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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.

Key insights



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

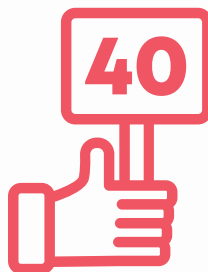


18+ Years of Age

Respondents



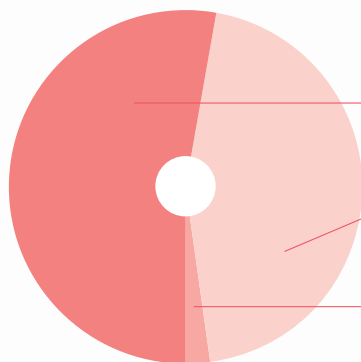
Total number of respondents



Average age of respondent



Representation:
41 of 50 states*



55% Male
42% Female
3% Non-binary

*(excluding AK, DE, HI, MT, ND, NM, SD, VT & WY)

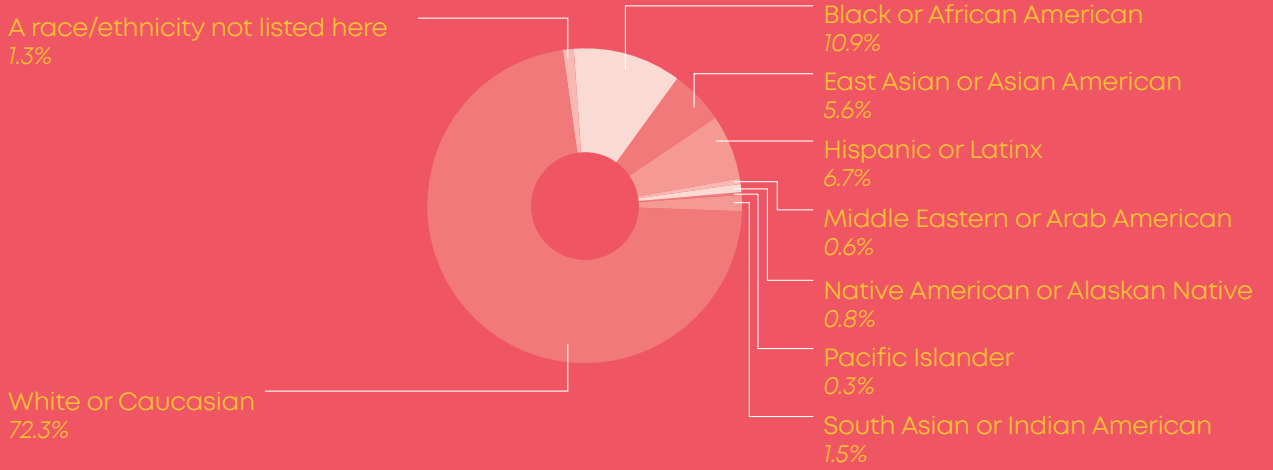
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Demographics

