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January 4, 2021

The Honorable Mitch McConnell Majority Leader United States Senate Washington, DC 20510

The Honorable Chuck Schumer Minority Leader United States Senate Washington, DC 20510 The Honorable Nancy Pelosi Speaker of the House United States House of Representatives Washington, DC 20515

The Honorable Kevin McCarthy Minority Leader United States House of Representatives Washington, DC 20515

Dear Leader McConnell, Speaker Pelosi, Leader Schumer, and Leader McCarthy,

On behalf of the American Health Information Management Association (AHIMA), we thank you for your leadership in Congress, and we applaud your dedication to improving the country's health system and ending the COVID-19 pandemic.

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.

Health information is complex, nuanced, and ever-changing. An electronic signifier of identity, its integrity is as essential as a fingerprint or social security number. The data that comes with every healthcare experience – every conversation, knee tap, and blood draw – generates essential information that can significantly impact our personal and collective wellbeing. The responsible collection, protection, and analysis of health information allows practitioners to provide effective care, fosters innovation, encourages researchers to make life-saving discoveries, and offers individuals an opportunity to maintain good health.

The importance of health information has never been more apparent than during the current COVID-19 pandemic. Across the country, individuals from patients to public health experts have relied on accurate, timely, and secure patient health information to address everything from test results, to contract tracing, to studying the long-term effects of the disease. Managing the access and use of health information has been integral in every part of the healthcare ecosystem in responding to the pandemic.

As an organization representing health information professionals, we would like to outline our top priorities as Congress works to bolster the health system as a whole and address the COVID-19 pandemic.

Patient Identification

One of the most pressing issues for patient safety and interoperability within the health system today is the lack of a national strategy around patient identification. Today, there is no consistent and accurate way of linking a patient to their health information as they seek care across the continuum. Countless times every day a patient record is either mismatched or goes unmatched. Medications are prescribed, allergies are missed, and duplicate tests are ordered. In addition to safety concerns, this problem increases costs to patients and providers. A 2018 Black Book market research survey found that the average expense of repeated medical care because of duplicate records cost a reported average of \$1950 per patient per inpatient stay and over \$800 per emergency department visit. Inaccurate patient identification costs the US healthcare system over \$6 billion annually. [1]

Beyond costs, there are serious patient safety concerns when data is mismatched and important data is missing. A 2016 survey found that 86 percent of respondents have witnessed or know of a medical error that was the result of patient misidentification. [2]

The ability to identify patients across the care continuum is critical in our efforts to address the COVID-19 pandemic. Accurate identification of patients is one of the most difficult operational issues during a public health emergency. Patient data collection at field hospitals and temporary testing sites intensify these challenges. Ensuring the correct patient medical history is accurately matched to the patient is critical for future patient care, patients' long-term access to their complete health record, and for tracking the long-term health effects of COVID-19. Furthermore, any large-scale immunization programs will depend on accurate patient information to identify who has had the disease, who has been vaccinated, and what their outcomes are.

The main barrier to the creation of a national strategy around patient identification is an appropriations rider, Section 510, that has been included in the Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) appropriations bill for the past two decades. Put in place before the Health Insurance Portability and Accountability Act (HIPAA) was fully implemented, the ban, which states that HHS is prohibited from "spending any federal dollars to promulgate or adopt a national unique patient identifier," has effectively halted HHS from taking any steps to put into place a national strategy to address patient identification.

AHIMA strongly encourages Congress to make patient identification a priority for patient safety and public health, and recommends that policy around patient identification:

- Supports the repeal of Section 510 from the Labor-HHS appropriations bills within the federal budget, and supports the adoption of a nationwide patient identification strategy;
- Addresses factors beyond technology by taking a holistic approach to consider underlying and fundamental data integrity and quality processes and practices;
- Prioritizes privacy concerns, and;

^[1] Improving Provider Interoperability Congruently Increasing Patient Record Error Rates, Black Book Survey, https://www.newswire.com/news/improving-provider-interoperability-congruently-increasing-patient-20426295
[2] 2016 National Patient Misidentification Report, Available at: https://www.psqh.com/resource/ponemon-institute-2016-national-patient-misidentification-report/#

• Embraces the role of health information professionals and their expertise in the development and prioritization of data elements, mitigation and remediation of patient identification errors, and improving data quality.

