

Clinical Trial Participation Among US Adults

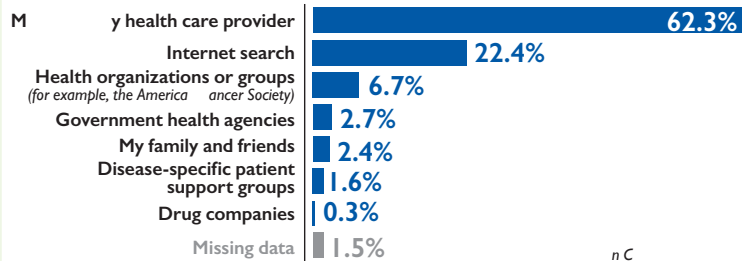
Clinical trials are necessary for evaluating new treatments and advancing the standard of care for patients. Unfortunately, many clinical trials close prematurely due to inadequate accrual, which may result in wasted resources, missed opportunities for advancing science, and reduced public trust. Greater and more representative participation in clinical trials would allow studies to be conducted more quickly and efficiently, improve the generalizability of trial results, and enable new treatments to be made available more readily.

Relatively low clinical trial enrollment rates have remained largely unchanged over time, suggesting that patients still face substantial barriers to participation. Structural barriers, such as the lack of trial availability in rural areas, and clinical barriers, such as narrow or complex eligibility criteria, limit access to trials. However, even when patients are eligible for a locally available trial, physicians may fail to discuss the trial with their patients—for example, due to time constraints, treatment preferences, or concerns about the potential impact on the physician-patient relationship. Finally, the ultimate decision regarding trial participation rests with the patient. When patients are offered clinical trial participation, they accept approximately 50% of the time. Reasons for declining include fear of side effects, concerns about costs, and logistical barriers to participation such as time burden and lack of transportation. These multilevel barriers to clinical trial participation disproportionately affect certain groups, such that older adults, medically underserved racial and ethnic groups, those of lower socioeconomic status (SES), individuals with comorbidities, and rural residents are often underrepresented in clinical trials. Disparities in clinical trial enrollment can hinder the equitable and effective translation of research, making it critical to implement targeted strategies to increase trial invitation and participation rates across diverse patient populations.

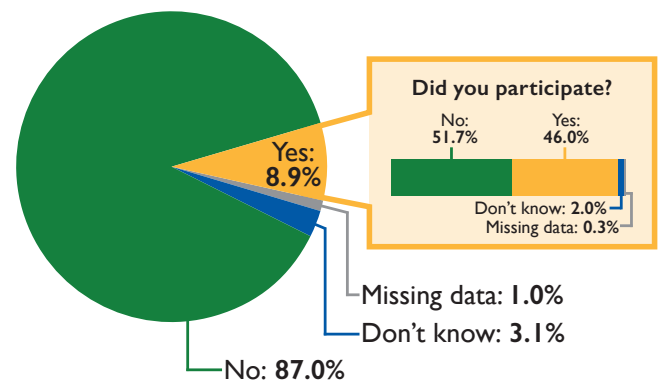
Quick Facts

- Clinical trials often close prematurely because of inadequate accrual.
- In 2020, 41% of Americans reported not knowing anything about clinical trials.
- Reducing barriers to trial participation would ensure more generalizable and timely data on new treatments, allowing them to be made safely available to the public sooner.
- Structural, clinical, attitudinal, and socioeconomic factors can affect clinical trial participation.
- Certain populations, including older individuals, racial/ethnic minority groups, individuals with comorbidities, those of lower SES, and residents of rural areas are often underrepresented in clinical trials.

Imagine you had a need to get information about clinical trials. Which of the following would you go to first?*



Have you ever been invited to participate in a clinical trial?*



Source: HINTS 5 Cycle 4, 2020

Clinical Trial Invitation, Participation, and Preferred Sources of Clinical Trial Information among American Adults

A recent study used HINTS 5 Cycle 4 (2020) data to examine clinical trial invitation and participation in a nationally representative sample of US adults. The analysis found that 9% of Americans reported having ever been invited to participate in a clinical trial, and, of those who were invited, 47% reported participating. Non-Hispanic Black individuals (compared to non-Hispanic Whites), those with a high school education or more (compared to those with less than a high school education), those who were single (compared to those married or living as married), and those who had at least one medical condition (compared to those who reported no medical conditions) had greater odds of being invited to participate in a clinical trial, whereas individuals in rural areas (compared to those residing in urban areas) had lower odds of being invited. The study also found that once invited, non-Hispanic Black individuals had lower odds of reported clinical trial participation compared to non-Hispanic Whites.

The researchers also analyzed the public's preferred sources of information about clinical trials to inform future communication efforts. They found that a majority of Americans (59%) would go to their health care provider first if they needed information about a clinical trial, while 21% would turn to the internet first. For most Americans (70%), health care providers were also the most trusted source of information about clinical trials.

*Percentages in the charts differ from the reported study results due to differences between the full weighted sample in the HINTS codebook and the analytic sample used in the study.

How Can This Inform Your Work?

HINTS data indicate a need for efforts to promote clinical trial invitation and participation among American adults. Structural solutions are needed to increase the availability and accessibility of trials, while education campaigns to increase awareness of clinical trials could both encourage individuals to proactively talk to their providers about available trials and help normalize trials so individuals are more likely to participate when invited. Presenting information about clinical trials in more engaging ways, for example through audio-visual formats or interactive digital health tools, may also increase interest in participation and support informed decision-making. Additionally, to reduce disparities and ensure equitable access to trials, specific outreach efforts focusing on populations currently underrepresented in clinical trials are needed. Employing trained staff with experience recruiting from the target population, partnering with communities (e.g., through community liaisons), and providing translated, culturally adapted materials could help increase accrual from underserved groups.

HINTS data also demonstrate that health care providers are a highly trusted source of information about clinical trials and therefore can play an important role in raising awareness and encouraging participation. Communication skills training may help providers more effectively discuss clinical trial options, benefits, and risks with patients, while tools or services that enable providers to easily access information about available clinical trials (e.g., through clinicaltrials.gov) could make referring patients less onerous. Instituting a systematic pre-screening program at the institutional level could also increase clinical trial enrollment while reducing provider burden. Similarly, dedicated clinical trial navigation services (such as those offered by the NCI Cancer Information Service) may also facilitate trial enrollment by helping identify appropriately matched trials, educating patients, and addressing barriers to participation.

About HINTS

hints.cancer.gov

The National Cancer Institute (NCI) created the Health Information National Trends Survey (HINTS) to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use communication channels to obtain health information for themselves and their loved ones. HINTS data can also help practitioners create more effective health communication strategies. The HINTS survey has been fielded 13 times to date.

HINTS Briefs provide a snapshot of noteworthy, data-driven research findings. They introduce population-level estimates for specific questions in the survey and summarize significant research findings resulting from analyses of how certain demographic characteristics influence specific outcomes. Many Briefs summarize research findings from recent peer-reviewed journal articles that have used HINTS data.

For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit <https://www.cancer.gov>
- Order NCI publications at <https://pubs.cancer.gov/ncipl/home.aspx>
- Visit [Facebook.com/cancer.gov](https://www.facebook.com/cancer.gov) and <https://www.youtube.com/ncigov>

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