Preparing for the Next Pandemic

June 26, 2020

The Honorable Lamar Alexander
Chairman
U.S. Senate Committee on Health, Education, Labor and Pensions
455 Dirksen Senate Office Building
Washington, DC 20510

Submitted electronically to PANDEMICPREPAREDNESS@HELP.SENATE.GOV :

Re: Request for Input, Preparing for the Next Pandemic White Paper

Dear Senator Alexander,

On behalf of the Strategic Health Information Exchange Collaborative (SHIEC), which represents more than 80 health information exchanges (HIEs) and health information networks (HINs) across the nation, we are pleased to have the opportunity to provide input on this pandemic preparedness white paper. As the keepers, aggregators, normalizers, and connecters of health data, America's HIEs are uniquely positioned to aid their states and communities in times of crisis. HIEs have supported their communities through hurricanes, wildfires, and other public health emergencies for years. Just as SHIEC previously provided feedback on the drafting of the latest reauthorization of the Pandemic and All-Hazards Preparedness Act (PAHPA), we appreciate the opportunity to respond to this RFI and, in so doing, to emphasize the critical role that HIEs can and do play in the public health infrastructure.

As the unbiased, vendor-neutral data trustees for their communities, SHIEC member HIEs serve more than 92% of the United States population and are critical to achieving better health care and quality in America. HIEs uniquely provide patient-level identity resolution services and linking of data beyond certified electronic health record systems, including data from pharmacies, post-acute care, behavioral health, social services, and many others. The dedication, energy, and passion exhibited by SHIEC's member HIEs over the past 20+ years have laid the foundation for nationwide health data interoperability in our communities and regions.

We have highlighted the specific sections and questions SHIEC is responding to on behalf of our members below:

Disease Surveillance – Expand Ability to Detect, Identify, Model, and Track Emerging Infectious Diseases

1. *What other barriers, in addition to limited testing capacity, and insufficient and outdated technology, make it difficult to detect and conduct public health surveillance of emerging infectious diseases?*

   The national public health infrastructure is a patchwork of state-based systems that do not interoperate and that lack appropriate health information technology due in large part to chronic underfunding. The COVID-19 pandemic has laid bare the inadequacy of the current public health communications and surveillance networks and systems and the need for funding and modernization.

   The pandemic has also revealed an alarming lack of awareness and understanding of existing health information technology infrastructure, leading to a delayed reliance by those tasked with leading the COVID-19 response on the existing networks and a push to spend significant sums building systems and networks from the ground up. As a relatively young trade association, SHIEC has already established a track record of proactively conducting outreach and education with lawmakers and health care stakeholders on the benefits of HIE. However, overcoming the knowledge gap has been challenging, especially since many policymakers and health care providers think only of EHRs when they think of health information technological infrastructure. Congress has authorized and appropriated hundreds of millions of dollars to help create and integrate regional and statewide HIEs and HINs all over the country. Given this years-long and substantial financial investment, it appears Congress intended to support and build out HIE technology in regions, states, and nationwide. To demonstrate this Congressional intent, any legislation or programs related to public health surveillance, health data exchange, and technological infrastructure should specifically mention HIEs and HINs. Furthermore, public health officials should be encouraged to educated themselves about any and all HIEs and HINs serving their states or communities.

   More directly, the substantial investment by the Federal Government and individual states that has already been made to develop and integrate HIEs and HINs should continue with enhanced federal matching assistance. The HITECH Act, passed as part of the 2009 ARRA stimulus, moves from a 90-10 to a 75-25 federal-state match in 2021 and, as currently constructed, the activities that can be conducted with these funds will change and become more limited. Especially in light of nationwide state budget shortfalls the Federal Government should commit to, at least temporarily, increasing its assistance to 100% of the FMAP.

   Similarly, the SUPPORT Act passed in 2018 to combat the country's opioid crisis included funding to help states integrate with HIE and HIN services such as Prescription Drug Monitoring Programs (PDMPs). These funds expire later this year and should be extended. States that were in the process of SUPPORT Act-related HIE integration have had to halt that work to address COVID-19 and therefore have not been able to take advantage of the SUPPORT Act's provisions under the originally-envisioned timeline.

Funding made available in HITECH and the SUPPORT Act demonstrates Congress' commitment to HIEs and HINs, but these investments are at risk of being wasted if they are not renewed. There is no need for states or the Federal Government to start from scratch when HIEs offer infrastructure that already covers most patients in the nation. Federal dollars could be better spent expanding the reach of HIEs and helping state and local governments connect to the HIEs serving their communities.

3. *What privacy protections should accompany new technology? Would these technologies be utilized and maintained by HIPAA-covered entities or others?*

   HIEs are generally covered by HIPAA under Business Associate Agreements (BAAs). HIPAA already includes requirements around individual consent, individual right of access, individual right to corrections, data retention, and security requirements. Therefore, SHIEC asks that any additional legislation include an exception or safe harbor for entities that are already subject to HIPAA. HIPAA also already allows for public health disclosures, so there should not be an immediate need to create additional public health surveillance privacy regimes to counter the current and future pandemics.

   It would be helpful for Congress to consider and understand the patchwork of state and federal regulations regarding privacy. SHIEC was pleased to see that 42 CFR Part 2, which governs substance use data, was amended to conform more closely with HIPAA in the CARES Act. Several states have substance use disorder data privacy laws that are more stringent than Part 2, which means that HIEs operating in those states must continue to bifurcate different types of patient data. This is onerous, and HIEs generally err on the side of caution when unable to segregate data rather than transmit health information that would be a breach of privacy. As the country pursues more meaningful interoperability and HIEs serve patients across state lines, this issue will need to be addressed.

