CONSUMER PRIVACY FRAMEWORK FOR HEALTH DATA

eHI
eHEALTH INITIATIVE

As health data liquidity rapidly increases, collection of health and "health-ish" data has dramatically outpaced existing regulatory safeguards. There are a wide variety of new vehicles for patient-directed electronic data exchange from health care providers or health plans to entities not covered by HIPAA, in addition to a sharp rise in consumer- and patient-generated data – including from wearable and remote-monitoring devices and on-demand genetic testing services. This is leading to the ever-growing collection of identifiable and individually attributable data, as well as its mining for a diverse assortment of purposes.

Imperative for Change

Although HIPAA and its regulations continue to play a valuable role in traditional healthcare spaces, unbeknownst to most consumers, once data leaves a healthcare provider or health plan, including when it is sent to a health or wellness application at the patient's request, it is no longer covered by HIPAA. Further, data that individuals upload themselves into health apps is not protected by HIPAA, either. Given that even personal data related to diet, exercise or purchasing habits has the potential to reveal sensitive information about an individual's health status, this lack of both protection and transparency is hugely concerning from a consumer standpoint.

The FTC has become the default regulatory and enforcement body for all consumer-facing technology companies, but it is not ideally suited to regulate in the health space. Given this, combined with significant gaps in federal privacy laws, the risk of non-action includes conflicting state law requirements, consumer confusion and the potential misuse of data. In the absence of new federal legislation, there is a critical need – and opportunity – for the private sector to set self-governing "rules of the road" that establish a new health privacy framework and provide actual accountability for the handling of health data that falls outside the bounds of HIPAA.

Project Goals:

With funding from the Robert Wood Johnson Foundation (RWJF), the Foundation for eHealth Initiative (eHI) and the Center for Democracy & Technology (CDT) are collaborating on a Consumer Privacy Framework for Health Data, designed to address the current gaps in legal protections for health data outside HIPAA's coverage. Experts and leaders representing healthcare, technology and advocacy groups and consumers will collaborate on the project, which will build on the important work already done by key industry groups, involving constituencies beyond the "usual suspects" of hospitals, payers and vendors. The end goal is not a consensus document, as there is undoubtedly more than one way to approach this complicated set of issues. Rather, we will weigh the value of potential short-term solutions, such as incorporation of model privacy standards into Terms of Service, or industry self-regulation – including enforcement provisions – to address immediate concerns, even as we work toward the long-term solution of a comprehensive federal privacy law.

Project Overview:

The initial phase of this plan is a research effort designed to map the current legal landscape governing consumer health data, as well as current efforts to address the gaps in legal protection for such data. With RWJF funding, Manatt, Phelps & Phillips, LLP will specifically examine self-governance efforts in advertising, finance and other industries that may provide relevant guidance to the health technology industry.

On February 11, 2020, eHI and CDT will convene a group of 30-50 industry and advocacy leaders to serve on a Steering Committee for Consumer Health Privacy and review potential approaches to addressing the issue of non-HIPAA data, the appropriate way to define such data and preferred pathways for industry and stakeholder action. In addition to the Steering Committee, there will be smaller workgroups that will meet throughout 2020 to develop specific aspects of the Framework; the full Steering Committee will meet at least twice to review drafts of the Framework and provide feedback.

A transparent process is critical for the success of the Consumer Framework. Feedback from the industry and general public will be solicited and incorporated throughout the project. Immediately following the announcement of the project, the project team will manage a project webpage and a LinkedIn page detailing the work, timeline and deliverables. A mailing list for project participants, as well as the general public, will enable regular communication and material-sharing between meetings.

Key Project Team Members

• Jennifer Covich Bordenick, CEO, eHealth Initiative Foundation (jennifer@ehidc.org)
• Lisa Hayes, Co-CEO, Center for Democracy & Technology (lhayes@cdt.org)
• Alice Leiter, VP & Senior Counsel, eHealth Initiative Foundation (Alice@ehidc.org)
• Michelle Richardson, Director, Privacy and Data Project, Center for Democracy & Technology (mrichardson@cdt.org)
• Andrew Crawford, Policy Counsel, Privacy and Data Project, Center for Democracy & Technology (acrawford@cdt.org)

High-Level Timeline

WINTER 2020

• Steering Committee meets (February 11)
• Workgroups meet

SPRING 2020

• Workgroups meet
• Solicitation of public comment on Framework outline

SUMMER 2020

• Draft framework sent to Steering Committee
• Steering Committee meets to review draft Framework (July 21)

FALL 2020

• Framework finalized
• Final framework released

About eHealth Initiative

eHealth Initiative (eHI) convenes executives from every stakeholder group in healthcare to discuss, identify and share best practices to transform the delivery of healthcare using technology and innovation. eHI, and its coalition of members, focus on education, research, and advocacy to promote the use and sharing of data to improve health care. Our vision is to harmonize new technology and care models in a way that improves population health and consumer experiences. eHI has become a go-to resource for the industry through its eHealth Resource Center. For more information, visit ehidc.org.