A QUANTITATIVE SURVEY OF PUBLIC ATTITUDES TOWARDS CANCER CLINICAL TRIALS.

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Introduction

Background. In 1998 the Coalition of National Cancer Cooperative Groups, the Cancer Research Foundation of America, the Cancer Leadership Council, and the Oncology Nursing Society came together to initiate the Summit Series on Clinical Trials. Participants at the Summits include representatives of all of the stakeholders in the cancer research enterprise: patients and patient advocacy organizations; physicians, nurses, and other health care professionals; managed care organizations and third party payers; public and private funding agencies and the pharmaceutical industry.

The purpose of the Summit Series on Clinical Trials is to provide a platform for all stakeholders in the clinical cancer research enterprise to come together to express what each sees as positive and negative aspects in the existing system and to suggest ways in which it can be made better. The hope is that by building a more responsive and efficient system, trial enrollment will increase which will permit faster development of advances in cancer treatment, prevention, control and symptom management.

Fewer than 5 percent of adult cancer patients in the United States are enrolled in clinical trials. The reasons for such dismal participation has been examined in a number of studies which have raised a variety of real or perceived barriers from the perspective of physicians, patients and others. Participants in Summit Conferences I-III recommended that a quantitative survey of public attitudes toward clinical research be undertaken as a first step in the development of a national strategic plan on cancer research. Such a project was initiated in mid-1999 in collaboration with Harris Interactive. In all six surveys will be completed targeting (1) the public, (2) the news media, (3) cancer patients (those who have as well as those who haven’t participated in a trial), (4) family members of cancer patients, (5) primary care physicians, and (6) oncology nurses and physicians. [Slide 1]
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Background

• Undertaking recommended by participants of Summit Series on Clinical Trials I-III
• Target increasing participation to 10-15%
• Develop strategic plan to increase participation
• Strategic plan requires understanding attitudes of:
  — Public
  — Cancer Patients
  — Primary Care Doctors
  — Oncologists
  — Oncology Nurses
  — Journalists

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Methodology

• Survey of General Public and Patients:
  — Telephone survey of 1,000 American adults including oversamples of 200 African Americans and 200 Hispanics
  — Additional telephone interviews with 538 cancer patients
  — Online survey of 5,377 cancer patients:
• Survey of Physicians:
  — By mail with 200 primary care physicians and 225 oncologists
• All interviewing took place from March through May 2000

Survey Methodology. Interviews for the survey were conducted as follows: 1,000 telephone interviews with a nationally representative sample of adults aged 18 and older, including oversamples of 200 African Americans and 200 Hispanics; 538 telephone interviews with a national sample of cancer patients; and 425 “self-completed” interviews with a national sample of primary care physicians and oncologists. [Slides 2-3]
Telephone interviews of the general public and of cancer patients averaged 20 minutes in length and were conducted during March and April 2000. Online interviews of similar length were conducted in March 2000. Mail surveys, averaging approximately 80 questions in total were completed during March, April, and May 2000.

Executive Summary

**Awareness of Clinical Trials As A Treatment Option Is Extremely Low.** At a time when the inability to recruit adequate numbers of patients to participate in clinical trials is slowing the development of new treatments for cancer, lack of awareness among patients of the opportunity to participate in these trials appears to be a major factor inhibiting enrollment and participation. According to this landmark survey of nearly 6,000 cancer patients, more than eight out of ten don’t even consider the possibility of participating in a clinical trial for the treatment of their cancer because they are unaware that participation might be an option. [Slide 4]
Physician Involvement Is Key. The role of the physician is key in getting patients to participate. Patients who participate in clinical trials are much more likely than those who are “aware” but do not participate to have first learned about the possibility of participating through a doctor. Trial participants are also far more likely to have had a doctor educate them about the pros and cons of participating and help them find a clinical trial that was suitable for them. And, most of those who do participate say that a doctor had a great deal of influence on their decision to do so.

[Slide 5]
While primary care physicians and oncologists believe that more cancer patients should participate in clinical trials, these physicians do not uniformly encourage participation. Most believe patient reluctance is common. And, while most physicians say they encourage their patients to participate, this encouragement drops off dramatically when patients express a reluctance to participate. Physicians also note the impact of strict eligibility criteria and the amount of paperwork they need to fill out as inhibiting factors.

