

Racial and ethnic minorities may be less willing than others to participate in clinical trials

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A survey conducted in one cancer center's catchment area found that while a majority of respondents would be willing to participate in a clinical trial, members of racial and ethnic minority groups were significantly less likely to participate than non-Hispanic whites, according to results presented at the [16th AACR Conference](#) on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, held September 29–October 2, 2023. Reasons to participate or not participate varied across the groups, suggesting that tailored approaches to enrolling patients in clinical trials could lead to more diverse patient populations.

Clinical trials are a pivotal part of the drug approval process, but previous research has shown that only about 5% of Americans have ever participated in a clinical trial. Most racial and ethnic minority groups are underrepresented, exacerbating disparities in many areas of health care, including [cancer diagnosis](#) and treatment.

"This lack of representation means that most clinical trials do not show the full range of people that are afflicted by cancer and, therefore, are not fully informing our treatments," explained the study's lead author, Amy L. Shaver, Ph.D., PharmD, MPH, a postdoctoral research fellow at Thomas Jefferson University in Philadelphia. "We need to understand how to better attract and retain a more representative sample of people so that the care we deliver is best suited to the people it is delivered to."

In order to assess people's willingness to participate in clinical trials, Shaver and colleagues utilized data from an [online survey](#) of 2,744 adult

residents in the Sidney Kimmel Cancer Center's catchment area, which includes Philadelphia, Delaware, Bucks, and Montgomery counties in Pennsylvania as well as Camden, Burlington, and Gloucester counties in New Jersey. The Sidney Kimmel Cancer Center and Thomas Jefferson University are both part of the Jefferson Health system.

The survey, conducted from July to August 2022, assessed lifestyle behaviors, cancer screening frequencies, cancer attitudes or beliefs, health literacy, and numeracy. The survey was administered in English, Spanish, and Chinese. A majority of respondents (57.8%) were white; 19% were non-Hispanic Black, 9.3% were Hispanic, and 14% identified as "other," including Asian ethnic groups.

The survey showed that overall, 69.8% of respondents were willing to participate in clinical trials. However, distinct differences emerged in various racial and ethnic groups. Key highlights include:

- Respondents answering in Chinese were 40% less likely than those answering in English to say they would participate in clinical trials;
- Hispanic and non-Hispanic Black respondents were more than 30% less likely to say they would participate than white respondents;
- The most common reason given for not participating in clinical trials was fear of side effects (25.6%). Other reasons were concerns that the drug may not be effective; lack of awareness of trial locations; mistrust in doctors and/or drug companies; and worries about the time commitment.

The survey also asked participants about their personal experiences with discrimination. Shaver said she was surprised to discover that respondents reporting a high level of discrimination were 48% more likely to participate in a clinical trial than those who reported a low level

of discrimination. She said the respondents who reported a high level of discrimination cited wanting to "learn more about their health and [medical condition](#)" (66.3%) and a desire to "help my community" (54.5%) as potential motivating factors for clinical trial participation. Shaver suggested that a history of discrimination may fuel some respondents' desire to gain access to medical knowledge for themselves and for their broader community.

Shaver said the survey provides valuable information to researchers at both Thomas Jefferson University and the Sidney Kimmel Cancer Center, and could be replicated in other [cancer](#) centers to inform clinical trial recruitment.

"Our findings highlight the importance of catchment assessment when designing recruitment methods," she said. "Proactively engaging the community in [study design](#) may help repair the relationship between science and the people it serves."

Shaver also said the [survey results](#) highlight the importance of holding frank conversations with people to fully understand why they may or may not be willing to participate in [clinical trials](#). "It is important to ask people what motivates them; don't assume you know," she said.

Shaver noted that as a cross-sectional study, this survey did not fully assess causality between discrimination and clinical trial interest. Also, this [survey](#) specifically targeted people in the U.S. mid-Atlantic region. Further research would be necessary to determine if these results are generalizable to a broader population.

Provided by American Association for Cancer Research

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