



May 6, 2021

Acting Director Robinsue Frohboese
US Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building
Room 509F
200 Independence Avenue, SW
Washington, DC 20201

Re: RIN 0945-AA00, Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement NPRM

Submitted electronically via www.regulations.gov

Dear Acting Director Frohboese:

Thank you for the opportunity to provide comments on the *Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement Notice of Proposed Rulemaking (NPRM)*.

[Patient ID Now](#) is a coalition of healthcare organizations representing a wide range of healthcare stakeholders committed to advancing through legislation and regulations a nationwide strategy to address patient identification.

The Patient ID Now coalition commends the Office for Civil Rights' (OCR) intention to address "ongoing challenges and barriers to an individual's access to their health information" by prohibiting "a covered entity from imposing unreasonable identity verification measures on an individual...exercising a right under the Privacy Rule." Accurately and consistently matching patients with their health information is an increasingly complex undertaking as more and more digital health data is exchanged. This is because the nation lacks a national strategy around patient identification and matching. The implementation of a national strategy would assist in identity verification and add significantly to providers' ability to manage and coordinate care safely.

The Patient ID Now coalition has just released its [Framework for a National Strategy on Patient Identity: A Proposed Blueprint to Improve Patient Identification and Matching](#). We submit this Framework with recommendations for consideration in the creation and implementation of a national strategy on patient identification, which has direct implications on identity verification measures proposed in this rule (see Attachment A).

For more than two decades, the Department of Health and Human Services (HHS) has been hampered by the inclusion of Section 510 within the Labor, Health and Human Services, Education, and Related Agencies Appropriations bill within the federal budget. This section states, "None of the funds...may be used to promulgate or adopt any final standard...providing for, or providing for the assignment of, a unique health identifier for an individual." The language was originally included because of patient privacy concerns. However, in the years since, the full implementation of Health Insurance Portability

and Accountability Act (HIPAA) to address patient privacy, the increased use of electronic health records (EHRs), and the push for increased interoperability within the US healthcare system means that it is time to move forward on a national strategy on patient identity, which is [supported by organizations throughout the healthcare ecosystem](#). It is critical that HHS take a leadership role to work with the private sector to create a national strategy around patient identification and matching so that patient verification can be completed timely and accurately, without undue burdens to patients or health care providers. The HHS Office of the National Coordinator for Health Information Technology (ONC) is completing work on a congressionally-mandated patient identification report that will make recommendations around our current inability to consistently and accurately connect patients to their electronic health data as they seek care across the continuum. Should the more than two-decade old appropriations ban on a unique patient health identifier be lifted, progress could be made toward a national standards-based strategy.

The lack of a national strategy around patient identification and matching presents several troubling privacy issues for patients. Right now, the healthcare ecosystem faces an “inverse” privacy problem – individuals must repeatedly disclose a significant amount of individually identifiable information to each healthcare provider they see in an attempt to achieve an accurate match of the patient to their medical record. Even more worrying for patient privacy is the risk of overlays—i.e.,--the merging of multiple patients’ data into one medical record, causing a patient to have access to other patients’ health information, which could result in an unauthorized disclosure under HIPAA, or even worse, a patient receiving treatment for another patient’s disease.

Federal legislation, such as the Health Information Technology for Economic and Clinical Health (HITECH) Act, the American Recovery and Reinvestment Act of 2009 (ARRA), and the 21st Century Cures Act, requires federal agencies to promulgate rules to operationalize data sharing, exchange, and interoperability. Failure to share data effectively may implicate allegations of information blocking, penalties, and other consequences. However, without ensuring that the data being shared is complete and accurate, interoperability, care coordination, and patient safety is impeded. The need to resolve patient identification and matching issues is essential to moving toward nationwide interoperability.

The COVID-19 pandemic has highlighted the growing need to address patient identification. Accurate identification of patients is one of the most difficult operational issues during a public health emergency, including the collection of patient demographic information (*e.g.*, name, address, phone number) and the implementation of a method to ensure that the information remains attached to the patient. Field hospitals, temporary testing sites, and vaccination sites in parks, convention centers, and parking lots exacerbate these challenges. Collecting limited demographics in mass vaccination settings creates challenges for immunization information systems, which aim to consolidate immunization records for individuals across the lifespan, and to share them back with patients’ medical records. The increased number of sites and the lack of interoperability creates even more impediments to patient verification, which can result in additional burdens to patients, or potentially patients not being correctly matched with their information or test results, limiting access to their health information.

The Patient ID Now coalition thanks OCR for the opportunity to submit its *Framework for a National Strategy on Patient Identity: A Proposed Blueprint to Improve Patient Identification and Matching* to ensure that the larger systemic issue of the lack of a national strategy is considered when addressing patient verification. Should you or your staff have any additional questions or comments, please contact Kate McFadyen at kate.mcfadyen@ahima.org or 202-480-6058.

Sincerely,

Patient ID Now

CC: Micky Tripathi, ONC National Coordinator for Health Information Technology