**Trial Participants Report Positive Experience.** Patients who participated in a clinical trial generally report it as a very positive experience. Virtually every clinical trial participant said that he or she was treated with dignity and respect, that the quality of care was “good” or “excellent”, and that their overall experience was positive. More than three in four would recommend participation to someone else with cancer. Few report that the fears of non-participants, such as unnecessary tests and procedures or being treated like a guinea pig were ever experienced. Furthermore, physicians believe that clinical trials participants receive the best possible care and have outcomes at least as good as patients receiving standard treatment. [Slides 6-7]
Misconceptions High Among Those Who Are Aware. While most of these “unaware” patients say that they would have been receptive to the idea of participation had they known it was a possibility, the reality is that even among patients who are aware that they might be able to participate in a clinical trial, most do not. Among the most common reasons cited by patients for choosing not to participate are the belief that the “standard treatment” would be better, fear of getting a placebo in place of actual treatment, and fear of being treated like a “guinea pig”. The belief that insurance would not cover treatment was also a major barrier for many cancer patients. [Slide 8]
A Disconnect Exists Between Perception and Reality. There was little overlap between doctors' perceptions of why patients don’t participate and the reasons patients say they don’t participate. Half of the surveyed doctors said that patients didn’t agree to go on trial due to fears of being under-treated, fear of being treated like a “guinea pig,” fear of randomization and that they would be subjected to too many tests. Fewer than 25% of patients cited each of these reasons. [Slide 9]

<table>
<thead>
<tr>
<th>Fear of:</th>
<th>Doctors %</th>
<th>Aware Non-Participants* %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficiently tested treatment</td>
<td>77</td>
<td>26</td>
</tr>
<tr>
<td>Being treated like a “guinea pig”</td>
<td>59</td>
<td>22</td>
</tr>
<tr>
<td>Randomization</td>
<td>57</td>
<td>18</td>
</tr>
<tr>
<td>Too many tests</td>
<td>45</td>
<td>18</td>
</tr>
<tr>
<td>Receiving placebo</td>
<td>33</td>
<td>31</td>
</tr>
</tbody>
</table>

*Patients who are aware of clinical trials but choose not to participate

Discordance also exists between the level of participation and beliefs about clinical trials. Recall that fully 85% of surveyed patients said they were aware that participation in a clinical trial was an option for them. Yet when questioned unaware patients gave responses suggesting they hold a generally positive attitude about trials. The large majority of patients said they believed that trials would be of benefit to themselves and others, that they would receive newer or better treatments in a trial and that they would receive more care or attention. Conversely more than half reported that they feared having to travel to receive treatment and that they would be likely to receive a placebo – neither of which is the case. [slides 10-11]
Participation Would Be Greatly Increased By Improved Communication. When members of the general public are asked if they would consider a clinical trial if faced with cancer, eight out of ten say they would. In addition, more than two-thirds of Americans would be willing to participate in a clinical trial designed to prevent cancer. But, it seems clear that the clinical trial option is seldom raised at the time a patient is given such a diagnosis and even when patients are aware of the trial option the benefits are not being fully conveyed. [slides 12-13]
Insurance Issues Can Act As A Tremendous Deterrent. Patients who did not participate in a clinical trial cite possible denial of insurance coverage and increased out of pocket expenses for trial-based care as important negative factors in their decision. Yet three-quarters of trial participants said that they did obtain coverage and did not experience trouble obtaining in coverage. [slide 14]
Conclusions
The potential for increased participation in clinical trials exists. Greater participation is achievable if information about the benefits of trials is more widely disseminated, misconceptions about drawbacks are dispelled, treatment costs are reimbursed, and a more active role is played by physicians in getting patients to consider trials. The fact that patients who participate have positive experiences, the public is receptive to the idea of participation, and physicians would like to see more patients participate, can only help in efforts to make greater participation a reality. [Slide 15]

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Conclusions

- 85% of cancer patients are unaware that clinical trials are a treatment option in which they have a right participate;
- Patients who received treatment while on a clinical trial cite it as a very positive experience;
- The role of the oncologist is essential to securing patient participation in clinical trials;
- Even the perception that insurance coverage may be denied acts as a barrier to participation; and
- Public and patients are willing to consider trials if properly informed