

# Perceptions of Cancer Clinical Research Among African American Men in North Carolina

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**Objective:** The problem of cancer health disparities is substantial. Clinical trials are widely advocated as a means of reducing disparities and bringing state-of-the-art care to the broader community, where most cancer care is delivered. This study sought to develop a better understanding of why disproportionately few African American men enroll in clinical trials given their substantial cancer burden.

**Design:** This study applied community-based participatory research (CBPR) methods to design and conduct four focus groups of African American male cancer survivors and their caregivers in North Carolina.

**Results:** Among major themes, participants expressed confusion about the relationship between clinical trials, treatment, and research; signifying patient confusion and misinterpretation of common clinical trial terminology. Social norms including gender barriers and generational differences remain problematic; participants often reported that men do not talk about health issues, are unwilling to go to the doctor, and exhibit misapprehension and distrust regarding trials. Participants perceived this misunderstanding as detrimental to community health and expressed the need for more clarity in clinical trials information and a more fundamental social openness and communication about cancer detection and treatment.

**Conclusion:** Findings indicate the importance of clinical trial education in both traditional provider referral to trials and also in general patient navigation. To dispel pervasive misapprehension regarding placebos, clinical trial information should emphasize the role of standard care in modern cancer treatment trials. Many participants described willingness to participate in a trial upon physician recommendation, suggesting merit in improving patient-physician communication through culturally competent terminology and trial referral systems.

**Keywords:** Racial disparities ■ cancer ■ community-based participatory research ■ clinical research ■ African Americans

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## INTRODUCTION

In the United States, compared to Caucasians, African Americans are diagnosed with more advanced cancer, experience a 23% higher cancer mortality rate, and have 5-year survival rates that are as much as 34% lower among the cancers of greatest incidence.<sup>1</sup> In North Carolina, the disparity is even more stark: compared to Caucasians, African Americans have a 52% greater colon cancer mortality rate, a 40% greater breast cancer mortality rate, and nearly three-fold greater prostate cancer mortality rate.<sup>2,3</sup> Given these differences and the fact that African Americans comprise nearly one quarter of the state's population,<sup>1,4</sup> the problem of cancer disparities in North Carolina is particularly acute.

A large portion of these acute racial differences are attributed to racial barriers in high-quality medical care and disparities in treatment.<sup>1,5-7</sup> Clinical trials have been widely advocated by the Institute of Medicine and others as a means of reducing such disparities and bringing state-of-the-art care to individuals living in the broader community. This is where the majority of cancer care is delivered.<sup>8-10</sup> However, it is estimated that only 2% to 5% of the adult cancer population receives treatment through a National Cancer Institute (NCI)-sponsored clinical trial despite 80% of adults expressing interest, half of whom indicate a willingness to enroll.<sup>11-14</sup> The acute cancer health disparities in North Carolina and elsewhere in the United States further suggest that greater African American participation in clinical trials is needed for this population to benefit from advances in cancer research.<sup>9</sup>

The North Carolina Comprehensive Cancer Program has recognized the importance of cancer clinical trials and is addressing lack of clinical trial enrollment as a part of the *State Cancer Control Plan*.<sup>15</sup> It is suspected that patterns of trial enrollment follow similar patterns of health care resource availability in the state. The current state of which has been described as fragmented leaving regions and populations substantially underserved, most likely affecting minorities.<sup>16</sup> However, despite the promise of clinical trials and the rising interest in facilitating access to them, little is known about the characteristics of individuals enrolling in cancer trials in North Carolina.

A recent examination by the North Carolina Comprehensive Cancer Program found that overall statewide enrollment rates in NCI trials were comparable with the national estimates, though rates were lowest among African American men.<sup>11,13,14</sup> In several counties, African American men had no enrollment whatsoever (citation needed). The racial differences in the enrollment rates are particularly troubling as there are three medical schools, multiple major academic medical centers, and a provider-based cancer research network, and all offer clinical trials.

