



October 20, 2023

The Honorable William Cassidy, M.D.  
428 Dirksen Senate Office Building  
Washington, DC 20510

RE: Centers for Disease Control and Prevention (CDC) Modernization Request for Information

*Submitted Electronically to CDCModernization@help.senate.gov*

Dear Ranking Member Cassidy:

Thank you for the opportunity to respond to your request for information on how to improve the Centers for Disease Control and Prevention (CDC). The Health Innovation Alliance (HIA) has been focused on improving public health data use and reporting for some time, but the failure of our public health system the last few years is unacceptable. We look forward to working with you and your office to advance our recommendations, including:

- Authorization of the CDC to establish clear authority and limitations as well as requirements to cooperate with other offices and agencies in the federal government;
- Regular, transparent, and public meetings with private sector experts;
- Partnership with the private sector to ensure CDC's success, including developing and operating a modern public health data network through existing technologies;
- Ensuring CDC does not try to rebuild private sector capabilities in-house at the agency;
- Incorporating real-world data into public health analyses;
- Streamlining the grant process to make them more open, accessible, and transparent, as well as including accountability and core competency requirements of state and local public health systems;
- Implementing the 2006 law requiring an interoperable network of public health data;
- Ensuring bidirectional exchange of public health data; and
- Including industry-backed standards across the health care system, including standards used at pharmacies where the majority of Americans get their vaccinations.

HIA is a diverse coalition of patient advocates, healthcare providers, consumer organizations, employers, technology companies, and payers who support the adoption and use of technology and data to improve health outcomes and lower costs. We hope you will consider our comments as you work to reform the CDC.

### **Mission Creep and CDC Authorization**

HIA believes that Congressional authorization of CDC can help clarify CDC's role and its cooperation and coordination with other agencies in the federal government. CDC should not stray beyond core public health activities at the expense of those operations being ready to deploy at a moment's notice. Congress

should set clear duties and accountability for the agency to ensure its success. The agency can still be nimble and adjust to changing needs, but core competencies must take priority. Additionally, CDC's role must be clear with respect to other public health authorities like the Administration for Strategic Preparedness and Response (ASPR), the National Institute for Allergy and Infectious Diseases, the Department of Defense, states and localities, and others. HIA learned of many instances where CDC and ASPR failed to act effectively and efficiently because of bureaucratic turf wars. Clear duties and guardrails will help ensure appropriate function of the CDC and its coordination with other offices and agencies across the federal government.

We believe that partnership with the private sector should be a key priority for CDC going forward. As noted in the CDC Foundation's Summit 4 Action report, there is a recognized need to "strengthen partnerships between business and public health" as well as "invest in data systems integration for cross-sector partnerships."<sup>1</sup> A focus area should be greater engagement and data linkages with the private sector as this will enhance the agency's effectiveness for its ongoing public health work as well as preparedness and response to emergencies. CDC is uniquely positioned to support data linkages across multiple data sets acquired through federal, state, and local agencies.

Private sector partners can facilitate this data linkage through innovative solutions such as data enhancement and enrichment which incorporates new sources of data to improve quality. CDC may also consider tokenization techniques to improve quality of the data and ability to randomize data on individuals. This will help to identify any trends that may be occurring that will impact the overall public in the event of a public health emergency. Additionally, by collecting data over time, CDC can identify trends and coordinate with other agencies within HHS to improve data collection in programs to measure their efficacy in improving public health. Strengthening these partnerships with the business sector before the next emergency will enable our country to more rapidly respond to threats that can occur at any time.

## **Leadership Structure and "Moving Forward" Reorganization**

HIA supported making the CDC Director a Senate-confirmed position, as required by the 2023 Omnibus Appropriations bill. Requiring a nominee to go through the Senate hearing and confirmation process will give the role of CDC Director a higher profile and increase the accountability of the position and the CDC itself. HIA feels this was an appropriate move to shore up CDC's leadership and culture and to bolster coordination within the CDC and with other offices and departments.

We also believe there should be more transparency and direct engagement with private industry as the CDC and others at HHS work on modernization. The United States is the global leader in information management systems. It would be a disservice not to tap into this expertise in ways that are both meaningful and transparent to taxpayers. We suggest requiring the CDC to engage directly with the private sector on data modernization through at least quarterly meetings with stakeholders.

The Food and Drug Administration (FDA) conducts many public and private meetings with the industry to inform the FDA's work, inform industry of the FDA's thinking, and create an environment of collaboration between the public and private spheres. The CDC should hear directly from industry on capabilities in development and in use in the private sector that could be adopted or modeled by the CDC. The private sector should also hear what the CDC is thinking and be given the opportunity to provide comments and advice to the CDC as it works to improve public health. Establishing a process like this will not only provide a public view of the CDC's progress but will also create more support and buy-in on

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<sup>1</sup> [https://futureofpublichealth.org/wp-content/uploads/2022/08/LC\\_Summit-4\\_Accelerating-Action-Report-1.pdf](https://futureofpublichealth.org/wp-content/uploads/2022/08/LC_Summit-4_Accelerating-Action-Report-1.pdf)

the CDC's efforts. These stakeholder meetings could also address public concerns with the privacy and use of public health information by informing the public of current data protections and giving the CDC an opportunity to learn about common privacy and security practices in use outside of government. We believe requiring the CDC to engage with stakeholders will further the potential for success for all parties involved.