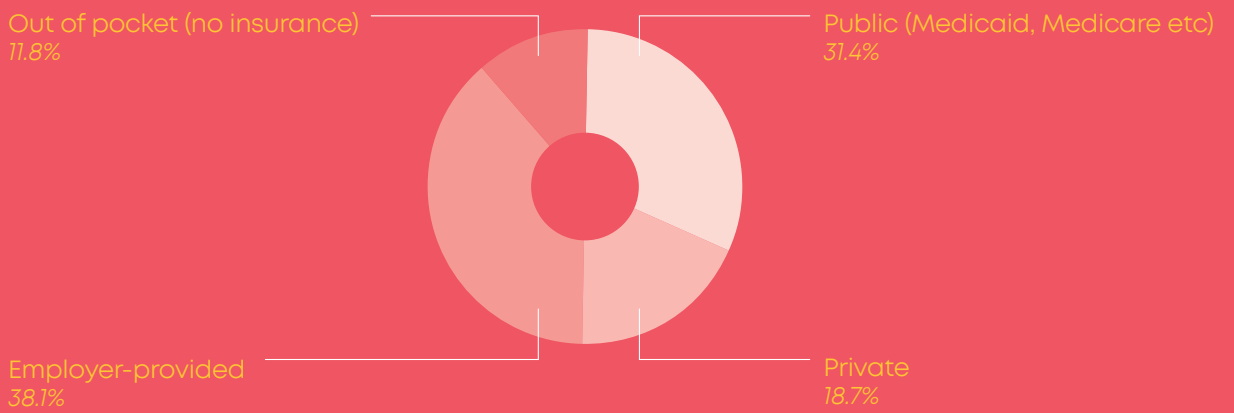




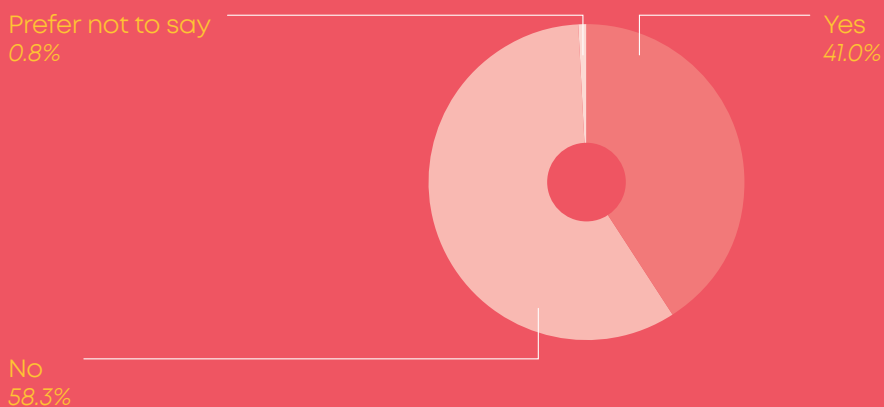
Race / Ethnicity



Access to healthcare

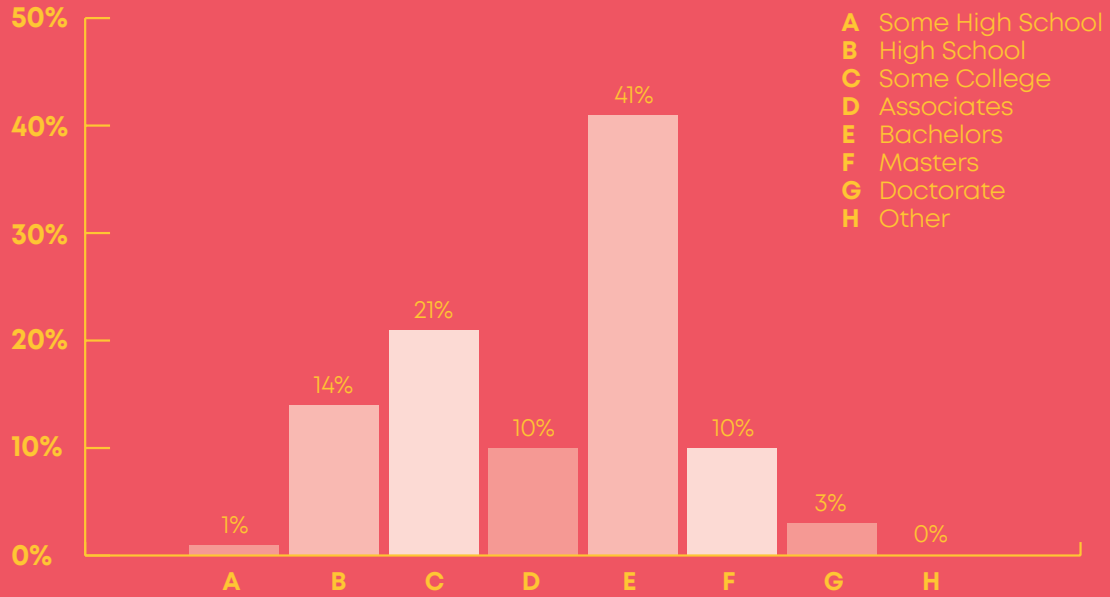


Parent / Guardian status

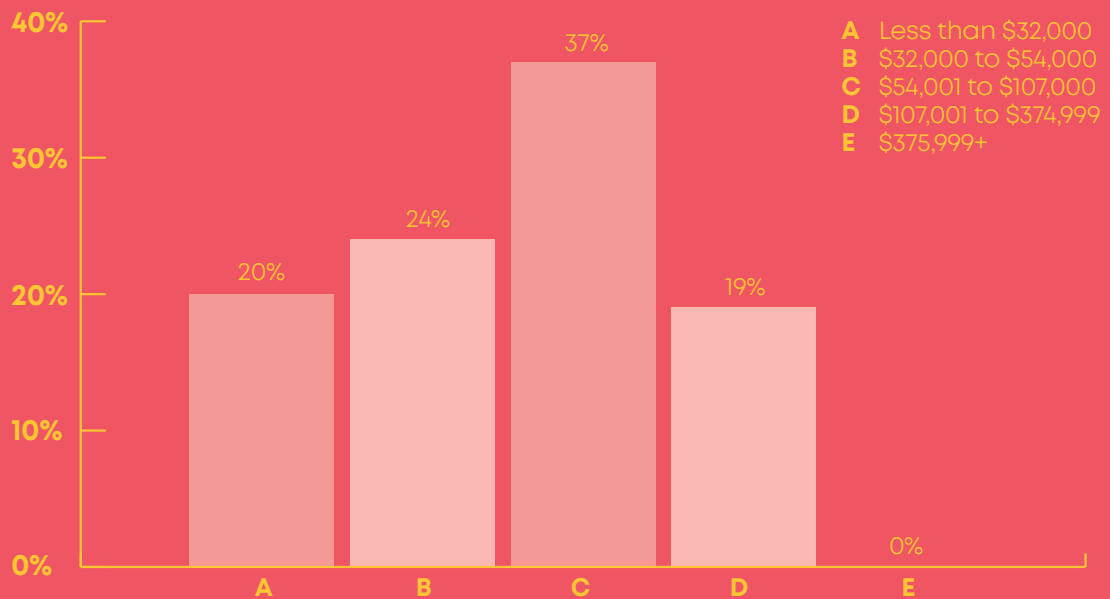




Education



Annual household income



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Key findings

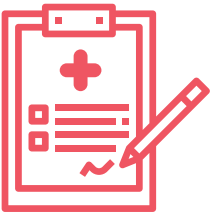


The American healthcare journey is marked by uncertainty...