This study examined clinical trial enrollment among cancer patients in an eight county region in central North Carolina. To gain a better understanding of why the proportion of African American men enrolling in clinical trials is substantially lower than Caucasian men, we met with focus groups of African American men and their caregivers to understand their thoughts regarding clinical trials and perceived barriers to participation.

## METHODS

### *Conceptual model and approach*

The study was guided by the Lay Health Advisor model, Flaskerud and Winslow's vulnerable populations framework, and the Behavioral Model for Vulnerable populations.<sup>17-19</sup> These were integrated to be comprehensive of the multiple, inter-relating characteristics associated with the health, health behaviors, and health service utilization of vulnerable populations. Combining frameworks allows us to move beyond individual-level factors that influence willingness to participate, to include the role of social networks and communities. The resulting framework allows us to explore and collect data on a variety of factors that may influence willingness to participate in research. Prior studies have shown that these factors exist on many levels and include those that are **trial-related** (e.g., unwillingness to enroll on a trial with a placebo arm, burdensome/time-intensive requirements),<sup>12,20,21</sup> **patient-related** (e.g., age, race, preferences, uncertainty, logistical concerns, education, additional cost),<sup>22-24</sup> **physician-related** (e.g., time constraints, protocol compliance issues, protocol incompatibility with normal practice, access to/awareness of trials),<sup>25-27</sup> **organization-related** (e.g., distance to facility, staff resources, organizational support systems),<sup>28-30</sup> and **environment-related** (e.g., competition, local health policies, social norms including trust/distrust of research).<sup>30-33</sup>

This study applied community-based participatory research (CBPR) methods and was conducted within the context of the Carolina Community Network (CCN), the Community Networks Program in North Carolina funded by the NCI Center to Reduce Cancer Health Disparities (CRCHD).<sup>1</sup> The CCN is a regional cancer network aimed at reducing cancer disparities among adult African Americans

in North Carolina.<sup>2</sup> CCN community research advocates (CRAs) and Community Advisory Board members affiliated with the CCN collaborated with academic researchers to develop study materials, recruit participants, analyze findings, and communicate them back to their communities.

### *Focus groups and participants*

Focus groups capture how participants think about an issue and articulate it in their own words, which is often enhanced by the interactive nature of the group.<sup>34-35</sup> A focus group moderator's script was developed, informed by the conceptual framework and the literature. In keeping with the CBPR approach, the focus group moderator script was further refined through incorporating feedback from the CRAs. The final script addressed perceptions of participation in clinical trials, practical barriers to trial participation, experience with clinical trials and medical decision making, and treatment preferences. Although the same moderator script was used in all four groups, the moderator interactively adapted her approach and emphasis to be responsive to each group's needs and observations. The study focused on male, African American cancer survivors in central North Carolina. Eligibility criteria included being an adult of any age who is physically and cognitively capable of participating, with a history of any cancer regardless of cancer treatment approach, actual participation in a randomized clinical trial, or year of diagnosis—though participants may not be undergoing treatment at the time of the focus groups. Four focus groups of 5 to 11 participants were conducted at various times and locations convenient for participants. Participants included cancer survivors and their caregivers or loved ones, who were included in order to both gain their insight and to help participants feel more comfortable in the focus group setting. Participants were recruited and focus groups were conducted over a three-month recruitment period in mid-2009. Recruitment occurred through county and hospital employee emails, churches, male civic organizations, health fairs, and newspaper media, as well as by word-of-mouth through community research partners. Each group lasted approximately two hours, and was audio taped and transcribed verbatim. Each participant received a \$60 gift card. Information on resources available at local cancer programs was provided, as were NCI materials on clinical trials and cancer treatment.

### *Data analysis*

A coding scheme was developed based on the conceptual framework and literature. New codes were added based on themes that emerged during the analysis process. All transcripts were first coded using Atlas.ti software by a member of the research team. Again, through CBPR methods, three CRAs

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