



'What Do They Know About It?'

How the North Carolina Public Views Cancer Clinical Trials: Implications for Primary Care Doctors

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Cancer is the second leading cause of death in the nation and in North Carolina.^{1,2} Clinical trials are the primary way in which we advance our understanding about cancer prevention, detection, and treatment. Despite the large number of clinical trials available, few (<3% of eligible adult cancer patients) in the United States participate in one;³ even fewer join prevention trials.⁴ Patient perspectives on clinical trials significantly influence the decision to participate or not.^{5,6}

The North Carolina Advisory Committee on Cancer Coordination and Control (NCACCCC), recognizing the importance of public awareness of cancer clinical trials, set the objective of launching "a state-wide educational campaign focusing on the value of clinical trials in cancer prevention, early detection, and treatment."⁷ In 1999–2000, the NCACCCC, the National Cancer Institute (NCI), and the Cancer Information Service jointly sponsored a state-wide campaign to increase public awareness of clinical trials ("*Cancer Trials...because LIVES depend on it*").

In preparation for the campaign, the NCACCCC's Care Subcommittee convened a series of focus groups to obtain North Carolinians' views on medical research and cancer clinical trials. This article describes the focus group findings that informed the campaign, discusses the implications of the findings for primary care doctors, and briefly describes the training of educational ambassadors.

Scope of the Problem

Several studies examining recruitment of subjects into clinical trials have identified personal and cultural barriers to participation. There are a number of barriers, particularly among minority populations.^{3,5,6,9-11} They include (1) the

perception of being a "guinea pig"; (2) fear of receiving unproven treatments; (3) lack of education, which impedes understanding or communication about clinical trials; (4) rural residence, which limits access to health care; (5) previous negative experience by family or friends; and (6) distrust of medical and government research and researchers. It is clear that any campaigns to increase participation in clinical trials must identify misconceptions about such trials, and address barriers arising from a lack of education or knowledge. We used focus groups to elicit perceptions of urban and rural North Carolinians about participation in clinical trials.

Methods

Thirty-seven participants were recruited in four focus groups (from one urban and three rural locations). Eligible participants had no previous cancer diagnosis (except for non-melanoma skin cancer) and no prior participation in cancer clinical trials. One participant had participated in a non-cancer trial, and three had had skin cancer. Demographic characteristics (Table 1) show that participants were predominantly middle-aged white women with at least a high school education. Focus groups lasted approximately 90 minutes and were led by one of the authors (BRD). Each group was tape recorded (for later transcription by MedScribe services), and written notes were kept. Participants were questioned about their experience with and exposure to clinical trials (Table 2). Each group was asked to respond to questions and statements designed to elicit participants' knowledge of, opinion about, and sources of information about cancer clinical trials. The note-taker identified the group responses in contrast to those of one individual.

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Table 1. Demographic characteristics of 37 focus group participants

| | | | |
|------------------------|----------|---------------------------|----------|
| Number of focus groups | 4 | Race/ethnicity | |
| Number of participants | | White | 21 (58%) |
| Durham (urban) | 10 (27%) | Black | 11 (31%) |
| Wendell (rural) | 11 (30%) | Hispanic/Latino | 1 (3%) |
| Roxboro (rural) | 10 (27%) | Native American | 2 (6%) |
| Moncure (rural) | 6 (16%) | Other | 1 (3%) |
| Age (in years) | | Highest year of education | |
| mean | 55 | < High school | 2 (6%) |
| range | 18-72 | High school | 12 (39%) |
| Gender | | Some college | 6 (18%) |
| men | 8 (22%) | College grad | 5 (15%) |
| women | 29 (78%) | Post-college | 7 (21%) |

Table 2. Responses of 37 participants in cancer clinical trials focus groups, 1999

| | | | |
|---|----------|--|----------|
| Ever diagnosed with cancer? | | Know anyone who participated in a clinical trial? | |
| yes | 3 (8%) | yes | 11 (30%) |
| no | 34 (92%) | If yes, who? | |
| Know anyone who has had cancer? | | family member | 3 (30%) |
| yes | 35 (95%) | friend/neighbor | 5 (50%) |
| If yes, who? (Check all that apply.) | | other person | 3 (30%) |
| family member | 25 (76%) | If yes, was it a cancer clinical trial? | |
| friend/neighbor | 14 (42%) | yes | 1 (9%) |
| other person | 5 (15%) | no | 7 (64%) |
| Ever heard the term clinical trial? | | don't know | 3 (27%) |
| yes | 20 (57%) | Have you ever received information about cancer clinical trials? | |
| Ever been offered the chance to participate in clinical trials? | | yes | 5 (14%) |
| yes | 5 (14%) | | |
| If yes, did you participate? | | | |
| yes | 1 (20%) | | |

Focus Group Results

Responses to questions were generally classified as to (1) sources of health information, (2) perception of clinical trials and medical research, and (3) suggested spokespersons for clinical trials awareness campaigns.

