

Humphrey Taylor

Chairman of the Harris Poll

Robert Leitman

*Group President, Health Care,
Education & Public Policy*

Misconceptions And Lack of Awareness Greatly Reduce Recruitment For Cancer Clinical Trials

- Four major cancer organizations sponsor survey of cancer patients
- Seek reasons for low enrollment in trials

Our research on clinical trials shows that there is potential to greatly increase cancer patients' participation in new medical research. That's good news for cancer research. The bad news is that, according to a landmark survey of nearly 6,000 cancer patients, an alarming number of these patients say they were never told or they didn't know about the possibility of enrolling in a clinical trial for their treatment. And many of those who considered participating, but did not, may have done so for reasons suggesting they were misinformed.

Ignorance of Clinical Trials

According to the Harris Interactive survey, about 85 percent of cancer patients were either unaware or unsure that participation in clinical trials was an option, though about 75 percent of these patients said they would have been willing to enroll had they known it was possible. The survey was supported by the Coalition of National Cancer Cooperative Groups, the Cancer Research Foundation of America, the Cancer Leadership Council, and the Oncology Nursing Society. Bristol-Myers Squibb provided an educational grant for the survey.

"Most patients simply do not know about clinical trials that could help them," said Robert Comis, MD, president of the Coalition of National Cancer Cooperative Groups, which conducts clinical trials for the National Cancer Institute (NCI). "Clinical trials represent the very best care we have to offer for many cancer patients, yet many do not take advantage of the opportunity because of lack of awareness or misconceptions of what a clinical trial really is."

Misperceptions of Clinical Trials a Major Barrier to Participation

The research also suggests that participation in clinical trials of new cancer treatments would increase dramatically if those who decline to participate were better informed about cancer clinical trials.

Of the 16 percent of cancer patients who were aware of the clinical trial option, three in four turned it down citing four primary reasons:

- They thought the medical treatment they would receive in a clinical trial would be less effective than standard care.
- They thought that they might get a placebo.
- They thought that they would be treated like a "guinea pig."
- Their insurance company would not cover costs.

TABLE 1
Major Reasons For Not Participating in Clinical Trials

% Who Responded "Major Reason"	"Aware" But Did Not Participate %
Belief that they would be better off taking "the standard treatment"	37
Fear that they might get a placebo rather than actual treatment	31
Belief that "the standard treatment" would be more effective	30
Fear of being treated "like a guinea pig"	22
Distance they would have to travel to obtain treatment	21
Belief that the cost of treatment would not be covered by insurance	20
Amount they would have to pay out-of-pocket	18
Fear that their doctor would not be able to choose best treatment	18
The effort involved in the informed consent process	6

On the other hand, the vast majority of those surveyed who did participate in a clinical trial said their overall experience was positive. Ninety-seven percent said they were treated with dignity and respect and that the quality of care they received was "excellent" or "good." More than 80 percent said they did not receive more tests than they felt were necessary and 86 percent said their treatment was covered by insurance. In other words, the fears of non-participants are generally inconsistent with the experiences of those who have participated in cancer trials.

TABLE 2
The Vast Majority of Patients Who Participate in Clinical Trials Have Very Positive Experiences

% Who	Clinical Trials Participants %
Say they were treated with dignity and respect	97
Rate the quality of care received "excellent" or "good"	97
Describe their overall experience as positive	93
Do not feel that they were treated like a "guinea pig"	82
Believe they were not subjected to more tests and procedures than they thought necessary	81
Would recommend participation to someone else with cancer	76

The Need for More Patients in Cancer Trials

“We have a shortage of patients for clinical trials and this slows down the development of effective new treatments,” said Ellen Stovall, a two-time cancer survivor and the executive director of the National Coalition of Cancer Survivorship. “We need to remove the roadblocks. Patients need to know that in most cases they will be getting as good or better care than standard therapy, that a placebo is never used in cancer treatment and that treatment, in most cases, is covered by insurance.”

The NCI reports that approximately five percent or 40,000 to 45,000 cancer patients are enrolled in clinical trials at any given time.

“There are many ways to access information about clinical trials. Ask your doctor, your nurse, and explore the Internet,” said Linda Krebs, RN, PhD, AOCN, a past president of the Oncology Nursing Society. “And once you find a clinical trial that may be appropriate, continue to ask questions of the health professionals to find out what you can expect from the trial itself.”

“We must work very hard to ensure [that] more people have access to clinical trials through greater education of doctors and patients,” said Carolyn Aldige president and founder of the Cancer Research Foundation of America and co-author of the study.

Many in the general public also have misconceptions about clinical trials. While 82% of the cancer-free people polled said they would consider enrolling in a clinical trial if faced with the disease, they shared some of the concerns of cancer patients who did not participate. More than half (56 percent) said they felt they might receive a placebo, 47 percent said they would have little decision-making power, and 44 percent worried about being treated like “guinea pigs.”

A clinical trial is a carefully designed study that closely monitors the progress of a patient as he or she proceeds through treatment with a new drug. Only patients that meet certain criteria may participate in a clinical trial.

Methodology

This research was based on interviews with 5,972 cancer patients. One-thousand interviews were conducted by telephone with a nationwide sample of American adults, including over-samples of 200 African Americans and 200 Hispanics. Of these, a total of 65 were cancer patients. Additional interviews were conducted by telephone with 538 cancer patients and online with another 5,377 cancer patients. Interviews averaged 20 minutes in length and took place in March and April 2000.

About Harris Interactive

Harris Interactive (Nasdaq: HPOL), the global leader in online market research, uses Internet-based and traditional methodologies to provide its clients with information about the views, experiences, behaviors and attitudes of people worldwide. Known for its Harris Poll, Harris Interactive has over 40 years experience in providing its clients with market research and polling services including custom, multi-client and service bureau research, as well as customer relationship management services. Through its U.S. and Global Network offices, Harris Interactive conducts research in more than 100 countries in multiple, localized languages. Harris Interactive uses its proprietary technology to survey its database of more than 7 million online panelists.
EOE M/F/D/V

For more information, please contact us at:

877-919-4765

or visit our website at

www.harrisinteractive.com