



September 28, 2023

The Honorable Bill Cassidy, M.D.
Ranking Member
Senate Committee on Health, Education, Labor & Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

Re: Improving Americans' Health Data Privacy

Submitted electronically

Dear Ranking Member Cassidy,

The Health Innovation Alliance (HIA) appreciates the opportunity to comment on your request for information on Improving Americans' Health Data Privacy. HIA is a diverse coalition of patient advocates, healthcare providers, consumer organizations, employers, technology companies, and payers who support the commonsense use of data and technology to improve health outcomes and lower costs. We are actively engaged in the policy discussion on ensuring the privacy and security of health information, particularly as health information becomes more liquid. We urge you to ensure any privacy policies considered by Congress:

- Avoid duplicative regulation for entities engaged in health care delivery; and
- Ensure that health information continues to flow to those who need it.

HIA has worked with Congress for over 15 years to advance the interoperability of health information. The 21st Century Cures Act passed in 2016 is still being implemented by the Biden Administration – the third administration to continue advancing the access, exchange, and use of health information. Our nation has made great advancements in health care interoperability, and we have a long way to go. In 2021, we released our Interoperability Workgroup Report recommending key actions Congress and the Administration should take to help us achieve true interoperability.¹ Health care interoperability is a bipartisan issue, and HIA will continue to push for a functioning system of accessible, exchangeable, and usable information across the industry.

We have also recognized that health information liquidity requires privacy and security. In 2020, we released principles to guide Congress in the creation of a new health data and privacy framework.² We urge you to examine our principles and use them as guidance as you consider privacy reform. Any health data framework should have the following attributes:

- Patient-centric;
- Strong privacy protections;
- Trusted and Secure;
- Transparent, Flexible, Consistent, and Sustainable;

¹ Available at <https://health-innovation.org/2022-5-11-healthcare-interoperability-report/>

² Available at <https://health-innovation.org/2020-3-9-health-innovation-alliance-calls-on-congress-to-adopt-new-health-data-and-privacy-framework/>

- Interoperable;
- Consistent Protections Regardless of Who Holds the Data;
- Strong Enforcement; and
- Nationwide and Uniform.

We have worked directly with your office on legislation to determine whether existing health care privacy laws and regulations need to be updated, and if so, how. The Health Data Use and Privacy Commission Act would establish a federal commission to make official recommendations to Congress.³ We still believe that this commission is the best path forward to generating robust federal policies. More recently we have worked with Congress to ensure that legislation intended to increase the privacy of consumer data does not unintentionally stop the use of health data in areas like care delivery, licensing, and medical research.⁴

The National Conference of Insurance Legislators (NCOIL) just adopted a resolution HIA drafted to ensure that state consumer privacy legislation include exemptions for health privacy laws that cover medical research, patient care delivery, and other aspects of health care that are already well regulated. We have attached this model resolution for you to examine to ensure policies you consider do not impede the active use of health information to produce new treatments and cures, protect patients from harm, and ensure caregivers have accurate information to treat their patients. We urge Congress to balance the advances made in health care interoperability, medical research, and care delivery with any proposals you consider to modernize privacy protections.

Use of de-identified data is incredibly important to a functioning health care system. Consistency in de-identification standards is instrumental for compliance. When California was first considering the California Consumer Privacy Act, the law set its own definitions for de-identification that were inconsistent with those in HIPAA. This inconsistency could have resulted in medical research stopping in its tracks while compliance officers determined how to comply, or if they even could comply, with both requirements simultaneously. We urge you to use the existing de-identification standards in HIPAA that are well understood and work to protect privacy. Creating duplicative regulation will result in burdensome and costly compliance and confusion – not just for vendors, but for consumers and patients as well.

We appreciate the opportunity to comment on your RFI and look forward to working with you to ensure the privacy and security of health information is consistent, trusted, and reliable for patients and consumers.

Sincerely,



Brett Meeks
Executive Director

³ Available at <https://www.congress.gov/bill/117th-congress/senate-bill/3620/all-info>

⁴ See <https://health-innovation.org/2022-6-14-draft-privacy-bill-misses-the-mark-national-framework-is-needed-to-work-for-patients-not-enrich-trial-lawyers/> and <https://health-innovation.org/2023-2-28-privacy-legislation-should-not-impede-advances-in-healthcare/>