Sources of Health Information. Respondents identified a variety of sources of information about general health issues and treatment, and cancer-related information and treatment: the Internet, medical books in personal or outside libraries, television, and newspapers and magazines. When asked about the best sources of medical information about treatment, respondents cited family doctors, family, and friends who work in health care, the Internet and teaching hospitals (library or doctors).

The preferred sources of clinical trial information were the personal physician, Internet searches, and advertisements in newspapers and magazines. Many felt that although local doctors (especially rural doctors), might not have information about clinical trials, they would know where to refer patients for more information or for treatment by specialists who were aware of clinical trials. Very few respondents knew about the 1-800-4-CANCER information line.

Perceptions of Clinical Trials and Medical Research. Participants had an overwhelmingly negative response to the term "medical research," associating it with phrases like "guinea pig," "experimentation on animals and humans," and "placebo." There was much misunderstanding about clinical trials (most respondents believed that a two-arm trial tests a drug against placebo). There was little awareness of clinical

trials of preventive or early cancer detection methods. When asked about medical researchers' participation in clinical trials, many respondents suspected that physicians encouraged patients to enroll in clinical trials for financial or professional gain. A number of participants said that doctors had more allegiance to the pharmaceutical industry than to the best interest of their patients.

Despite general agreement among participants that medical research led to important advances in disease prevention, detection, and treatment, few said that they would consider clinical trial participation unless they were desperate, and had no hope of cure from standard treatment. Reasons for their unwillingness to enroll included travel distance, lack of time, fear of getting a placebo rather than a drug, religious beliefs, fear of becoming sicker from "experimentation" than from the disease itself, and the belief that certain interventions would actually spread cancer. Cancer prevention trials were more acceptable to participants than treatment or detection trials.

When asked why anyone would participate in a cancer clinical trial, participants suggested motivation by altruism (a desire to help others in the family or their community), reimbursement (being paid to participate), and the belief that a clinical trial offered the only hope for cure (so there was nothing left to lose). Respondents felt that persons most likely to consider participating in a clinical trial would be young, curious, open-minded, educated, and have few responsibilities for the care of other family members (children, sick spouses, or elderly parents). Conversely, they felt those unlikely to participate would be deeply religious, fearful, ignorant, or burdened by responsibilities for others.

Focus groups responded negatively to the statement, "Clinical trials are the gold standard of medical care today. Every patient gets either the best new treatment or the most promising treatment not yet available elsewhere." Participants believed the statement to be false, citing slow recruitment to clinical trials as evidence. In contrast, their reactions to the statement, "Clinical trials *can* offer state-of-the-art medicine to all kinds of people, not just those who can afford it," were positive. The word "can" appeared to add a sense of honesty and realism, as though no one were trying to fool them into thinking that trials were the only treatment option.

Suggestions for a Clinical Trials Awareness Campaign. All focus groups said that the most credible spokesperson for a clinical trials public education campaign would be a trusted community member who was a known cancer survivor, and who had had a successful or positive experience with clinical

trials. Participants favored this type of spokesperson over a celebrity or an unknown doctor. A second choice was a well-respected community doctor who had personal experience (say, a family member with successful clinical trials experience). A celebrity who had been treated for cancer and had a positive experience with clinical trials would be credible, but less effective.

The focus group findings were helpful in designing a cancer clinical trials awareness campaign. Participants felt that we should publicize the 1-800-4-CANCER number. They also felt that the Internet would be an effective way of educating the public about clinical trials, and they thought it would be useful to cross-list information about clinical trials on multiple websites. The Internet could greatly increase public access to cancer clinical trials information.

A key finding from our survey was the perception that

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personal testimony from those with positive experiences in cancer clinical trials, particularly someone known and respected by members of the community, would greatly influence how others felt about medical research and clinical trials. Participants recommended that personal testimony be combined with statistics and information about the scientific and medical advances that resulted from such clinical trials. This would enlighten people and make them more receptive to joining clinical trials. Finally, they recommended that awareness campaigns appeal to people's altruism by emphasizing the personal and societal benefits of clinical trial participation.

