

Awareness of Clinical Trials and Attitudes About the Use of Personal Medical Information for Research

Clinical trials, which are health-related or biomedical research studies, are conducted to develop or test new medical treatments and medications. Clinical trials may benefit individual volunteers by providing access to new treatments before they are available outside of trials. Clinical trials also serve the overall population by evaluating the safety and efficacy of medical treatments, which may lead to improved treatment options in the future. In addition to research that involves direct treatment of patients in a clinical setting, other medical research involves the analysis of existing medical records and clinical data to assess the effectiveness of various treatment methods and patient care approaches.

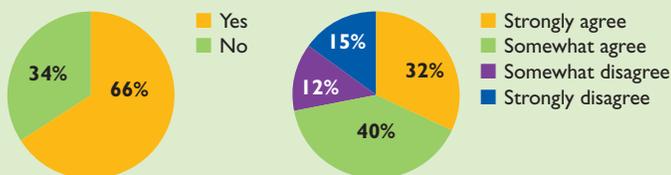
Clinical trials and medical records research rely on the willingness of volunteers to participate in research protocols and share their medical data for research purposes; however, encouraging participation in research can be challenging. Understanding current levels of awareness of clinical trials, assessing attitudes toward sharing clinical data for research, and identifying factors related to awareness and attitudes can inform efforts to promote participation in health-related and biomedical research.

In this HINTS Brief, we explore U.S. adults' awareness of clinical trials and attitudes about the use of personal medical information for research.

“Have you ever heard of a clinical trial?”

“Scientists doing research should be able to review my medical information if the information cannot be linked to me personally.”

Estimated U.S. Population Percentages



Health Information National Trends Survey, 2008 (HINTS, 2008);
URL: cancercontrol.cancer.gov/hints; HINTS 2008 database, National Cancer Institute, DCCPS, Behavioral Research Program, Health Communication and Informatics Research Branch. Data collection January-May, 2008; Public data release February 2009.

Sociodemographic Differences in Awareness of Clinical Trials and Attitudes Toward Research

A study using HINTS data from 2008 shows that overall, awareness of clinical trials is fairly high, with over 65 percent of the population indicating that they had heard of clinical trials. Agreement with the statement that scientists should be able to use medical information for research purposes was also encouraging, with over 70 percent of the population indicating at least some agreement with this statement. However, awareness of clinical trials and attitudes toward use of medical information for research differed by race/ethnicity, income, and education.

Race/Ethnicity

Compared with white respondents, a significantly smaller proportion of black respondents and Asian American respondents had heard of clinical trials. This trend also held true for Hispanic respondents compared with non-Hispanic respondents. Black respondents reported less positive feelings about sharing their medical data than white respondents.

Income

Awareness of clinical trials increased with respondents' level of annual income. Compared with respondents reporting incomes less than \$35,000 per year, those with higher incomes demonstrated greater awareness of clinical trials. Meanwhile, when awareness of clinical trials was controlled for in a multivariable model, no significant differences in attitudes toward sharing medical data were observed across income levels.

Education

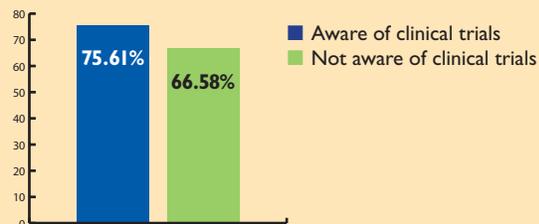
HINTS respondents who reported very low levels of education were significantly less likely to be aware of clinical trials than those who had at least some college education, a college degree, or a postgraduate degree. Attitudes toward sharing medical information varied significantly with education in a multivariable model. The percentage of respondents who agreed that their medical information should be available for research purposes increased with increases in level of education.

In this HINTS Brief, we explore awareness of clinical trials and attitudes about the use of personal medical information for research in the United States.

Influence of Awareness of Clinical Trials on Attitudes Toward Sharing Medical Data

Having heard of a clinical trial was significantly and independently associated with attitudes toward the use of medical information for research. Respondents who were aware of clinical trials were significantly more positive about sharing medical data for research than individuals who were not aware of clinical trials.

Percent of Respondents Agreeing That Their Medical Information Should Be Made Available for Research, by Clinical Trials Awareness



How Can This Inform Your Work?

Overall, rates of clinical trial awareness suggest that there is room for improvement. Furthermore, differences in awareness observed by race/ethnicity, income, and education can inform targeted efforts to promote awareness and participation in research. Awareness of clinical trials is associated with more positive feelings toward the use of medical information for research, suggesting that general familiarity with research may be an important factor in shaping attitudes toward research. Creative outreach efforts to foster awareness and participation among groups who have historically been under-represented in research are warranted.

Quick Facts

- Over 65 percent of the U.S. population has heard of clinical trials.
- Higher levels of clinical trial awareness are observed among non-Hispanic whites, adults with annual incomes greater than \$35,000, and adults with at least some college education.
- Over 70 percent of the U.S. population agrees that their medical information should be made available to scientists conducting research if it could not be linked to them personally.
- Black respondents show less positive feelings about sharing their medical data than white respondents.

About HINTS
<http://hints.cancer.gov>

The National Cancer Institute (NCI) fielded the first Health Information National Trends Survey (HINTS) in 2002 and 2003, surveying 6,369 Americans. Subsequent surveys followed in 2005 (5,586 Americans surveyed) and 2008 (7,674 Americans surveyed). HINTS was created to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use different communication channels to obtain health information for themselves and their loved ones, and to create more effective health communication strategies across populations.

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 that are a result of analyzing how certain demographic characteristics influence specific outcomes. Many *Briefs* summarize research findings from recent peer-reviewed journal articles using HINTS data.

For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit <http://cancer.gov>
- Order NCI publications at <https://cissecure.nci.nih.gov/ncipubs/>
- Visit [Facebook.com/cancer.gov](https://www.facebook.com/cancer.gov) and <http://www.youtube.com/ncigov>

References Used in This HINTS Brief

Brown M, Moyer A. Predictors of awareness of clinical trials and feelings about the use of medical information for research in a nationally representative US sample. *Ethn Health*. 2010 Jun;15(3):223-36.