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

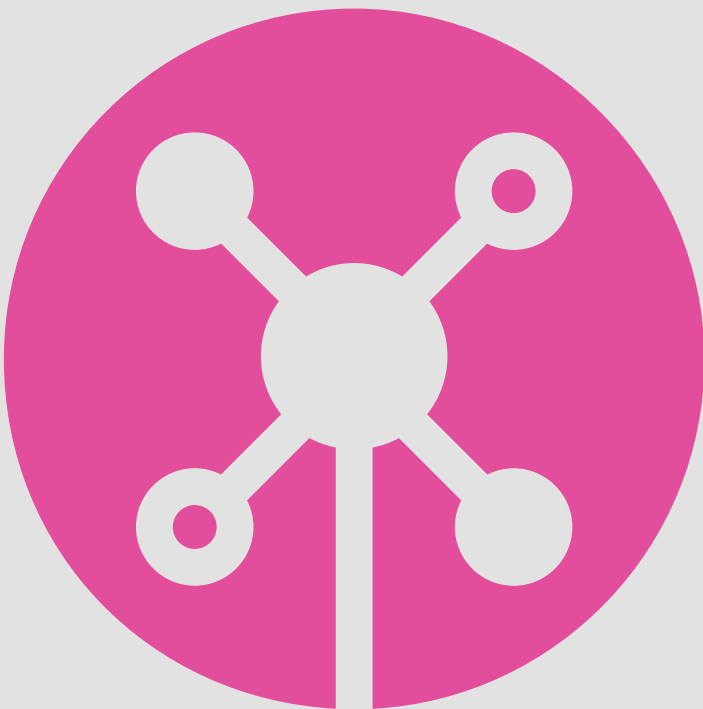
66%

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



1/2

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...

A gauge graphic with a needle pointing to 92% on a scale from 0 to 100. The gauge is semi-circular and has a red background.

92%

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

A gauge graphic with a needle pointing to 91% on a scale from 0 to 100. The gauge is semi-circular and has a yellow background.

91%

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

A gauge graphic with a needle pointing to 94% on a scale from 0 to 100. The gauge is semi-circular and has a teal background.

94%

Prefer healthcare providers with robust data protection measures

...And embrace a tech-forward...



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

...And transparent approach...

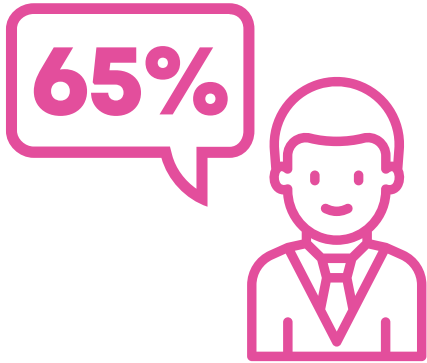
9 in 10

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

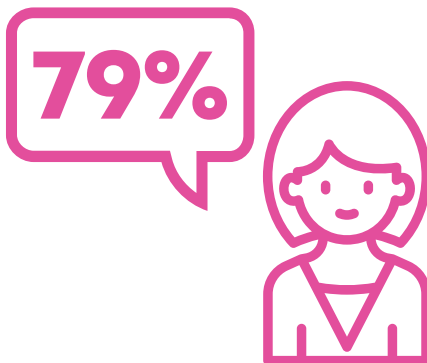
82%

Are uncertain to the legal implications of selling health data to third-party entities

...To provide consent in a consumer-friendly way



Have received a data consent notice that is hard to understand



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.

Data compliance with regulation



Data security



Patient Education



Transparency



Consent and control options



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

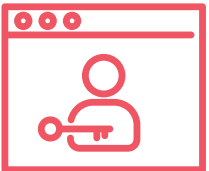
Struggle to keep up with the rapidly changing data privacy landscape themselves

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...



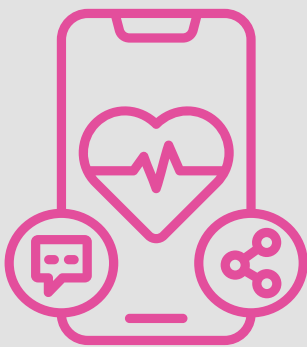
96%

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 organization 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%



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

Centralized patient consent

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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