Further, the CDC should build on a foundation of what works. Over the past three years, there have been immense resources provided to the CDC and other public health agencies specifically for data modernization and infrastructure updates. Instead of using that money to build in-house systems that would duplicate work that has already been done, Congress should focus on ensuring agencies partner with, or at the very least include, experts who have developed technology and systems from the ground up.

We urge you to require the CDC and its state and local partners to collaborate with private industry to modernize our public health data network. This public health network should not be built in-house by the government. It should be built, maintained, and operated by the private sector through grants, contracts, or cooperative agreements with trusted entities that have experience and expertise in public health information, interoperability, and privacy and security. Any contract to build the system should be open, transparent, and competitively bid.

### **Morbidity and Mortality Weekly Reports Development**

CDC's Morbidity and Mortality Weekly Reports (MMWRs) are an important resource for health care providers and individuals in public health. These reports also provide the most recently available quality data on the science in the field. We agree that data can lag longer than the public would like, as it is important for data to be accessible to the public in a form that can be analyzed effectively for decision making. The mission of the CDC's Center for Forecasting and Analytics shows promise as a supplement to MMWRs.

Incorporating best practices in data analytics and real-world data can help CDC to ensure that the MMWR weekly reports are informative, insightful, and actionable. This requires a structured approach to data analysis, utilizing appropriate statistical techniques, and leveraging specialized tools and techniques for real-world data analytics. The use of real-world data and analytics involves the analysis of large and complex data sets to identify patterns, trends, and insights. It requires specialized tools and techniques to handle the volume, velocity, and variety of data being analyzed. Some best practices for real-world data analytics include data visualization, machine learning, and predictive modeling. These techniques can help to uncover insights that may not be apparent through traditional data analysis methods. CDC should also consider tokenization techniques to improve the quality of the data and ability to randomize morbidity and mortality data on individuals to identify any trends that may be occurring that will impact the overall public. By enriching existing data with additional information, it will become more valuable and useful to private and public stakeholders.

Additionally, it is important to consider the impact of social determinants of health (SDOH) on the data and ensure that the MMWR reports reflect this information and derived insights. Beyond next-generation tokenization, private sector partners can provide data enrichment to the CDC program's focus areas – SDOH, medical claims, mortality, and geolocation – to paint a whole-person picture of its population. Utilizing identity and medical claims insights can enhance the agency's understanding of the current and historical trajectory of person-centered health outcomes through longitudinal insights.

By following these best practices, CDC can effectively communicate insights to government stakeholders more effectively during a public health emergency. Leveraging key private sector expertise will allow CDC to regain the public's trust and build a truly reliable and authoritative public health monitoring and reporting system.

### **State Block Grant Programs**

HIA believes that CDC should recognize and support state public health surveillance networks that work. Many states have successful surveillance networks that report near real-time, accurate data. CDC should work to model these state systems for adoption by other states and stay away from a central database. CDC's Vaccine Administration Management System (VAMS) program had a poor implementation, demonstrating that the CDC needs help navigating something as straightforward as vaccination scheduling.

Congress should encourage the improvement of existing state systems to ensure their continued use, including robust protections for the privacy and security of the information included. There are legitimate reasons that the CDC would need certain data collected by state and local level surveillance systems, but that data should be aggregated, deidentified information with additional parameters placed on use, reuse, and sharing. We also urge you to require direct consumer access to one's own immunization information to streamline data collection for families and individuals that need proof of vaccination for travel or other purposes.

Simplification of the grant application and submission process would benefit all states seeking funds to support the variety of CDC projects with their populations. Centralizing these into a single grant system with clear application, prerequisites, and contract line item numbers would streamline processes, reducing administrative overhead and need for additional staffing to obtain funds. Such a grant system should be completely transparent and available for public access and Congressional scrutiny.

States would also benefit from a wider variety of block grant funding to modernize, integrate, and enrich their population data. Current funding is generally specific to individual disease states or initiatives and while this benefits individual research opportunities resulting in siloed and disparate data that is difficult to update and enrich for research. Regardless of the individual initiative, state data collection should be standardized, centralized, and leverage a robust matching methodology that grants accuracy and precision with the flexibility to expand context through real-world data. Congress should focus on opportunities for broader modernization and standardization within each state.

