

What would happen if consumers owned their health data?

Article

The data: A new [survey](#) from **Q-Centrix** revealed what US health consumers think of health data sharing.

- Most aren't well informed about their own health data and how it's shared, and this leads to distrust.

- The survey was conducted in December 2021 on 1,191 US adults.

Key findings:

- **61% of US consumers never discussed** how their health data was being used.
- **35% were very concerned** about how their health data is shared.
- **Many weren't sure if they would want to share** even their deidentified data **for clinical research purposes (21%), to help improve hospital services (22%), or advance care equity (24%).**

Who's in the driver's seat with consumer health data? After consumers consent to a company's terms of use, there's rarely any transparency around how the company buys, sells, and uses their health data—or how it may be profiting off of it.

- The flow of healthcare data exchange from consumer to third-party buyers is steered by the healthcare companies (like health apps) that initially collected consumers' data.
- But that data sharing doesn't always consider consumer preferences. **32% of adults are "very concerned" or "somewhat concerned" about the privacy of their healthcare information** on healthcare apps, [according to](#) a September 2021 Morning Consult poll of over 2,000 US adults.

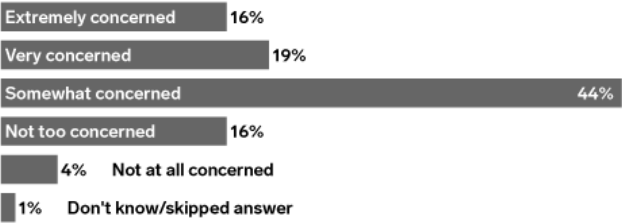
What's next? With more healthcare data swimming through the healthcare ecosystem, companies far and wide are trying to cash in on it. But one thing to look out for is how consumer ownership of health data may divert company profits from selling/licensing data into consumer profits.

This begets the question: What would happen if consumers owned their data?

- We're already seeing a glimpse of this with small projects like [The Sovereignty Network](#) and blockchain development company HashCash, which uses NFTs to enable patients to own their own health data so third-parties would have to pay for it before using it.

Level of Concern that US Adults Have About the Privacy of Their Medical Information and Data on Health Apps, July 2020

% of respondents



Note: includes data on health apps they have selected to use on their smartphone, desktop/laptop, or tablet
Source: Pew Charitable Trusts, "Pew HIT National Survey" conducted by Public Opinion Strategies and Hart Research Associates, Sep 16, 2020