

# FTC Enforcement of Health Data Sharing

BY RUTH READER AND GRANT SCHWAB | 05/02/2023 05:00:00 AM EDT

## PRO POINTS

- **The Federal Trade Commission has made protecting online data, particularly health data, a priority of its enforcement agenda.**
- **The Department of Health and Human Services has also taken steps to better guard online health data via the federal health data privacy law HIPAA.**
- **The FTC is likely to issue new rules on commercial surveillance and data security later this year.**
- **HHS has signaled it plans rules to ensure information about patients who receive legal abortions isn't shared with law enforcement.**

## HOW WE GOT HERE

In the absence of new federal data privacy legislation, the Federal Trade Commission has looked into its enforcement tool box to find ways to protect consumer data online. The agency has focused on protecting health data not currently guarded by the 1996 Health Insurance Portability and Accountability Act, which requires providers, insurers and other medical industry firms to safeguard patient data.

The FTC largely uses its principal power — to police “unfair and deceptive” practices — to crack down on companies that either misrepresent their data privacy policies or collect and share data in ways that the agency deems unfair.

Earlier this year, it also cited a cybersecurity regulation, its health breach notification rule, in justifying a fine and settlement with GoodRx, a telehealth provider and drug discounter, for allegedly sharing customer data with business partners.

Congress directed the FTC to write the breach rule into the [2009 economic stimulus law](#). The agency finalized [the rule later that year](#). It requires any entity not covered by HIPAA that collects personally identifiable health information to tell consumers when their data is breached.

# Federal agencies cracking down on health data sharing

Key moments since 2021

## Federal Trade Commission

## Department of Health and Human Services Office for Civil Rights

June 2021

**June:** FTC settles with Flo Health for sharing sensitive user data with third parties including Facebook and Google despite telling users their data was protected.

**September:** Health breach notification rule update. The FTC publishes a policy statement clarifying that mobile apps and fitness wearables that collect personal health data must notify the public if they share that data with third parties.

**October:** Dark patterns. FTC issues enforcement guidance against using design choices to trap consumers into consenting to subscriptions and other arrangements.

2022

**January:** HBNR second update. Two pieces of guidance explain who the rule applies to and what steps covered parties should take to comply.

**August:** FTC sues Kochava for selling sensitive geolocation data from hundreds of millions of mobile devices that could indicate if they sought an abortion.

**August:** New rules on surveillance. The agency issues an advanced notice of proposed rulemaking on commercial surveillance and data security.

**December:** Data tracker guidance. The OCR issues guidance saying that data collected on the websites of covered entities, like insurers and health care providers, is protected by HIPAA.

2023

**February:** First use of the health breach notification rule. FTC fines GoodRx \$1.5 million for unfair data-sharing practices.

**March:** Notice of proposed rulemaking that would amend HIPAA to information surrounding a legal abortion.

**March:** FTC proposes settlement with BetterHelp for unfair and deceptive data sharing and fines the company \$7.8 million.

**March:** Cerebral files a data breach notification.

**April:** OCR promises to amend HIPAA to protect legal abortions.

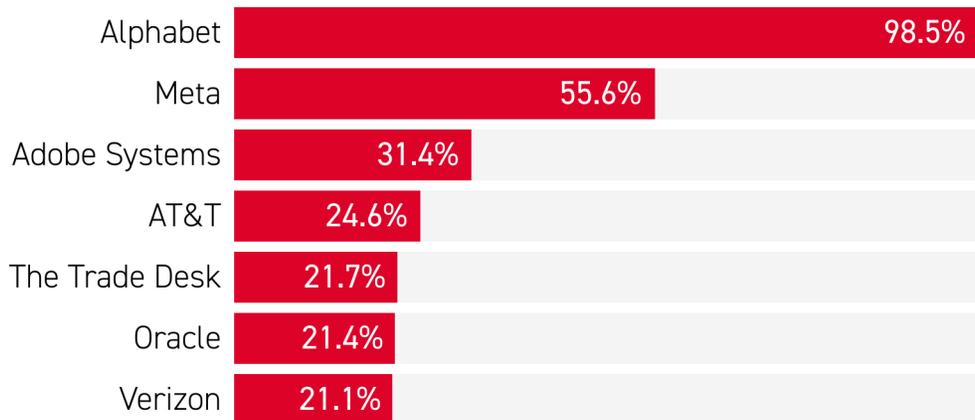
Source: POLITICO reporting

The FTC has also warned firms that it will police [dark patterns](#), web advertising design choices aimed at influencing a person to accept terms or buy a product. Samuel Levine, director of the FTC's Bureau of Consumer Protection, said firms are using those patterns "to trick people into buying products and giving away their personal information." A [September report](#) says "these traps will not be tolerated."

While the FTC's actions have largely focused on telehealth companies, a [study published](#) in April in "Health Affairs" found that 98.6 percent of hospital websites send data to third party marketers. Google was by far the most common data tracker. These data practices have spawned several lawsuits that argue sharing personal health data from a hospital website violates HIPAA.

## Google's parent company collects user data on nearly all U.S. hospital websites

Percentage of hospital websites sending user data to the following companies, as of 2021:



Note: Total sample comprises 3,747 nonfederal acute care hospitals included in the American Hospital Association annual survey

Source: Health Affairs

As a result, divisions within the Department of Health and Human Services are also trying to increase protections for personal health data. In December, the Office for Civil Rights [issued a bulletin](#), noting that data collected on the websites of HIPAA-covered entities, such as insurers and providers, is protected by HIPAA and cannot be disclosed to third party marketers.

Since then, online mental health company Cerebral, [New York-Presbyterian Hospital](#), [UC San Diego Health](#), [Brooks Rehabilitation](#) and alcohol abuse recovery [telehealth company Monument](#) have filed breach reports.

## WHAT'S NEXT

The FTC plans to propose a rule that will more directly regulate commercial surveillance and data security online. The agency has received [1,250 comments](#) on the advanced notice it released last year.

In the meantime, the agency has said it will continue policing companies that deal in unfair and deceptive data practices.

However, it needs more money, which it recently asked for [in a hearing](#) before the House Energy and Commerce Subcommittee on Innovation, Data and Commerce.

Meanwhile, HHS' Office for Civil Rights plans to start enforcing its December guidance, according to [a recent interview](#) with director Melanie Fontes Rainer, who said tracking technologies are a "big priority area for us."

OCR has also issued [a notice of proposed rulemaking](#) that updates HIPAA to explicitly bar health care providers and insurers from giving patient information to law enforcement about a legal abortion. The public can comment on the proposed rule until June 16.



## POWER PLAYERS

- **Lina Khan, Federal Trade Commission chair:** Kahn has said she wants to rein in common industry data-collection practices. Notifying consumers about data collection practices and obtaining consent is not enough, she says. There need to be limits on the kinds and amounts of data that can be collected written into regulations.
- **Melanie Fontes Rainer, director of HHS' Office for Civil Rights:** The director recently called online health data collection practices "problematic" and "widespread." She is pushing the agency to look more closely at how it can leverage HIPAA to better protect consumer health data.
- **The Interactive Advertising Bureau:** A trade group for online advertising firms, is lobbying to get clarity around the regulations and advocate for data privacy rules that allow businesses to continue to market their products legally.