

FTC Holds Privacy Seminar on Health Data, Emphasizes Transparency

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Last week, the FTC held its third and final spring privacy seminar on the implications of consumer generated and controlled health data. The seminar featured presentations by Latanya Sweeney, the FTC's Chief Technologist, and Jared Ho, an attorney in the FTC's Mobile Technology Unit, and a panel discussion with representatives from the Department of Health and Human Services, the Center for Democracy and Technology, and the private sector. During the two-hour seminar, the presenters and panelists recognized the benefits of health-related apps, but expressed concerns that consumers may be unaware of the apps' information collection and transmission practices, as well as that the apps may not be covered by HIPAA. There was no consensus on the type of regulation, if any, needed.

Ms. Sweeney's presentation, while highlighting the maxim that transparency establishes trust, documented the flow of consumer health data provided to hospitals, noting that consumer health data may flow – and often does flow – from hospitals to entities that are not covered by HIPAA. Additionally, although de-identified when sold, this information may be easily re-identified. Mr. Ho presented the results of an FTC study on the health information collected and transmitted by 12 mobile apps and two wearables. While the Commission did not review privacy policies, the study results revealed that the apps transmitted consumer health information to 76 third parties, many of which collected device information or persistent device identifiers (sometimes from multiple apps) and additional information, such as gender, zip code, and geolocation. Mr. Ho stated that there are significant health concerns when data is capable of being aggregated.

The panel, moderated by two FTC Division of Privacy and Identity Protection attorneys, featured Dr. Christopher Burrow, the Executive Vice President of Humetrix, Joseph Lorenzo Hall, Chief Technologist for the Center for Democracy and Technology, Sally Okun, Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe, and Joy Pritts, Chief Privacy Officer in the Department of Health & Human Services' Office of the National Coordinator for Health Information Technology. The panelists spent a significant amount of time discussing the various entities covered – and not covered – by HIPAA, as well as the array of health-related websites and apps that are available to consumers. Some of the concerns raised were: (1) the potential for sensitive health information to be shared in ways consumers would not reasonably anticipate (and the inability to predict what consumers may deem "sensitive"); (2) the lack of a standard definition of "de-identified data"; (3) the potential for data re-identification; and (4) the ever-expanding definition of what constitutes "health" information.

Information on the seminar, including a transcript, is available [here](#), and the FTC is accepting comments until June 9.