



July 27, 2021

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

Dear Chair Schakowsky and Ranking Member Bilirakis:

On behalf of the Confidentiality Coalition, we thank you for holding a hearing on, "Transforming the FTC: Legislation to Modernize Consumer Protection."

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, patient groups, and others founded to advance effective patient confidentiality protections. The Coalition's mission is to advocate policies and practices that safeguard the privacy 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 new protections for this information will build public trust in data collection so that the information can be used to improve health outcomes and create conveniences for consumers.

The Confidentiality Coalition appreciates the Federal Trade Commission's (FTC) emphasis on developing robust consumer privacy protections¹ and we encourage the FTC to explicitly

¹ David Uberti, *FTC Vote Could Pave Way for New Privacy Rules*, The Wall Street Journal (July 1, 2021), <https://www.wsj.com/articles/ftc-vote-could-pave-way-for-new-privacy-rules-11625171274>.

examine steps to protect health data. A September 2020 survey² found that 90% of Americans are concerned about the privacy of their health data when not protected by HIPAA or other federal regulations. By implementing steps to protect this information, the FTC can help build trust in data collection and improve care outcomes.

Additionally, we encourage Congress to also pass bipartisan national privacy legislation. Such legislation could grant FTC necessary authority to develop privacy regulations and provide stakeholders better clarity about how to sufficiently protect consumers' health information. Any privacy legislation should 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 patient consent for sharing of health data not governed by HIPAA as well as prohibitions on the use of data beyond the expressed purpose for which consent 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 cursive script that reads "Tina O. Grande".

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

² Ben Moscovitch, *Americans Want Federal Government to Make Sharing Electronic Health Data Easier*, The Pew Charitable Trusts (September 16, 2020), <https://www.pewtrusts.org/en/research-and-analysis/articles/2020/09/16/americans-want-federal-government-to-make-sharing-electronic-health-data-easier>.