

February 9, 2022

Senator Bill Cassidy  
520 Hart Senate Office Building  
Washington, DC 20510

Senator Tammy Baldwin  
709 Hart Senate Office Building  
Washington, D.C. 20510

Dear Senators Cassidy and Baldwin,

We write to thank you for your leadership in introducing the Health Data Use and Privacy Commission Act. The Commission established by this bill will make recommendations to Congress to help modernize health data use and privacy policies to ensure clear, consistent, and reliable patient protections while simultaneously ensuring health data gets where it needs to go to improve care and outcomes.

As the nation continues to adopt new and evolving technologies that surround everyday life and digitize nearly every interaction we have, personal privacy has never been a more important issue for policymakers. Congress is considering comprehensive privacy reform – and we support these efforts – but most of these conversations are focused on consumer technology and data. Health data is either carved out of these proposals or included in a new category of “consumer health data” which could lead to many entities being subject to duplicative requirements. The Health Insurance Portability and Accountability Act (HIPAA) law that led to today’s HIPAA Privacy Rule was passed over 25 years ago, and while HIPAA is still functioning well, it does not address the growing concerns regarding third-party applications or other technologies accessing health data that fall outside of HIPAA’s reach. Providers, health plans, and other covered entities and their business associates covered by the Privacy Rule as well as the patients they serve need clarity and consistency in health data privacy and use rules.

Given the advancements Congress has made in improving the interoperability of health care information and systems, your efforts to ensure robust consideration of health care data and privacy through the Health Data Use and Privacy Commission will provide useful perspective to the ongoing privacy debate. Secure and private health information should not be the enemy of medical innovation, clinical process improvement, or public health response. Careful consideration of these issues by the commission will inform policy makers to achieve the necessary balance of data liquidity and confidentiality necessary for a highly functional and trusted health system.

According to the International Association of Privacy Professionals (IAPP), “state-level momentum for comprehensive privacy bills is at an all-time high.”<sup>1</sup> The patchwork of proposals across all 50 states could lead to further complexity and compliance burdens. According to the Information Technology and Innovation Foundation, should all 50 states pass privacy legislation in the absence of a federal law, compliance costs “could exceed \$1 trillion over 10 years, with at

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<sup>1</sup> <https://iapp.org/resources/article/us-state-privacy-legislation-tracker/>

least \$200 billion hitting small businesses.”<sup>2</sup> All of this stresses the need for a federal law governing data privacy, and there are at least 24 proposals related to data privacy before the 117<sup>th</sup> Congress according to the IAPP.<sup>3</sup>

As Congress considers privacy reform, your privacy commission will add much needed recommendations specific to the future of health information privacy and use. This issue is far too important to the functioning of our health care system and the trust of patients to get wrong, and we appreciate your thoughtful legislation to help get these policies right. We look forward to working with you on passing the Health Data Use and Privacy Commission Act into law.

Sincerely,

American College of Cardiology  
Association for Behavioral Health and Wellness  
Association of Clinical Research Organizations  
athenahealth, Inc  
Epic Systems Corporation  
Executives for Health Innovation  
Federation of American Hospitals  
Health Innovation Alliance  
IBM  
National Multiple Sclerosis Society  
Teladoc Health  
United Spinal Association

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<sup>2</sup> <https://itif.org/publications/2022/01/24/looming-cost-patchwork-state-privacy-laws>

<sup>3</sup> <https://iapp.org/resources/article/us-federal-privacy-legislation-tracker/>