

Legislative Health Privacy Priorities

Consumers, patients, and innovators in connected health require a more certain and comprehensive privacy framework for digital health. Such a framework should guide collection and processing activities involving sensitive information like health data. Contrary to popular misconception, the Health Insurance Portability and Accountability Act (HIPAA), is a portability and interoperability—rather than privacy—regime designed for a narrowly-defined set of entities that process insurance claims. While HIPAA's Privacy Rule handles issues within the medical setting, HIPAA's scope and purpose make it an odd fit for general data processing activities that involve health-related information. Instead, Congress should enact explicit privacy prohibitions to better equip the Federal Trade Commission (FTC) to prevent likely privacy harms involving health data that are outside the scope of a hospital, doctor's office, or insurance company.

CHI's top three goals in health privacy for legislators are:

- Strengthen privacy and security protections for consumers' health information outside the HIPAA umbrella outside by classifying health information as "sensitive" personal information, subject to stricter requirements in a general consumer privacy law.
- Maintain the current statutory scope of the Health Insurance Portability and Accountability Act (HIPAA), which is ill-suited for commercial activity involving health data because it is a portability and interoperability regime designed for healthcare providers and their vendors in the context of the caregiver-patient relationship.
- Protect patient safety by ensuring that HIPAA and general privacy laws work in concert and avoid harmful gaps or conflicts.



CHI Priorities and General Consumer Privacy Bills in the 117th

Provisions	SAFE DATA Act (Wicker bill, S. 2499, 117th)	COPRA (Cantwell bill, S. 2968, 117th)	ADPPA (H.R. 8152, 117th)	HIPAA expansions: S. 3620; S. 500; S. 24
Maintains scope of HIPAA?	Yes	Yes	Yes	No
Strengthens privacy/security for consumer health data as part of consumer privacy?	Yes	Yes	Yes	No (instead, expands HIPAA)
Effectively exempts PHI?	No	No	No (but updated language would address this issue)	No

