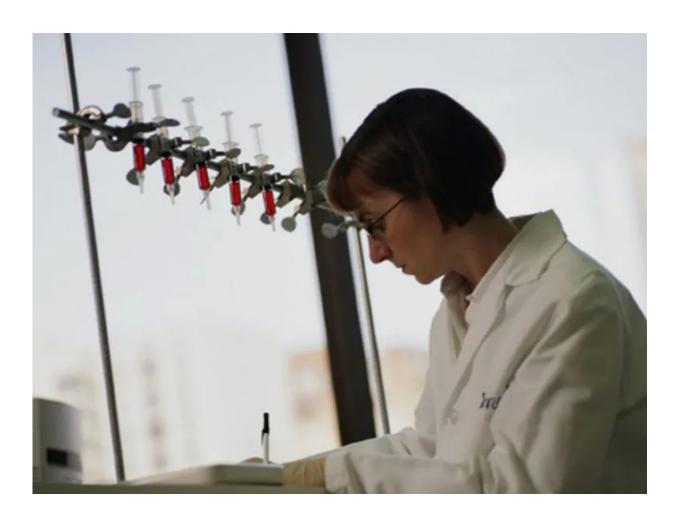


## Most research participants not concerned about data sharing

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(HealthDay)—Few participants in clinical trials have strong concerns



about the risks of data sharing, according to a study published June 7 in the *New England Journal of Medicine*.

Michelle M. Mello, J.D., Ph.D., from Stanford University in California, and colleagues conducted a structured survey of 771 current and recent participants from a diverse sample of clinical trials at three U.S. academic medical centers. The survey was distributed by mail (350 completed surveys) and in clinic waiting rooms (421 completed surveys).

The researchers found that fewer than 8 percent of respondents felt that the potential negative consequences of <u>data sharing</u> outweighed the benefits. The vast majority (93 percent) were very or somewhat likely to allow their own data to be shared with university scientists, while slightly fewer (82 percent) were very or somewhat likely to share with scientists in for-profit companies. Expressed concerns included: that data sharing might make others less willing to enroll in <u>clinical trials</u> (37 percent very or somewhat concerned), that data would be used for marketing purposes (34 percent), or that data could be stolen (30 percent). Discrimination and exploitation for profit were less often reported as concerns (22 and 20 percent, respectively).

"Provided that adequate security safeguards were in place, most participants were willing to share their data for a wide range of uses," conclude the authors.

**More information:** Abstract/Full Text

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