As part of the CDC's mission for prevention and rapid response, a block grant structure could be put in place to enable rapid-response initiatives through infrastructure and contracting mechanisms for turn-key activation during future public health emergencies. Block grants for components of this prevention and response infrastructure could include needs for services in the areas of data aggregation; identity resolution; tokenization for deduplication, matching, deidentification, and data sharing purposes; mechanisms for transmission during the event, contact tracing infrastructure and applications; capacity tracking and insights on facilities, hospitals, and equipment; and socio-economic risk factors to enrich their understanding of the affected population. By creating a prevention and rapid response infrastructure grant, states could procure funds and contract to establish the bridges and pipes that will help to enable an effective public health response as future pandemic, epidemic, or infectious disease events occur.

Finally, Congress should encourage accountability among CDC grantees, including states and localities. Local and regional public health authorities should have core capabilities that are tested and certified to ensure functionality and operational integrity.

## **Data and Surveillance**

Since the passage of the 2006 Pandemic All-Hazards Preparedness Act, CDC has been directed to establish:

*“a near real-time electronic nationwide public health situational awareness capability through an interoperable network of systems to share data and information to enhance early detection of, rapid response to, and management of, potentially catastrophic infectious disease outbreaks and other public health emergencies that originate domestically or abroad. Such network shall be built on existing State situational awareness systems or enhanced systems that enable such connectivity.”<sup>2</sup>*

Seventeen years, an extensive amount of additional funding, and one global pandemic later, the provision still has not been implemented. The CDC is unable to accomplish its mission because it has not followed existing Congressional direction.

Despite failing to implement the law, the CDC is requesting increased funding and more authority over the public health system to develop in-house capabilities to collect public health data directly from state and local authorities and anyone else it chooses. This expanded authority and mission creep would duplicate successful public health work already occurring in the private sector and create additional reporting burdens for front-line providers and public health officials. Policy in this area should focus on the CDC complying with the intent of the original 2006 law along with subsequent reauthorizations but also guarantee that CDC leverages existing infrastructure before building a new and expensive in-house system.

Recently, the CDC has been using an updated data use agreement in its negotiations with states in an effort to gain more direct access to more types of information, including individually identifiable health information. We urge you and your colleagues to request copies of these data use agreements and to ask CDC how it intends to use the data. Specifically CDC should provide Congress with details on how it plans to align and resolve discrepancies among data collected from states and localities, how it plans to maintain an accounting of disclosures of the data collected to ensure compliance with data use and disclosure allowances under the agreements, how CDC will share this data with states and localities to improve local public health operations, and how CDC plans to help states and localities comply with requirements under the data use agreements.

Congress has an opportunity to streamline and simplify data collection, aggregation, and deidentification of data across CDC’s federal, state, and local agency partners in support of prevention and response initiatives. The current decentralization of this information makes it challenging to gain a comprehensive and accurate view of the current disease state, especially when compounded with duplication and a rapidly changing population. Incorporating CDC and industry data sets can fill demographic holes that might be present on key populations, shed a light on socioeconomic risk factors impacting the effected

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<sup>2</sup> P.L. 109-417, §202, available at <https://www.govinfo.gov/content/pkg/PLAW-109publ417/pdf/PLAW-109publ417.pdf>

population, identify capacity and specialties for facilities and treatment, and potential equity risk factors impacting access to those services.

Additionally, providers on the ground caring for patients and exposing themselves to pathogens deserve to have robust public health information shared back with them to inform their decision-making and better coordinate a response. Simply requiring providers to report information to the CDC and having that information shared between federal bureaucrats is not enough. We urge you to include laboratory information and the sharing of data back with providers as requirements of this system. This will add value to healthcare providers who see little return on burdensome public health reporting.

To ensure deidentification and a high degree of security, Congress should consider requiring CDC to adopt the best practice of marrying disparate datasets through hashed and encrypted information as well as selecting a tokenization vendor that leverages a robust set of secure attribute hashes for precise identity matching. Taking this approach across surveillance systems would enable them to significantly reduce discrepancies and duplication by accurately linking disparate datasets with precision for research.

HIA supports requiring the CDC to designate data and technology standards in consultation with the Office of the National Coordinator for Health Information Technology (ONC) within two years as required by the Omnibus last year. There is a need to have common data sets and elements across public health, and we believe HHS should encourage the harmonization and use of standards to improve data collection, dissemination, exchange, and use. The CDC and ONC have been narrowly focused on FHIR standards. We encourage your offices to require all ANSI-accredited SDOs to be included in public health standards development and adoption to ensure all applicable public health data is used in CDC decision making. Specifically, we urge you to include pharmacy transactions to ensure that the many public health activities in pharmacies are incorporated into the desired future state of an interoperable public health system. Throughout the COVID-19 pandemic, Americans across the country have relied upon their neighborhood pharmacies for testing and vaccinations. The inclusion of pharmacy information systems in these data standardization activities will help ensure a more complete picture to inform our public health capabilities.

Thank you again for the opportunity to respond to your RFI. We look forward to working with you to improve our public health system and ensure we do not repeat the failed policies of the COVID pandemic.

Sincerely,



Brett Meeks  
Executive Director