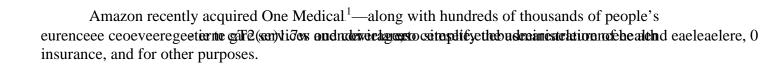


UNITED STATES OF AMERICA FEDERAL TRADE COMMISSION WASHINGTON, D.C. 20580



^{§ 264 (}codified at 42 U.S.C. § 1320d–2 note) (directing the secretary of Health and Human Services to submit standards for protecting privacy); HIPAA Privacy Rule, 45 C.F.R. §§ 164.102–.106, 164.500–.534, 160 (2023).

HIPAA Privacy Rule, 45 C.F.R. §§ 164.102–.106, 164.500–.534, 160 (proposed 1999) (codified 2000) (modified 2013, 2014, 2016); Office of Civil Rights, , HHS (Mar. 31, 2022), https://www.hhs.gov/hipaa/for-professionals/privacy/index.html.

This is more than trivia. It means that the substance of our health privacy law was not enacted through what can be a chaotic legislative process. Instead, it was crafted pursuant to the Administrative Procedure Act, which requires federal agencies to carefully explain the reasons behind proposed regulations.⁶—and gives modern audiences particularly clear insight into the rules exist.

In promulgating the Privacy Rule, HHS tried to balance the need to protect privacy with beneficial uses of data, such as medical research and the promotion of public health. So, it exempted from regulation health data that has been "de-identified"—stripped of some information that could be used to link that data back to a specific person.

Notably, HHS repeatedly insisted that the de-identification provision was intended to promote intended in the context of the c

HHS has clarified that once data is de-identified, it is

Those entrusted with the data can do with it as they please, as long as they don't "re-identify" it. ¹² The lack of a purpose limitation cuts against longstanding American information policy. ¹³ More worryingly, one of the methods the Rule sets out to de-identify data has been criticized by technology experts, because it is based on a fixed list of identifiers that will not keep pace with advances in technology. ¹⁴

To boil down this jargon: When you hear a company tell you that they will abide by HIPAA, it does not mean that they cannot use your data for other purposes. Rather, it means they must simply remove from that data certain markers that would tie that data back to you. I think that most people would be surprised to hear that.

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