Prescribing privacy
Patient perspectives on health data
Introduction

In a time where data flows like a digital current, technology has evolved rapidly to collect and utilize health data to optimize patient care outcomes.

From the digitization of medical records to the development of cutting-edge diagnostic tools and the proliferation of telemedicine, technology has opened new horizons in patient care.

The collection, utilization, and sharing of health data have never been more integral to the healthcare ecosystem, offering the potential to enhance patient outcomes, streamline processes, and reduce costs. Yet, with every step forward in medical development, a critical question looms: who has access to our most personal health information?

The sanctity of health data, a foundation of trust in the patient-provider relationship, now finds itself at the crossroads of technological advancement and ethical scrutiny.

The data privacy landscape is increasingly complex, marked by shifting regulations and a growing awareness of individual rights, raising pertinent questions about who has access to our health information, how it is used, and whether it is being safeguarded adequately.

We’ve spoken directly to US consumers to delve into the heart of consumer trust and confidence in the healthcare system’s ability to protect and uphold data beyond the initial agreement, as well as attitudes toward their own digital literacy and understanding of healthcare data privacy.

By examining the intricate interplay of consumer trust, data consent enforcement, and the actions healthcare providers can take to fortify this trust, we aim to shed light on the evolving dynamics that underpin data privacy in U.S. healthcare.
87% of Americans are willing to provide their data with the belief that it will lead to enhanced care.

72% are apprehensive about the potential misuse of their health information by external entities.

Half of Americans express greater trust in technology companies to safeguard their data compared to their trust in healthcare providers.

Lack of Informed Consent is the #1 concern of patients.

6 in 10 believe that healthcare providers are not keeping up well with new data privacy regulations and legislation.

92% of Americans believe that explicit opt-in consent should be a mandatory requirement for sharing health data.
Survey methodology and demographics

Survey conducted at 95% confidence, +/- 3% margin of error
Survey conducted from September 26th, 2023 - September 29th, 2023

**Respondent qualifiers**

- Live in the United States
- 18+ Years of Age

**Respondents**

- Total number of respondents: 803
- Average age of respondent: 40
- Representation: 41 of 50 states*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Male</td>
<td>55%</td>
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<tr>
<td>Female</td>
<td>42%</td>
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<tr>
<td>Non-binary</td>
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*(excluding AK, DE, HI, MT, ND, NM, SD, VT & WY)*
Demographics
**Race / Ethnicity**

- White or Caucasian: 72.3%
- Black or African American: 10.9%
- East Asian or Asian American: 5.6%
- Hispanic or Latinx: 6.7%
- Middle Eastern or Arab American: 0.6%
- Native American or Alaskan Native: 0.8%
- Pacific Islander: 0.3%
- South Asian or Indian American: 1.5%
- A race/ethnicity not listed here: 1.3%

**Access to healthcare**

- Out of pocket (no insurance): 11.8%
- Public (Medicaid, Medicare etc): 31.4%
- Employer-provided: 38.1%
- Private: 18.7%

**Parent / Guardian status**

- Yes: 41.0%
- No: 58.3%
- Prefer not to say: 0.8%
Education

- A: Some High School
- B: High School
- C: Some College
- D: Associates
- E: Bachelors
- F: Masters
- G: Doctorate
- H: Other

Annual household income

- A: Less than $32,000
- B: $32,000 to $54,000
- C: $54,001 to $107,000
- D: $107,001 to $374,999
- E: $375,999+
Key findings
The American healthcare journey is marked by uncertainty...

- **69%**
  Of Americans remain unaware of the security measures their healthcare providers have in place to protect their sensitive data.

- **53%**
  Are unaware of their rights pertaining to consent and control over their health data, and men were 17% more likely than women to say this.

- **73%**
  Go as far to say that they are uncertain about who can access their personal health data.
Yet in the face of doubt, the belief in the transformative potential of health data endures.

66%
Believe that the use of personal health data significantly impacts the quality of care they receive.

87%
Of Americans are willing to provide their data with the belief that it will lead to enhanced care.
But for some, data privacy concerns have tangible consequences

13%

Of those who are hesitant about the handling of their health data have let it hold them back from receiving medical treatment, and those who identify as Black/African-American were 62% more likely than average to say this.
For some, health data sharing happens outside of the doctor’s office

31%
Actively use wearable devices to track their health data, and of those, 61% share the data with at least one provider or third-party.

91%
Of those who share data from a wearable device believe it can lead to more personalized and effective treatment plans.

80%
Of those who do not share data from a wearable device would be more likely to do so if they could specify who could access it.
Data exposes a shift towards tech-driven trust: a critical wake-up call for healthcare providers

Half of Americans express greater trust in technology companies to safeguard their data compared to their trust in healthcare providers - this eye-opening revelation is more than just a number; it’s a reflection of evolving patient expectations and the urgent need for healthcare providers to invest in top-tier data security - those in Texas were 22% more likely than average to say they have higher trust in tech companies
And patients emphasize one major concern with healthcare data practices

Lack of informed Consent

Is the #1 concern of patients
Which is why providers should prioritize patient-centric data practices...