The focus groups provided the kind of information needed to design a campaign to educate communities about cancer clinical trials. The findings are strikingly similar to

those of previous studies of minority recruitment to clinical trials.^{9,11-14} These include lack of knowledge and understanding about clinical trials, fears of being a "guinea pig," and suspicion of the medical community, particularly researchers. The notion that well known and respected community leaders are preferred spokespeople and can improve the reputation of research studies within communities has been reported elsewhere.¹³ Finally, many viewed clinical trials as a "last hope" for a cancer patient's survival, thus implying that anyone taking part had little chance for survival.

We especially noted the inconsistency about sources of information and attitudes toward medical research and researchers. When queried about medical research, participants expressed distrust of the medical community in general (saying that doctors recruit to trials for personal gain), but the family doctor was identified as a primary source for information about clinical trials. Thus, the findings are particularly relevant for the community primary care doctors.

Focus Group Findings: Implications for Providers

Community interest in clinical trials is largely focused on hearing from those who have experience with cancer—either personally or through a family member or close friend. However, respondents considered the primary care doctor to be the chief source of information about clinical trials, and consequently this position is a key, trusted resource for medical information. Even the suspicion with which respondents viewed medical research and medical researchers in general suggests that the family doctor commands a special place of trust and respect, a first-line resource for patients concerned about clinical trials and cancer. Primary care providers are in a position to provide accurate information that the patient will accept. Educational materials (see the information for patients in this issue of the *Journal*) can be placed in waiting rooms, or given to newly diagnosed patients to provide information that initiate a discussion about clinical trials.

The Cancer Clinical Trials Awareness Campaign

In November 1999 the NCACCCC, in partnership with the National Cancer Institute, launched a campaign entitled *Cancer Trials...because LIVES depend on it*. Using information obtained from the focus groups, the Clinical Trials Awareness Campaign planners designed a series of sessions to train clinical trials “ambassadors,” lay and professional people interested in educating their communities about cancer clinical trials. Volunteer participants attended a one-day, seven-hour training session designed to provide them with an understanding of the following: (1) how clinical trials operate; (2) barriers to and promoters of participation in cancer clinical trials; (3) the roles and responsibilities of “ambassadors”; (4) practice in how to use educational materials provided; and (5) development of an action plan for work in their communities.

The training program was designed by NCI staff and consultants to be highly interactive and was based on principles of adult learning. There was a participant training manual, a video, brochures and other informational sheets to be used in community presentations, and a resource manual with additional information and references. Participants were taught how to use the Physician’s Data Query (PDQ) to locate clinical trials for specific types of cancer. They were encouraged to use the 1-800-4-CANCER (Cancer Information Services) number for their own use and to give it to others who wanted more information.

More than 225 participants attended one of 12 sessions, all but one of which, because of logistical and other constraints, took place in rural and urban areas of the state’s 50

western counties. Training sessions included both lay and professional community participants. Since clinical trials research was not a high priority in the community, recruitment of volunteers for the training required the efforts of a full-time outreach specialist. The original plan to recruit from voluntary health organizations, particularly those with a mission of cancer education and treatment, was only moderately successful. It proved more fruitful to use cancer support groups, other community-based organizations, and local hospitals to identify potential participants.

Summary and Recommendations

No one disputes the public’s need for accurate information about cancer clinical trials. Many people, even some health professionals, have a negative view of the importance of clinical trials in translating research to clinical practice. In this paper we have described a cancer clinical trials awareness campaign launched by the NCACCCC and NCI. Based on information derived from community focus groups about community perceptions of clinical trials research, the campaign trained community “ambassadors” to educate their communities about cancer clinical trials. Participants who attended the training sessions rated them highly, but participation was limited. If others want to replicate the model, they should budget the time and effort needed to recruit participants.

Findings from our focus groups, and the outcome of recruiting and training, confirm the need for innovative cost- and time-effective outreach strategies to encourage greater participation in this experience. Close collaboration of cancer treatment center staff with health professionals involved in cancer education, screening, detection, treatment, and research may yield better participation. Our findings highlight the special role of primary care providers (and specialists who diagnose and treat cancer patients) in providing educational materials and information to their patients. They can help correct misconceptions about clinical trials. In the meantime, the materials we used in our campaign are available through NCI by calling 1-877-74-LIVES.

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