



*A driving force for health equity*

*Submitted via email*

September 28, 2023

The Honorable Bill Cassidy, MD  
Ranking Member  
U.S. Senate Committee on Health, Education, Labor and Pensions  
520 Hart Bldg., Washington, DC 20510

Re: *Request for Information on the Health Insurance Portability and Accountability Act (HIPAA)*

Dear Ranking Member Cassidy,

On behalf of OCHIN, I appreciate the opportunity to provide comments on the *Request for Information on the Health Insurance Portability and Accountability Act (HIPAA)*. OCHIN is a [national nonprofit health information technology innovation and research network](#) that serves nearly 2,000 community health care sites with 25,000 providers in over 40 states, serving more than 8 million patients. Our network includes rural health clinics, critical access hospitals, federally qualified health centers, community health clinics, Ryan White HIV/AIDS Program Health Centers, school-based health clinics, Tribal health clinics, and local public health agencies.

For over two decades, OCHIN has supported interoperability, while championing patient privacy which has also extended to consumer privacy with the proliferation of health-related commercial products. OCHIN provides leading edge technology, data analytics, research, health IT workforce training and development, technical assistance, and additional operational support. In the OCHIN network HIPAA covered clinical summaries have been securely exchanged 325+ million times across all 50 states. The OCHIN network is one of the largest health center-controlled networks in the country, providing unparalleled capabilities to securely exchange patient information. Our network's diverse patient population includes patients who are uninsured or publicly-insured and have limited access to health care – making the OCHIN network the most comprehensive source on the health care and outcomes of patients facing significant structural inequality.

OCHIN applauds your focus on safeguarding open and trust-based communications between patients and their clinicians as well as protecting the privacy interests of consumers. Both are essential to deliver high quality care while promoting patient and consumer safety and privacy. OCHIN strongly supports efforts to **establish clear, uniform national standards** and requirements governing patient and consumer privacy as **the proliferation of competing and varied state laws governing consumer and patient privacy increases complexity and cost and potential liability** that fall heaviest on providers in rural and underserved communities with the least resources to implement. Furthermore, the **proliferating standards perversely weaken informed patient and consumer consent for use of health information (both within the context of HIPAA covered patient health information (PHI) and consumer health data)**. Ensuring all health care information (whether collected by HIPAA covered entities or not) will strengthen the patient-clinician relationship by safeguarding patient and consumer reasonable expectation of privacy.

In response to the RFI the following delineates OCHIN's views on the need for a national, uniform framework that should govern all health data, including health data collected from consumers:

- OCHIN supports a single federal framework for health data including consumer, biometric, genetic, financial and location data that should be leveled up to HIPAA and for research the Common Rule governing Human Subject Research.
- Any use of data should all be treated under the same standard and requirements.
- All entities should have the same obligations and all should have a duty of loyalty to consumers/patients.
- Having separate systems is inequitable and imposes a disparate burden on providers who serve the underserved relative to other entities.
- In the context of social determinants of health (SDOH), non-covered HIPAA entities and HIPAA covered entities will need to exchange health related information which should be governed by the same rules.

I have included in the appendix additional comments. We thank you for the opportunity to comment. OCHIN strongly supports a single federal framework to govern health privacy data. Please contact me at [stollj@ochin.org](mailto:stollj@ochin.org) if we can be of further assistance.

Sincerely,

A handwritten signature in blue ink that reads "Jennifer Stoll". The signature is cursive and fluid.

Jennifer Stoll  
Executive Vice President  
External Affairs

## Appendix

***Improving Care Coordination.*** OCHIN supports expanding the definition of HIPAA treatment, payment, and operations (TPO) to include social service agencies and community-based organizations in order to improve patient safety and outcomes. To meet the holistic needs of patients who are more medically and socially complex, we need to streamline secure communication along the full continuum of clinical and social services providers to reduce errors and duplication, particularly for patients/clients. When patients already face undue burden due to structural inequality, having the ability to share records between clinical providers and care coordination or social service entities improves patient outcomes.

***Identity Verification.*** OCHIN supports reducing the documentation burden on patients and providers in the process of verifying a patient's identity. We support flexibility in allowing varied documentation as long as these are reasonably likely to minimize incorrect patient identification, reduce duplicate patient records, avoid undue burden on patients, and prevent unauthorized disclosure of patient health information. OCHIN strongly urges that OCR issue education and detailed sub-regulatory guidance that includes examples and best practices.

***Disclosure of Personal Health Information (PHI) to a Third Party.*** OCHIN supports efforts to empower patients to use their health information to engage more fully in their care, coordinate with an extended care team, and support prevention measures and research. It is important to consider, however, that there is a proliferation of applications that are not regulated under HIPAA and the growing divide between the HIPAA covered environment and the non-covered environment. **OCHIN urges Congress to address the impact on meaningful consent. Patients may not understand that their PHI will not be subject to HIPAA and that state privacy laws may or may not apply when their PHI is released to third parties. OCHIN strongly urges Congress to require written or verifiable digital requests to authorize release to third parties.** Furthermore, OCHIN strongly urges that Congress require the U.S. Department of Health and Human Services' Office of Civil Rights with the Federal Trade Commission (FTC) to coordinate with each other and regularly convene State Attorneys Generals to ensure that third party app developers authorized by a patient to obtain or receive digital PHI (1) provide clear and standard disclosure of risks, (2) identify all authorized uses of the previously HIPAA covered PHI (not simply initial intended uses), and (3) specify recourse that the consumer/patient has under state and federal consumer protection laws if the recipient of the information fails to provide adequate disclosure, uses information in an unauthorized manner, or otherwise violates state or federal law.<sup>3</sup> **OCHIN recommends that federal agencies work with states to offer draft standard release language that personal health applications must use to ensure that patients are aware of the risks of disclosure.**