Public Health

Public health is a vital component of our health system, and AHIMA encourages policies around public health to ensure the soundest, most reliable, and responsible use of health information. For too long, our public health system has been underfunded and has had to contend with inaccurate and incomplete patient data in electronic health records (EHRs), inconsistent and duplicative data reporting requirements at the state and federal level, and inadequate patient privacy and security protections. AHIMA strongly recommends that policies around public health:

- Encourage standards to ensure accurate and timely data are used for public health responses and initiatives;
- Adequately fund public health infrastructure to improve interoperability and sharing of public health data;
- Adopt modern technical standards and requirements to enhance interoperability, decrease unnecessary reporting duplication, and ensures data is consistent, comparable, and meaningful across the US and internationally;
- Enhance communication and transparency with patients, and;
- Protect patient privacy and security.

Social Determinants of Health

AHIMA strongly supports the use of public policy to encourage the collection, access, sharing, and use of social determinants of health (SDOH) to enrich clinical decision-making and improve health outcomes, public health, and health iniquities in ways that are culturally respectful. Today, there are a lack of data standards to encourage the collection and use of SDOH data, and a lack of digital infrastructure and robust technical capabilities to support functional, structural, and semantic interoperability across clinical and community-based organizations and service providers. As Congress works to address SDOH issues, AHIMA recommends that policy:

- Establishes global standards to promote the capture, use, maintenance, and sharing of SDOH data;
- Promotes healthcare delivery and financing models designed to integrate SDOH into the clinical setting in ways that are culturally respectful;
- Builds patient trust and fosters positive patient-provider relationships to encourage patients to share their social challenges;
- Enhances the sharing of SDOH data across clinical and community-based organizations and service providers;
- Prioritizes privacy;
- Recognizes workforce training needs;
- Promotes the ethical collection and use of SDOH data, and;
- Embraces the role of health information professionals.

Cybersecurity and Information Security

Data breaches are an ever-growing threat in healthcare. The average total cost of a data breach in the healthcare industry is \$6.45 million: 65 percent higher than the average data breach across all sectors. The healthcare sector today continues to face challenges in information sharing. While steps have been taken to increase cybersecurity, there is still a patchwork of laws and regulations and a lack of resources that must be improved and harmonized. As Congress tackles the issue of cybersecurity and information security within the health sector, AHIMA recommends that policy:

- Enhance and improve information sharing of cyber threats, risks, and cyber hygiene practices in real time while providing strong and clear leadership to the industry on cybersecurity threats and risks:
- Support each principle of the CIA triad² (confidentiality, integrity, availability) at the highest level possible;
- Harmonize laws and regulations, including state and federal laws, and;
- Provide funding and/or incentives to bolster the healthcare workforce and resources for information security and cybersecurity.

Health Information held by HIPAA Non-Covered Entities

The state of health data privacy in the US is rapidly evolving as the digitization of the healthcare sector accelerates. Historically, the US has followed a patchwork approach, applying sector-specific approaches to data privacy, versus a single data privacy regime. HIPAA governs health privacy in traditional healthcare settings. However, an increasing number of consumer-facing technologies, applications, products, and services that access, produce, and manage health information are not bound by or required to abide by the rules established under HIPAA, because they are not considered "covered entities" or "business associates." Rather, the privacy practices of such applications, products, and services are generally regulated by state law and/or the Federal Trade Commission (FTC) Act. This oversight does not provide the same type or level of protections for consumers as HIPAA. Therefore, in protecting health information held by HIPAA non-covered entities, AHIMA recommends that policy:

- Guarantee individuals' access to their health information regardless of where their information travels;
- Improve accountability;
- Limit the collection, use, and disclosure of health information;
- Ensure the completeness, accuracy, and integrity of health information;
- Prioritize the protection of health information against privacy and security risks;
- Address health information retention concerns;
- Facilitate disposition and destruction of health information, and;
- Assign appropriate oversight and enforcement responsibilities.

Thank you for your leadership and attention to the many pressing health issues the country contends with today. We encourage Congress to ensure that health information is a central tenet while

¹IBM Security: Cost of a Data Breach Report 2019. Available at: https://databreachcalculator.mybluemix.net/complete-findings.

² The CIA Triad is a well-known, venerable model for the development of security policies used in identifying problem areas, along with necessary solutions in the arena of information security. Available at: https://www.forcepoint.com/cyber-edu/cia-triad.

addressing these health issues. And we look forward to working with your offices to bolster the use of accurate, timely, trusted and complete health information in our nation's health system.

Sincerely, Myluai Majos Harres

Dr. Wylecia Wiggs Harris, PhD, CAE

Chief Executive Officer

AHIMA