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What Are the Most Common Misunderstandings About Clinical Trials?

A Patient Advocacy Foundation survey reveals knowledge gaps about clinical trials, barriers to participation and possible solutions.

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Findings from a survey conducted by the nonprofit Patient Advocate Foundation revealed cancer patients' knowledge gaps and misperceptions about clinical trials. The findings also shed light on some of the common barriers that prevent cancer patients from joining clinical trials. While practical barriers, such as time, location and insurance concerns, were common, trust and safety mattered too.

The Patient Advocate Foundation helps patients with chronic, life-threatening illnesses navigate and access the complex healthcare system, including through financial assistance and patient education. The foundation also offers clinical trial resources and helps patients find clinical trials through its TrialFinder.

"People are open to participation [in clinical trials], but they need clearer information, stronger guidance from their providers and fewer practical barriers. This represents a meaningful opportunity. Improving education could help clarify how trials work, particularly around concepts such as randomization and the role of physicians," wrote the report's authors.

The researchers highlight four key takeaways from the survey findings:

- Understanding of clinical trials is uneven and often uncertain.
- Misconceptions about physician roles are common.
- Barriers are primarily practical—like cost and transportation—but trust and safety matter too.
- Willingness to participate is high if barriers are addressed.

Clinical trials play a vital role in many aspects of our fight against cancer. Not only do they help test cutting-edge treatments that could be more effective and better tolerated, but they also help experts develop new methods of prevention, screening, diagnosis and care. Trials can even lead to improved communication models, medical devices and much more.

Clinical trials can also give participants access to experimental therapies. Regardless of a trial's outcome, the research contributes to the knowledge necessary to extend lifespan, enhance quality of life and, yes, cure cancer.

Researchers from the Patient Advocate Foundation surveyed 423 patients over age 19 who received navigation or financial assistance services from the nonprofit in 2021. The patients completed 12 questions focused on their personal experiences with and beliefs about clinical trials. Another section of the survey asked respondents to identify potential barriers to clinical trial participation and how removing those barriers would influence their willingness to enroll in a trial.

Fewer than half (44%) knew that treatment in a randomized clinical trial is assigned by chance, and one third (34%) did not know. Nearly half (46%) correctly disagreed with the idea that clinical trials are used only when standard treatments fail, and one third again stated they did not know (33%). Still, most respondents understood that clinical trials are important for treating serious diseases like cancer, with 66% rejecting the idea that clinical trials are inappropriate for complex care.

Only 22% of patients reported taking part in a cancer clinical trial, and 77% had no prior or current experience with clinical trials. Similarly, 59% of patients said a provider had never discussed a clinical trial with them, and 67% had never been offered one.

Practical barriers were the most common reasons patients might not participate in a clinical trial, with cost (38%) and location (37%) being most reported, followed by transportation (27%), insurance concerns (28%) and time demands (23%). Concerns about safety (33%) and reliance on a doctor's opinion (31%) were also common, highlighting the emotional barriers to clinical trials.

"Ultimately, most respondents are not rejecting clinical trials; they are responding to the conditions surrounding them," the authors wrote. "By improving those conditions, participation could increase substantially."

Although clinical trials are a common choice for people who have exhausted other treatment

options, they're often available for cancer patients at any stage of the disease. The National Cancer Institute, the National Institutes of Health and American Cancer Society all provide information on clinical trials.

In related news, the Patient Advocate Foundation recently merged with the PAN Foundation; the two nonprofits now operate as the Patient Advocate Foundation. Its leaders, Alan Balch and Keven Hagan, were included in this year's Cancer Health 25, which highlights financial helpers and fundraisers.

For more news about clinical trials, click #clinical trial to find stories such as:

- "Federal Health Department Aims to Strengthen Clinical Research and Boost Trial Participation,"
- "How Clinical Trials Help to Increase Cancer Survivorship in Quantity and Quality,"
- "Reflections on Progress and Partnership at ASCO 2026" and
- "2024 Cancer Health 25: People Who Power Clinical Trials."

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