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Clinical Trial Knowledge, Discussion, and Participation Among Cancer Survivors

Clinical trials (CTs) that test the safety and efficacy of new cancer treatments are essential to advancing cancer care and improving outcomes for cancer patients. Sufficient participant accrual is fundamental to the success of CTs; however, few adult cancer patients participate in trials, with estimates of participation rates ranging between 2% and 8%. Additionally, those who enroll in CTs tend to be younger; healthier; and less socioeconomically, geographically, and racially diverse than cancer patients overall. Ensuring that CTs are representative is necessary to produce valid, generalizable results and reduce disparities in cancer outcomes.

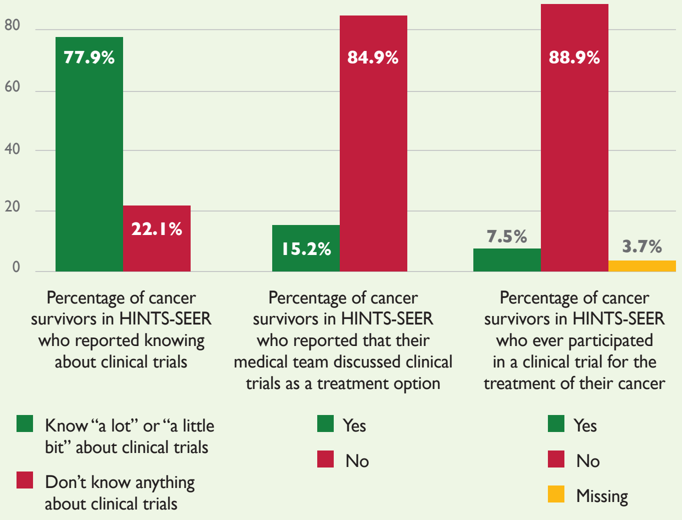
Knowledge is key to informed CT participation. Cancer patients need to be aware of, and knowledgeable about, CTs to make appropriate decisions about enrollment. Although CT knowledge and awareness have increased over time, disparities in CT knowledge persist and may contribute to differences in enrollment.

Being given an opportunity to participate in a trial is also critical. Most patients are referred to CTs by their oncologist; however, providers do not routinely offer CTs as a treatment option to all potentially eligible patients. Providers face logistical barriers to referring patients, including lack of awareness about available trials and insufficient time to identify trials and evaluate patient eligibility. Additionally, even if a trial is available, providers may not offer it due to concerns about the patient–provider relationship, practical considerations (e.g., clinic resources, insurance reimbursement), or assumptions about who is interested and able to participate in CTs. High-quality patient–provider communication about CTs with all eligible patients has the potential to increase CT knowledge and enrollment because health care providers are a highly trusted source of trial information for most patients, and discussion with a provider is one of the strongest predictors of CT participation.

Quick Facts

- CTs are essential to developing new cancer treatments and improving outcomes for cancer patients.
- The rate of CT participation among adult cancer patients is low.
- There are differences in CT participation by sociodemographic characteristics such as age, race/ethnicity, and geographic location.
- Lack of awareness about CTs and not being offered a trial by a health care provider are barriers to CT participation.
- Although nearly 78% of cancer survivors sampled from three Surveillance, Epidemiology, and End Results (SEER) registries in 2021 reported having at least some knowledge of CTs, only 15% had discussed CTs with their providers, and fewer than 8% had ever participated in a trial.

Knowledge, Patient–Provider Discussions, and Participation in Clinical Trials Among Cancer Survivors in HINTS-SEER



Source: Analysis of HINTS-SEER (2021) data in Wissler Gerdes (2025)

NOTE: The HINTS-SEER dataset includes 1,234 cancer survivors sampled from three SEER cancer registries (Iowa Cancer Registry, Greater Bay Area Cancer Registry, and New Mexico Tumor Registry). The weighted data from HINTS-SEER represent the total populations of the three registries who met the eligibility requirements.

This HINTS® *Brief* examines knowledge of, discussions about, and participation in clinical trials among cancer survivors.

Patient–Provider Communication About CTs, CT Knowledge, and CT Participation Among Cancer Survivors

A recently published analysis of HINTS-SEER (2021) data[1] found that nearly 78% of cancer survivors reported knowing at least "a little" about CTs, although there were significant differences in self-reported CT knowledge by education level, race/ethnicity, and experience discussing CTs with a provider. Only 15% of cancer survivors reported having discussed CTs with their health care providers, despite the fact that most survivors (72%) said they would turn to a health care provider first if they needed to get information about CTs, and 76% said their own provider would be their most trusted source of information about CTs. Additionally, although 7.5% of cancer survivors overall reported participating in a CT, among those who discussed trials with a provider, nearly half (47%) reported participating, compared to 1% among those who did not discuss CTs with their providers.

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[1] NOTE: The HINTS-SEER dataset includes cancer survivors sampled from three SEER cancer registries. The weighted data from HINTS-SEER provide point estimates for, and represent, the total populations of the three registries who met the eligibility requirements, not all cancer survivors in the United States.

How Can This Inform Your Work?

HINTS-SEER data suggest a need to ensure information about CTs is provided to all cancer patients and to support patient–provider discussions about CTs. Although health care providers are the preferred source of CT information for most patients, improving access to understandable and usable CT information from both digital and community-based sources may help increase knowledge of CTs among populations underrepresented in research. Culturally sensitive and linguistically appropriate patient education materials, communication campaigns, and programs developed with input from cancer survivors, caregivers, and community members can help raise awareness, understanding, and interest in CTs. These efforts could also empower patients to discuss CTs with their providers and help patients make informed decisions about trial participation.

Patient–provider discussions about CTs are a strong predictor of cancer survivors' CT knowledge and play a key role in CT enrollment, but providers face barriers to discussing CTs with patients, including lack of awareness about available trials, limited time during clinic appointments, and lack of infrastructure support. Dedicated staff who are knowledgeable about available trials and can review patients for eligibility, patient navigators who can provide patients with additional education and practical support, and user-friendly and comprehensive clinical trial matching services could facilitate CT enrollment and reduce provider burden—particularly in community-based oncology practices. Patients and providers can also take advantage of NCI's Cancer Information Service (https://www.cancer.gov/contact) to receive accessible information about CTs as well as expert assistance with CT searches.

Finally, research suggests that one of the most important ways to achieve higher—and more representative—enrollment in cancer CTs is to ensure that all eligible patients are invited to participate. To this end, the adoption of policies and procedures by health care organizations to ensure all patients are routinely screened for trial eligibility and eligible patients are informed about clinical trial options could help increase CT 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 17 times to date.

HINTS *Briefs* provide a snapshot of noteworthy, data-driven research findings that may be of interest to the HINTS community. The *Briefs* summarize research findings from recently published peer-reviewed journal articles analyzing HINTS data.

For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit https://www.cancer.gov
- Download NCI publications at https://pubs.cancer.gov/ncipl/home.aspx
- Visit Facebook.com/cancer.gov and https://www.youtube.com/ncigov

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