June 25, 2020

Senator Lamar Alexander
Chairman
US Senate Committee on Health, Education, Labor, and Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

RE: Preparing for the Next Pandemic

VIA E-MAIL

Dear Chairman Alexander:

Thank you for the opportunity to provide feedback on the white paper entitled "Preparing for the Next Pandemic." The coronavirus pandemic has had a devastating effect on the nation, and now is the time to prepare for the next inevitable widespread disease to ensure our country is well-resourced to handle new and emerging threats.

AHIMA is a global nonprofit association of health information (HI) professionals. AHIMA represents professionals who work with health data for more than one billion patient visits each year. AHIMA's mission of empowering people to impact health drives our members and credentialed HI professionals to ensure that health information is accurate, complete, and available to patients and clinicians. Our leaders work at the intersection of healthcare, technology, and business, and are found in data integrity and information privacy job functions worldwide. AHIMA members also bring the expertise around health information and data that is necessary to inform disease surveillance, including public health, social determinants of health (SDOH), and privacy implications surrounding that data.

We appreciate the Chairman's commitment to addressing specific issues and gaps identified during the COVID-19 pandemic. To address the readiness of disease surveillance systems within the US, AHIMA has identified three critical areas of focus: (1) accurate patient identification; (2) protections for consumer privacy when an individual's data in maintained by a HIPAA non-covered entity , and; (3) the need for comprehensive data collection for public health.

Accurate Patient Identification

Issue 2.4 in the white paper notes that "improving public health data systems at the state and local levels, as well as the Centers for Disease Control and Prevention (CDC), are needed to support an effective biosurveillance system in the future." But to improve public health data systems, we must first ensure that the patient information within these systems is accurate.

Patient misidentification has long been an issue for patient care. Today, lack of widespread operational principles as well as limitations in processes and technologies result in inaccurate patient identification.

For two decades, innovation and industry progress has been stifled due to a narrow interpretation of language in Labor-HHS appropriations bills that prohibits the US Department of Health and Human Services (HHS) from spending any federal dollars to promulgate or adopt a national unique patient identifier (UPI).

While this issue is an immense risk to patient safety (so dire, in fact, that the ECRI Institute named patient misidentification among the top ten threats to patient safety), it has major public health implications as well for both the current pandemic and future epidemics. Accurate identification of patients is one of the most difficult operational issues during a public health emergency, including the collection of patient demographic data (e.g. – name, address, phone number) and ensuring medical information remains attached to the correct patient. Field hospitals and temporary testing sites in parks, convention centers, and parking lots exacerbate these challenges. Evidence suggests that since the beginning of the COVID-19 pandemic, ensuring the return of laboratory results to the correct individual has been challenging given the inconsistent and scant amount of demographic information included with the sample.

Ensuring the correct patient medical history is accurately matched to the patient is critical for both short-term and long-term public health responses to widespread diseases. A complete and accurate health record is essential for tracking the long-term health effects of diseases like COVID-19. Contact tracing also relies on accurate demographic information to verify any exposure to a virus. Furthermore, large-scale immunization programs also depend on accurate patient information to identify who has had the disease, who has been vaccinated, and what their outcomes are.

Despite the importance of accurate patient information, the lack of a nationwide patient identification strategy means that the underlying data informing public health may not always be correct. Public health agencies, including the CDC, are increasingly relying on electronic health record (EHR) data in their disease surveillance systems. In a recent AHIMA survey of health information (HI) professionals, nearly 20 percent of respondents noted that their EHRs have error rates of over four percent. HI professionals handle millions of patients in their databases, so even a small percentage of incorrectly matched patient records can result in hundreds of thousands of incorrect records feeding into the public health surveillance systems.

Congress must take swift action to address the issue of patient misidentification and its implications for public health data. Removing Section 510 from the Labor-HHS appropriations bills would allow HHS the ability to evaluate a range of patient identification solutions and would enable it to work with the private sector to identify a solution that protects patient privacy and is cost-effective, scalable, and secure.

Protections for Consumer Privacy

While in the course of a pandemic it is likely that entities covered by the Health Insurance Portability and Accountability Act (HIPAA) will utilize and maintain a large portion of technology related to health information. However, the growing availability of consumer-facing health-related technologies, applications (apps), products, and services suggests that an increasing number of HIPAA non-covered entities are entering the health data space. While encouraging innovation is necessary, especially concerning pandemic response and preparedness, consumer privacy must be protected.

