



June 13, 2022

The Honorable Jan Schakowsky
Chair
House Committee on Energy & Commerce
Subcommittee on Consumer Protection
& Commerce
Washington, D.C. 20515

The Honorable Gus Bilirakis
Ranking Member
House Committee on Energy & Commerce
Subcommittee on Consumer Protection
& Commerce
Washington, D.C. 20515

RE: June 14 “Protecting America's Consumers: Bipartisan Legislation to Strengthen Data Privacy and Security” Hearing

Dear Chair Schakowsky and Ranking Member Bilirakis:

The Confidentiality Coalition thanks you for holding a hearing on, “Protecting America's Consumers: Bipartisan Legislation to Strengthen Data Privacy and Security.”

The [Confidentiality Coalition](#) is composed of a broad group of hospitals, medical teaching colleges, health plans, pharmaceutical companies, medical device manufacturers, vendors of electronic health records, biotech firms, employers, health product distributors, pharmacies, pharmacy benefit managers, health information and research organizations, and others, committed to advancing effective patient privacy and security protections. Our mission is to advocate policies and practices that safeguard the privacy and security of patients and healthcare consumers while, at the same time, enabling the essential flow of patient information that is critical to the timely and effective delivery of healthcare, improvements in quality and safety, and the development of new lifesaving and life-enhancing medical interventions.

Accessing and sharing health data allows healthcare providers to deliver quality care and enables patients to become more engaged in their health decisions. While the Health Insurance Portability and Accountability Act (HIPAA) safeguards a specific subset of “protected health information” (PHI) and applies only to traditional healthcare entities and their business associates, a vast amount of health-related information does not fall within the HIPAA regulatory framework and is largely unprotected from misuse. The COVID-19 public health emergency (PHE) has led to significant amounts of personal health information collected outside the HIPAA regulatory structure. This information should be afforded privacy and security protections that align with HIPAA. Creating protections for this information will build public trust in data collection and sharing so that the information can be used to improve health outcomes and create conveniences for consumers.

The Confidentiality Coalition thanks you for your work on the bipartisan, bicameral “American Data Privacy and Protection Act.” This bill provides a meaningful step to ensure that patients can receive robust privacy protections for their personal information and as we evaluate it, and assess its interaction with HIPAA covered information, we look forward to working with the Committee on the protection of healthcare information. As the Committee continues its work on this and other legislation, we encourage you to recognize the need to protect health data not covered by HIPAA. The Confidentiality Coalition has developed “[Beyond HIPAA](#)” principles to govern the sharing of this information. These principles emphasize harmonization with HIPAA’s privacy and security rules. They also advocate for individual authorization processes (including revocation of authorization) for use and disclosure of identifiable health information not covered by HIPAA. Furthermore, Coalition members support limits on the use of identifiable data beyond the expressed purpose for which authorization was given. Developing legislative and regulatory solutions to protect consumers’ health information not covered by the HIPAA rules will build trust in data collection, give stakeholders better certainty about how to protect such information, and ultimately help improve health outcomes.

The Confidentiality Coalition looks forward to working with you on steps to improve privacy protections for non-HIPAA health data. Please contact me at tgrande@hlc.org or 202-306-3538 with any questions.

Sincerely,

A handwritten signature in black ink that reads "Tina O. Grande". The signature is written in a cursive style with a large, stylized "T" and "G".

Tina O. Grande
Chair, Confidentiality Coalition and
Executive VP, Policy, Healthcare Leadership Council