is the suggested language:

Under SEC. 103. IMPROVING MEDICAL READINESS AND RESPONSE CAPABILITIES

(Line 17 of page 8), insert

"...under subsection (b)(1)(A) and, as appropriate, including health information exchanges, health data utilities, and other coalitions that are in close geographic proximity to each-other."

OR

Section 319C-2 of the Public Health Service Act (42 U.S.C. 247d–3b) is amended—

(1) In subsection (b) –

In paragraph (1) –

By adding new subsection (v) that says, “one or more health information exchanges and/or health data utilities.”

Rationale: The rationale for the second priority is similar to the first. As currently written, PAHPA’s grant program supporting “Partnerships for State and Regional Hospital Preparedness to Improve Surge Capacity” (PHSA Section 319C-2) predates COVID-19’s unprecedented real-life test of hospital preparedness and surge capacity. Multiple waves of acute COVID case surges over 18 months proved the value of high-capacity, flexible, and interoperable health data systems that could rapidly assimilate patient and provider information from multiple sources and cross-reference it with the needs of public health authorities. HIEs and HDUs were at the core of these systems for the hospitals and communities within their jurisdictions (typically statewide service areas, or large geographic regions within the largest states), while also assisting the CDC, ONC, CMS, ASPR, and other federal agencies.

These HIEs and HDUs will be the systems in place during any future pandemic, which is why requiring them to be part of the state, local government, and hospital grantee coalitions described in 319C-2 is a valuable revision to the PAHPA text. The discussion draft already reauthorizes funding for this grant program at \$385 million annually between 2024 and 2028. With the recommended language change, the funds can also support investments in HIE and HDU hardware, software, and personnel training integrated into larger preparedness regimes that further break down information “siloes” between stakeholders to improve coordinated action.

Other Changes to Consider: Include HIEs and HDUs in the following lines of the discussion draft to ensure their integration into the new pilot program consultative process and the associated National Public Health Data Board. Below is the suggested language:

Under SEC. 205: PILOT PROGRAM FOR PUBLIC HEALTH DATA AVAILABILITY

(Line 21 of page 26), insert

(II) by inserting “the sharing of information from applicable public health data systems, including state health information exchanges and health data utilities, as allowed by law.”

(Line 8 of page 27), insert

(C) by inserting “facilitate bidirectional communication between agencies and offices of the Department of Health and Human Services and State, local, and Tribal public health officials, leveraging state health information exchanges and health data utilities to the extent practicable.”

(Line 23 of page 31), insert

by inserting a new section “(cc) state health information exchange and/or state health data utility infrastructure.”

Rationale: Should the HELP Committee have enough time and latitude during the drafting process, Civitas has included for consideration three additional changes to Section 205 of the discussion draft that would further reinforce HIE and HDUs' place in the next version of PAHPA. The first change would ensure that HIEs and HDUs operating on the state and regional levels are part of the mandated "coordination and consultation" process for developing the "interoperable network of systems" described in PHSA Section 319D, subsection (c) alongside ONC and other HHS agencies. Given that PAHPA already describes the network as "built on existing State situational awareness systems," formalizing consultation with state-level HIEs and HDUs is a logical update to the text. The second change would likewise add HIEs and HDUs to the next paragraph of PAHPA on "bidirectional communication" between federal, state, local, and tribal authorities for the sake of consistency. The third change is the most significant, in that it would specifically make HDI and HDU representatives non-federal members of the new "National Public Health Data Board" (proposed PHSA Section 319D-2, Subsection (b)) alongside federal members including the heads of ONC, CDC, ASPR, and CMS. The discussion draft creates this Board to oversee the planned public health data pilot, which makes giving it an HDI/HDU voice important to ensure the effectiveness of state and regional-level surveillance and coordination activities.

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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