Medical Xpress

Most patients willing to share medical records for research purposes

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As medicine becomes both bigger and more personalized, the need for massive databases of patient records, such as the 1 million person All of Us Research Program, become increasingly essential to fueling both new discoveries and translational treatments.

But the looming, lingering question is to what degree are individual patients willing to share medical records and biospecimens with researchers and institutions beyond their personal physician or health care system? And more specifically, how should patients be asked and what information are they most likely to share?

In a novel attempt to answer these questions, researchers at University of California San Diego School of Medicine, with collaborators in California, North Carolina and Texas, asked patients at two academic hospitals to respond to a variety of different approaches seeking to share their medical data with other researchers.

The findings are published in the August 21, 2019 online issue of *JAMA Network Open*.

The survey was conducted at two academic hospitals—UC San Diego Health and UC Irvine Health between May 1, 2017 and September 31, 2018. Participants were randomly selected to one of four options with different layouts and formats for indicating sharing preferences: opt-in simple, opt-in detailed, opt-out simple and opt-out detailed. In the simple forms, there were 18 categories where participants could choose to share information; in the detailed forms, there were 59 items. The items ranged from demographics like age, sex and race and socioeconomic status to lab results (genetic tests, drug screening, etc.), imaging (x-rays, MRI) and biospecimens (blood, urine, tissue).

Participants were also asked to what degree they would be willing to share their medical data: with researchers only in the same health care organization or with those working at other nonprofit or for-profit institutions.

Among 1,800 eligible participants, 1,246 completed the data sharing survey and were included in the analysis and 850 responded to a satisfaction survey. Slightly less than 60 percent were female and slightly less than 80 percent were white. The mean age was 51 years old.

More than 67 percent of survey participants indicated they would share all items with researchers from the home institution (which patients presumably already trust with their health care), with progressively smaller percentages for sharing with other nonprofit institutions or with other for-profit institutions. Many of the respondents indicated that they were only unwilling to share a few items.

"These results are important because data from a single institution is often insufficient to achieve statistical significance in research findings," said the study's senior author, Lucila Ohno-Machado, MD, Ph.D., professor of medicine, associate dean for informatics and technology in the UC San Diego School of Medicine and chair of the Department of Biomedical Informatics at UC San Diego Health. "When sample sizes are small, it is unclear whether the research findings generalize to a larger population. Additionally, in alignment with the concept of personalized medicine, it is important to see whether it is possible to personalize privacy settings for sharing clinical data."

Generally speaking, the current state of affairs concerning the sharing of "anonymized" patient health data for secondary research is uneven and unsettled. It has been shown that anonymization methods—in which data sets are either encrypted or stripped of personally identifiable information—are not 100 percent effective. Since 2013, newly enrolled patients are required to proactively consent to sharing their personal health information for research studies or future secondary use. In California, a patient's specific permission is required to share mental health, substance abuse, HIV status and genetic information, but other items or conditions are not specified. In many states, there is no requirement for a patient's specific permission on these types of items before they can be shared. Today, for practical purposes, patients have the option to decline any part of their medical record be used for research. They cannot indicate what types of research or researcher should be able to obtain their records.

Almost three-quarters of respondents—67.1 percent—said they would be willing to share all items with researchers from their health care institutions; almost one-quarter said they would be willing to share all items with *all* interested researchers, a finding the authors said was reassuring and could help in the planning of studies based on EHRs and biospecimens that would be expected to be broadly shared.

Equally encouraging: Less than 4 percent of participants said they were not willing to share any information with anyone.

Ohno-Machado said the way in which preferences are elicited also has an influence. There was greater sharing per item when respondents were asked to opt-out than when they were asked to opt-in. Whether the form had details about the items or used broad categories did not have an influence on sharing.

"This is important because a simple form could be used in the future to elicit choices from all patients, saving their time without significantly affecting their privacy preferences," said Ohno-Machado. "However, different rates of sharing are expected for opt-in and opt-out of sharing clinical records for research."

A key finding was that a majority of survey participants identified at least one item that they did not want to share with a particular type of researcher (for example, a scientist at another for-profit institution), though they were willing to share other items.

"This finding is important," wrote the authors, "because the item to withhold may not be of relevance to a certain study, but the current all-ornothing option, if chosen, would remove that patient's data from all research studies."

The authors said the survey's tiered-permission system that allows specific removal of data items or categories proves both doable and appealing to patients, in part because there are differences among individuals in where and with whom they share what.

The findings, said the authors, trigger further questions about the ideal balance between giving patients the ability to choose what portions of their data they want to share for research and with whom and the "greater good," i.e., how fast research can be accelerated for the benefit of all.

"Institutions currently make decisions on sharing on behalf of all patients who do not explicitly decline sharing. It is possible that asking patients directly would increase the amount of data shared for research. On the other hand, it is also possible that some types of research would suffer from small sample sizes if patients consistently decline certain categories of items," Ohno-Machado said.

More information: Jihoon Kim et al. Patient Perspectives About Decisions to Share Medical Data and Biospecimens for Research, *JAMA Network Open* (2019). DOI: 10.1001/jamanetworkopen.2019.9550

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