6. *How can the private sector innovations to support and modernize federal and state surveillance be better leveraged?*

   The Federal Government should support public-private partnerships to enhance and conduct meaningful public health surveillance. The private sector can drive advancements in technology, but without public sector resources and access, technology alone will not be sufficient to conduct meaningful health surveillance. HIEs have created vendor-agnostic technology that allows them to translate and share varied health records and software. HIEs also offer bidirectional data sharing, but this only works when public health agencies, and public and private laboratories share their data with HIEs. Throughout the COVID-19 pandemic, several states have directed labs to share information with state and federal health agencies, but not to HIEs. This monodirectional data-sharing creates holes in the surveillance apparatus, leaves providers out of the loop, and creates an incomplete understanding of community health. The public sector could leverage the vendor-agnostic data-sharing technology offered by HIEs and improve it by encouraging bidirectional flow of information.

SHIEC emphasizes the importance of continued financial investment in HIEs and HINs, as well as the investment of time and attention of public health officials at every level of government.

Public Health Capabilities – Improve State and Local Capacity to Respond

1. *What specific changes to our public health infrastructure (hospitals, health departments, laboratories, etc.) are needed at the federal, state, and local levels?*

   HIEs are part of the existing public health infrastructure but can be greatly enhanced with more bidirectional data-sharing capabilities with federal, state, and local public health and health care authorities, in order to better prepare for and respond to health crises. The White House has considered building out new public health surveillance systems in response to COVID-19 when it would be more efficient to encourage connection with existing HIEs already serving most of the country. Federal, state, and local health departments should be encouraged to exchange data with HIEs. Throughout the COVID-19 crisis, HIEs have shared laboratory testing data, ICU bed and ventilator availability, and monitored demographic disparities.

   Health departments and other stakeholders should be encouraged to utilize HIEs wherever possible to satisfy data sharing requirements. Recently HHS released guidance regarding COVID-19 data reporting by laboratories. In this guidance, dated June 4, 2020, HHS enumerated three methods by which these reporting requirements could be satisfied, one of which was through a state or regional HIE. This language was helpful to the public entities collecting the data, demonstrated a federal commitment to leveraging HIE infrastructure, and HIEs are confident that providers who opt to use HIEs for data reporting will find the systems user friendly.

2. *What changes can be made to Public Health Emergency Preparedness and Hospital Preparedness Program to help states prepare and respond more quickly?*

   SHIEC's members have been supporting communities in crisis long before the COVID-19 pandemic. SHIEC HIEs have thwarted ransomware attacks, backed up health systems in communities devastated by natural disasters like hurricanes and wildfires, and stood up services like PDMPs and immunization monitoring. SHIEC was involved in the most recent reauthorization of the Pandemic and All Hazards Preparedness Act (PAHPA), advocating for broader language about which organizations should be involved in pandemic preparedness. SHIEC was happy to see language we recommended around "technological infrastructure" included in PAHPA, where previous authorizations had left technology out of preparedness conversation. SHIEC encourages Congress to continue to open eligibility for the Public Health and Emergency Preparedness Program (PHEP) and the Hospital Preparedness Program (HPP) and to include more community entities in pandemic preparations.

Stakeholders under these programs should include private sector entities like HIEs and HINs, especially when those entities are engages in public-private partnerships.

3. *How can the federal government ensure all states are adequately prepared without infringing on states' rights and recognizing states have primary responsibility for response?*

   SHIEC's membership includes approximately 80 HIEs across the country, and while each one does the critical work of sharing health data and connecting stakeholders within a given state or community, each HIE differs in important ways. HIEs are purpose-built to meet the unique needs of the communities and states they serve. They operate according to the governance, stakeholders, and laws particular to their localities. The deviations in state laws regarding substance use data perfectly illustrates these differences.

   By continuing to support and invest in state and regional HIEs, the Federal Government will advance public health surveillance infrastructure while respecting the bounds of states' rights. By including HIEs in any legislation or guidance promulgated around public health and surveillance, the Federal Government can demonstrate support of HIEs that meet the needs of their communities. State and local health leaders should take this cue and should also be actively encouraged to understand which HIEs and HINs serve their states and regions.

4. *How should the federal government ensure agencies like CDC maintain an appropriate mission focus on infectious diseases in the periods between emergencies to strengthen readiness to respond when a new threat arises?*

   SHIEC strongly believes that long-term changes to the way public health response is funded in this country are urgently needed. Emergency supplemental funding is important to respond to public health emergencies like the COVID-19 pandemic, but supplemental and short-term appropriations do not allow for sustained investments in the public health infrastructure and pandemic preparedness activities. Senator Bill Frist's testimony to the Senate HELP Committee illustrated these issues perfectly:

   "*Future health and economic security can best be protected by changing the way we allocate funds to protect us all from health threats. We have all seen the limitations that caps and sequestrations cause for discretionary funding. We have seen that even mandatory funding doesn't ensure stable support as those funds are often siphoned off during calm periods when outbreaks are out of the news. We propose a new approach for specific public health programs that are critical to prevent, detect, and respond to health threats.*

   We call this the Health Defense Operations (HDO) budget designation, and it would exempt critical health protection funding lines at the CDC, NIH, FDA the office of the Assistant Secretary for Preparedness and Response from the spending caps so our public health agencies can protect us."

SHIEC is supportive of this or other long-term, proactive funding for pandemic preparedness, and we would also stress that long-term, proactive funding for the public health data infrastructure should include funds to further integrate HIEs and HINs into local, state, and federal public health response systems, in order to make the best use of investments already made by Congress, the Federal Government, and the states.

We appreciate the opportunity to provide our feedback on this important work. For follow-up questions or resources about SHIEC's membership, please contact SHIEC's CEO, Kelly Thompson, at kelly.thompson@strategichie.com.

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