AHIMA is concerned that these technologies, applications, products, and services that access, produce, and manage health information may not be bound by or required to abide by the rules established under HIPAA because they are not considered "covered entities" or "business associates." To ensure the confidentiality, privacy and security of individuals' health information, AHIMA believes any related privacy protections accompanying such new technologies must:

- Guarantee individuals' access to their health information regardless of where it travels;

- Improve accountability by ensuring that data holders develop, document, communicate, assign, and are held accountable for their privacy policies and procedures;

- Enhance communication and transparency including what information will be collected and maintained, and generally how the data may be processed and disclosed, including whether data will be sold or commercialized;

- Limit the collection, use, and disclosure of health information to the minimum necessary;

- Ensure the accuracy, completeness, and integrity of health information;

- Prioritize the protection of health information against various privacy and security risks, including breaches and unauthorized disclosures;

- Address health information retention concerns to safeguard that health information is retained no longer than necessary by data holders;

- Facilitate disposition and destruction of health information; and

- Assign appropriate oversight and enforcement responsibilities including the designation and adequate funding of oversight and enforcement responsibilities.

AHIMA believes the privacy principles outlined above should apply to the protection of health information through its entire lifecycle, and are not intended to supersede, alter, or affect HIPAA. This framework would also not apply to de-identified information, such as de-identified information used by public health departments during the course of an outbreak or epidemic.

Comprehensive Data Collection for Public Health Purposes

The COVID-19 pandemic has laid bare healthcare disparities in underserved communities and populations. Data suggests that low income individuals, of which racial and ethnic minorities make up a disproportionate number, are more likely to have chronic illnesses and for those chronic illnesses to be more severe.[1] This trend has continued with the coronavirus. Black people account for 13 percent of the US population, and yet 24 percent of deaths where race is known.[2] In 42 states and Washington, DC, Latinos make up a disproportionate share of COVID-19 cases compared to their share of the population,

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[1] https://www.ajmc.com/newsroom/5-vulnerable-populations-in-healthcare
[2] Available at: https://covidtracking.com/race

and in eight states it is more than four times greater.[3] Adding complexity to this challenge is the incomplete collection of race and ethnicity information for COVID-19 cases and deaths. Today, 22 states collect race information for less than 80 percent of cases, including three states that do not collect that data at all. While we know racial minorities are disproportionately impacted, it is impossible to fully address the problem without ensuring that health information is complete and accurate.

The collection of social determinants of health (SDOH) data elements could also be highly relevant in responding to a public health pandemic. Social determinants of health are conditions in the environment in which people live, work, and play that affect a range of health risks and outcomes.[4] Such SDOH conditions as occupation could be highly relevant from a preparedness perspective not only in identifying individual that may be at higher risk for exposure due to their occupation but in getting certain parts of the workforce back to work more quickly following a pandemic due to low exposure risk.

To be fully prepared for future pandemics, we must be able to collect and access data, including racial and ethnic demographic information as well as SDOH data to allow public health and clinicians to rapidly respond to communities at high-risk and to address health disparities. Complete, accurate, and timely health data can help identify patients and populations that may need additional support during health crises. Furthermore, there must be a national strategy to prioritize what SDOH data is relevant for public health purposes, what data must be collected, how the collection of SDOH data should be standardized, and who should have access to that data for interventional purposes.

Pandemic preparedness relies on ensuring that resources are allocated equitably and within the populations that are most at risk. Without integrating and collecting the necessary data to allow those decisions to be made, underserved communities will continue to suffer disproportionately.

AHIMA thanks Chairman Alexander for his leadership in preparing for the next pandemic and for the opportunity to provide feedback. We also look forward to working with you to ensure the nation's readiness for future pandemics. Should you or your staff have any additional questions or comments, please contact Kate McFadyen, Director, Government Affairs, at kate.mcfadyen@ahima.org or (202) 480-6058.

Sincerely,

Dr. Wylecia Wiggs Harris, PhD, CAE
Chief Executive Officer
AHIMA

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[3] Available at: https://www.npr.org/sections/health-shots/2020/05/30/865413079/what-do-coronavirus-racial-disparities-look-like-state-by-state

[4] Available at: https://www.cdc.gov/socialdeterminants/index.htm.