

Most clinical trial participants find benefits of sharing personal data outweigh risks

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Most participants in clinical trials believe the benefits of broadly sharing person-level data outweigh the risks, according to a new study by Stanford University researchers.

And despite low levels of trust in [pharmaceutical companies](#), most of those who take part in clinical [trials](#) are willing to share their [data](#) with drug firms, the researchers found.

The study will be published in the June 7 issue of *The New England Journal of Medicine*. The lead author is Michelle Mello, JD, Ph.D., professor of law and of health research and policy. Steven Goodman, MD, Ph.D., professor of medicine and of health research and policy, is the senior author.

The researchers surveyed 771 current and recent participants from a diverse sample of clinical trials at three [academic medical centers](#) in the United States. They asked about the practice of making personal data collected in medical research widely available after the removal of information that could identify individual participants. Nearly 80 percent of those surveyed responded to the questions—and fewer than 8 percent of the respondents felt that the potential negative consequences of [data sharing](#) outweighed the benefits.

Some 93 percent of those surveyed said they were very or somewhat likely to allow their data be shared with university scientists, and 82 percent were either very or somewhat likely to allow their data to be share with scientists at for-profit companies. The researchers found that the willingness to share was high regardless of the purpose for which their data would be used, unless that purpose was litigation.

Although some researchers and trial funders have worried that participants might object to data-sharing as an invasion of privacy, the respondents' greatest concern was that "data sharing might make others less likely to enroll in clinical trials," the authors wrote. "Less concern was expressed about discrimination (22 percent) and exploitation of data for profit (20 percent.)"

The authors acknowledge there is no turning back from clinical data sharing.

"We are rapidly moving toward a world in which broad sharing of participant-level clinical trial data is the norm," they wrote.

Expanding access to data

Major research sponsors and journal editors have begun promoting data sharing, and the National Institutes of Health now requires its grantees to describe how they will share their data with others.

Pharmaceutical industry associations have committed to making data more accessible, and several data platforms are now available, such as the Yale Open Data Access Project.

Mello said she was somewhat surprised by the survey results, "given the amount of consternation one hears at conferences about data sharing."

"Interestingly, nearly half our sample had experienced a breach of their [personal data privacy](#) in another context, yet they were still willing to share their clinical trial data," she said.

Then again, she said, people who take part in clinical trials may be special.

"I suspect that clinical trial participants may be different from the public at large," Mello said. "They are already incurring risks to benefit science by dint of their trial participation."

Most of those participants, along with clinical researchers, believe the benefits of sharing data include accelerating scientific discovery and improving accurate reporting of trial results.

Companies leery of data sharing

Yet some investigators and industry sponsors of [clinical trials](#) are leery of the swift move toward broad data sharing because of "potential harm to research participants," the authors wrote. "Investigators express worries that participants' privacy cannot be adequately protected, particularly in light of the fact that experts have demonstrated that it is possible to reidentify participant-level data."

Furthermore, the authors wrote, some pharmaceutical companies have warned that data sharing could chill people's willingness to participate in trials, thereby delaying the availability of new therapies. In fact, 31 percent of those surveyed were somewhat or very concerned about having their personal information stolen. Nevertheless, most felt the benefits of data sharing were more important.

"Reaching a world in which the sharing of [clinical trial data](#) is routine requires surmounting several challenges—financial, technical and operational," the authors wrote. "But in this survey, [participants'](#) objections to data sharing did not appear to be a sizeable barrier."

Provided by Stanford University Medical Center

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