Why COVID-19 tracking will flounder without privacy protections

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What’s the news: Poll results show the American public has deep privacy concerns about using the tech-enabled COVID-19 tracking and tracing systems that could help limit the pandemic's deadly toll, making the release of a document outlining the AMA's privacy principles especially timely.

The AMA privacy principles support an individual's right to control, access and delete personal data collected about them. Using the new privacy principles, the AMA will actively engage the administration, Congress and industry stakeholders in discussions on the future direction of regulatory guardrails that are needed to restore public confidence in data-privacy protections.

“Patients’ confidence in the privacy and security of their data has been shaken by repeated technology sector scandals and the wired economy’s default business model that quietly gathers intimate glimpses into private lives—often without patient knowledge, consent or trust,” said AMA President Patrice A. Harris, MD, MA.

“As a result, patients are less willing to share information with physicians for fear that technology companies and data brokers will have full authority over the use of their indelible health data,” added Dr. Harris, an Atlanta psychiatrist. “Unfortunately, recently finalized federal regulations will make this more likely to happen.”

Why it’s important: Google and Apple are working with public health authorities on an infection-alert system using smartphone apps, yet nearly 60% of Americans tells pollsters they are either cannot or will not use such a system. A Washington Post-University of Maryland poll highlights that a majority expressed doubts about whether big tech companies would protect the privacy of their health data.

In a post-pandemic world without a proven SARS-CoV-2 vaccine or breakthrough treatment, public health experts agree that quickly tracking new COVID-19 infections and tracing those patients’
contacts is essential to limiting spread of the deadly respiratory illness. “A well-resourced public health system for surveillance and contact tracing” is one of the four signposts for safely reopening America that have been laid out by the AMA.

The AMA notes that the primary purpose of boosting guardrails around data use is to build public trust, not inhibit data exchange. “The AMA privacy principles set a framework for national protections that provide patients with meaningful control and transparency over the access and use of their data,” explained Dr. Harris. “Preserving patient trust is critical if digital health technologies are to facilitate an era of more accessible, coordinated, and personalized care. To restore confidence in data privacy and security, the AMA privacy principles promote individual rights, equity and justice, corporate responsibility to the individual, applicability and federal enforcement.”

Learn more: For more than a decade the AMA has advocated for the fundamental right of patients to access their complete medical record and promoted the use of health data to enhance patient experience, improving population health, reducing costs, and improving the work life of physicians and other health professionals.

The AMA Patient Access Playbook, for example, helps guide physicians and their staff on best practices for providing patients their medical records. The AMA and the Centers for Disease Control and Prevention are closely monitoring the COVID-19 pandemic. Learn more at the AMA COVID-19 resource center, and consult the AMA’s physician guide to COVID-19.