

Health Data Use and Privacy Commission Act

Introduced by Senators Bill Cassidy, M.D. (R-LA) and Tammy Baldwin (D-WI)

Legislation would stand up a commission to make official recommendations on how to modernize health privacy laws and regulations.

Americans are increasingly concerned about the confidentiality, security, and use of their personal information – especially when it comes to health care. Currently, Congress is considering numerous proposals on comprehensive privacy reform, but these bills focus on consumer information, leaving the complicated issue of how to handle health data unanswered. The presence of technology companies is increasing in health care, and health information is expanding beyond the reach of HIPAA (a 25-year-old law). Thus, Congress needs informed recommendations on how to modernize the use of health data and privacy laws to ensure patient privacy and trust while balancing the need of doctors to have information at their fingertips to provide care.

The Health Data Use and Privacy Commission Act would establish a commission to –

- Conduct a coordinated and comprehensive review and comparison of existing protections of personal health information at the state and federal level, as well as current practices for health data use by the health care, insurance, financial services, consumer electronics, advertising, and other industries;
- Provide recommendations to Congress on whether federal legislation is needed to modernize health data privacy, and if so, how to do it; and
- Be charged with submitting a report to Congress and the President six months after all members are appointed, and include 17 members to be appointed by the Comptroller General.

Specifically, the Commission is charged with drafting recommendations and conclusions on the following:

- The potential threats posed to individual health privacy and legitimate business and policy interests.
- The purposes for which sharing health information is appropriate and beneficial to consumers and the threat to health outcomes and costs if privacy rules are too stringent.
- The effectiveness of existing statutes, regulations, private sector self-regulatory efforts, technology advances, and market forces in protecting individual health privacy.
- Recommendations on whether federal legislation is necessary, and if so, specific suggestions on proposals to reform, streamline, harmonize, unify, or augment current laws and regulations relating to individual health privacy, including reforms or additions to existing law related to enforcement, preemption, consent, penalties for misuse, transparency, and notice of privacy practices.
- Analysis of whether additional regulations may impose costs or burdens, or cause unintended consequences in other policy areas, such as security, law enforcement, medical research, health care cost containment, improved patient outcomes, public health or critical infrastructure protection, and whether such costs or burdens are justified by the additional regulations or benefits to privacy, including whether such benefits may be

achieved through less onerous means.

- The cost analysis of legislative or regulatory changes proposed in the report.
- Recommendations on non-legislative solutions to individual health privacy concerns, including education, market-based measures, industry best practices, and new technologies.
- Review of the effectiveness and utility of third-party statements of privacy principles and private sector self-regulatory efforts, as well as third-party certification or accreditation programs meant to ensure compliance with privacy requirements.

Supporting organizations include the Health Innovation Alliance, IBM, National Multiple Sclerosis Society, Executives for Health Innovation (EHI), Association for Behavioral Health and Wellness, ACRO, and athenahealth.

Contact Patrick Fox (Patrick_Fox@cassidy.senate.gov) in Senator Cassidy's office and Erin Dugan (Erin_Dugan@baldwin.senate.gov) in Senator Baldwin's office for more information on how you can support this bill.