92% Of Americans believe that explicit opt-in consent should be a mandatory requirement for sharing health data.

91% Would have more trust in the healthcare system if providers were more transparent about what happens to their data once they’ve consented.

94% Prefer healthcare providers with robust data protection measures.
90%

Say that healthcare providers that invest in data security technology are more reliable than those that don’t, and of those, 43% are looking to switch to a provider that places a stronger emphasis on data privacy protection.
9 in 10 Americans support regular third-party audits of healthcare providers’ data security practices – Interestingly, among this group, 61% were more concerned about financial data leaks than actual health data leaks.

82% Are uncertain to the legal implications of selling health data to third-party entities.
...To provide consent in a consumer-friendly way

65%

Have received a data consent notice that is hard to understand

79%

Say that data consent notices include too much jargon
Safe data sharing leads to better health outcomes for all

76% Are willing to share anonymized health data for research purposes
In the eyes of patients, providers show much room for improvement

The average scores across key healthcare data aspects reveal ample room for growth. With an average rating of 3 out of 5 in categories such as data security, patient education, transparency, and consent and control options, it is clear that patients are calling for improvements. Additionally, the score of 2 out of 5 for compliance with regulations underscores the need for healthcare providers to enhance their regulatory adherence.
And some are willing to choose privacy over price and convenience.

23% say that they look into data security measures before committing to a practice (although Baby Boomers were 52% less likely than average to say this).

Among this group, a resounding 84% of patients express their willingness to commute to a healthcare practice further away if it offers better data security. This commitment to data security is further evident as 76% of patients are prepared to choose a provider with less availability if it means better data security, and 64% of patients are even willing to opt for a more expensive practice if it guarantees enhanced data security.
The trust conundrum: Americans don’t know who to trust

6 in 10
Believe that healthcare providers are not keeping up well with new data privacy regulations and legislation, and those who look at data privacy measures before choosing a practice were 25% more likely than those who do not to say this.

83%
Are skeptical of how well government regulations protect their health data.

7 in 10
Struggle to keep up with the rapidly changing data privacy landscape themselves.
Highlighting the need for more transparency...

- **88%**
  Would like to be informed of their rights and protections every time they are asked to volunteer their information.

- **97%**
  Believe they should have access to their rights and protections at their own convenience.

- **81%**
  Would be more likely to trust a provider that works with a third party to ensure consent management and compliance.
...And better patient education...

- **96%**
  
  Would benefit from easily understandable information about healthcare data privacy

- **79%**
  
  Believe that improving their digital health literacy can lead to better health outcomes

- **92%**
  
  Are more likely to consent to data sharing for research purposes when they receive clear and concise educational materials about how their data will be used
...That is easily accessible so that patients don’t have to search

66%

Admit that they do not actively seek educational resources on healthcare data privacy, however, men were 34% more likely than women to say they do actively seek these materials.
In fact, education is paramount to building trust.

9 in 10

Of those who would like more information say that their trust in a healthcare provider would be substantially enhanced if they offered educational materials on healthcare data.
Aside from education, what else can healthcare providers provide?

- 69% of Americans would like access to their records.
- 65% would like transparent privacy policies.
- 57% desire access controls.
Conclusion

Analyzing this survey data, three vital storylines emerge. First, the impact of social determinants on patient outcomes is undeniable. Addressing these broader factors is crucial for equitable care.

Second, people’s fear of data exposure is deeply tied to their trust in the healthcare system. Privacy breaches have eroded this trust, emphasizing the need for robust data protection.

Third, the challenges in enforcing data safeguards and the minor penalties for breaches present significant hurdles.

In connecting these points, our hypothesis gains strength: the U.S. healthcare system rewards companies that prioritize patient privacy. Partnerships with organizations like Cassie can rebuild trust, yield financial benefits, and enhance patient outcomes.

As healthcare evolves, stakeholders must balance innovation and security. Navigating data privacy complexities is an ongoing challenge, but it is the key to a future where patients trust a system that not only cares for their health but also safeguards their information. This report is just the beginning, and we anticipate a future where data privacy and patient trust lead the way in U.S. healthcare.

Key fact

87% of Americans are willing to provide their data with the belief that it will lead to enhanced care.
Introducing Cassie

Cassie is a powerful consent management platform that secures sensitive PHI, enables granular patient control and protects patient privacy.

From hospitals, medical institutions and health information exchanges to life science and technology companies, Cassie has been developed to help you manage data related to complex relationships throughout the patient journey.

As a person moves through the care continuum, from anonymous, to patient, to advocate, Cassie can solve data usage, privacy permissions, restrictions and permissions across the entire patient journey.

You get compliance without compromise:

- Capture anonymous data to drive awareness around preventative care and healthy living
- Collect customer preferences to send relevant, personalized communications on their terms
- Connect consent across the organization, third-party platforms and channels
- Create a single source of truth
- Compliance by default

If you’d like to learn more about how we can help you on your compliance journey, our team of dedicated consent and preference management experts will be able to guide you every step of the way.

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