Patient perspectives around data privacy

The American Medical Association partnered with Savvy Cooperative, a patient-owned source of health care insights, to survey 1,000 patients across the U.S. on their perspectives toward the privacy of their medical information. We found that by understanding the patient perspective on data privacy, industry and government can better act to help patients and their care team protect medical information and strengthen trust. The survey illustrates that patients are deeply concerned over the lack of security and confidentiality of personal health information.

Physicians are committed to protecting patients' privacy—a crucial element for honest health discussions. Yet, we learn more each day that personal health information is no longer private. With recent rulings by the Supreme Court, the lack of data privacy raises many questions that could put patients and physicians in legal peril. Our survey findings shed light on fundamental data privacy issues that can impact individuals nationwide. The AMA is calling on all policymakers—Congress and the administration—to take much needed action to protect health information.

PRIVACY IS A RIGHT

More than 92% of people believe privacy is a right and their health data should **not** be available for purchase by corporations or other individuals.

- People are unclear about rules to protect their privacy, and have concerns about who has access
- Nearly 75% of people are concerned about protecting the privacy of their health data

The AMA is highly concerned that patients' private medical information is increasingly vulnerable and digital patient data is being shared beyond the confines of the HIPAA framework without protections of federal privacy.

- Patients are **most comfortable** with their physician or hospital having access to their data
- Patients are **least comfortable** with social media sites, employers and big technology companies receiving access to their health data

PATIENT DATA USE: COMFORT LEVEL

Most comfortable

My doctor's office

75.2%

Hospital or health system

64.2%

Least comfortable

Social media sites

71.2%

Big tech

67.4%

Prospective employer

62.9%

NEED FOR STRONG REGULATIONS

Strong regulations are needed to support an individual's right to control, access and delete personal data collected about them. The AMA believes the primary purpose of increasing data privacy is to build public trust, not inhibit data exchange.

- Ninety-four percent of patients state that companies that collect, store, analyze or use health data should be held accountable by the law

When considering whether to use health applications (apps), technologies or platforms in light of privacy concerns, nearly 70% of surveyed patients **hesitate** at least sometimes, and more than 60% decide not to start using the tool.

The **AMA's Privacy Principles** outline five key aspects of a national privacy framework—individual rights, equity, entity responsibility, applicability and enforcement. As Congress continues discussions around federal privacy legislation, the AMA seeks to ensure that resulting privacy law protects the sacred trust at the heart of the patient-physician relationship. As health information is shared—particularly outside of the health care system—patients must have meaningful control and a clear understanding of how their data is being used and with whom it is being shared. Above all, patients must feel confident that their health information will remain private. Preserving patient trust is critical.

TRANSPARENCY AND CONTROL ARE KEY

Almost 93% of patients want health app developers to publicize if and how their product adheres to industry standards for handling health data. Patients and consumers are demanding transparency.

When asked to indicate how comfortable they are with certain types of companies gaining access to their health data, patients were overwhelmingly **most comfortable** with their doctor's office having such access.

- Almost 88% of patients believe their doctor or hospital should have the ability to review and verify the security of health apps before those apps gain access to their health data. Unfortunately, federal regulations prevent providers from conducting necessary privacy and security reviews of apps.

People want choices on how their information is used …

- Almost 80% of participants want to be able to "opt-out" of sharing some or all their health data

- More than 75% of patients want to opt-in **before** a company uses any of their health data

- More than 75% of people want to receive requests prior to a company using their health data for a new purpose

More needs to be done to create transparency on how apps use patient medical information. The AMA **has identified and recommended** additional actions to increase transparency on what apps are doing with medical information. The **AMA's "Privacy by Design"** toolkit can assist a developer in building privacy-forward technology into their products.

IMPACT ON HEALTH EQUITY

Fifty-nine percent of patients worry about health data being used by companies to discriminate against them or their loved ones or to exclude them from opportunities to find housing, gain employment and receive benefits.

Privacy efforts must include non-discrimination protections to avoid exacerbating existing inequities or creating new ones. Patients must be able to trust that the information captured using digital health tools will not be used against them (e.g., in immigration/removal proceedings; impeding access to insurance coverage, government benefits and social services).

- Over one-half of surveyed patients stated they are very or extremely concerned about negative repercussions related to insurance coverage, employment or opportunities for health care resulting from access to their health data.

- When asked about negative consequences from access to health data there was a discrepancy, especially when it came to employment and insurance impact.

  ○ More than 50% of Hispanic/Latinx and American Indian or Alaskan Natives were highly concerned about obtaining or keeping insurance and 66% of transgender individuals answered that they were extremely concerned their health data could negatively impact their employment status

The AMA's **Privacy Principles** and **"Privacy by Design" toolkit** provide the structure and methods to enable app developers and digital health innovators the ability to create products that advance health equity and build trust in their use. Strong regulations are needed to support patients' right to data privacy and restore trust in data exchange that facilitates accessible, equitable, and personalized care. The AMA continues to advocate for near-term app transparency requirements, including **app privacy attestations collected by EHRs,** that will increase transparency and bolster individuals' choice in which apps to use.