# Enrolling Minority and Underserved Populations in Cancer Clinical Research

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Research suggests that community involvement is integral to solving public health problems, including involvement in clinical trials—a gold standard. Significant racial/ethnic disparities exist in the accrual of participants for clinical trials. Location and cultural aspects of clinical trials influence recruitment and accrual to clinical trials. It is increasingly necessary to be aware of defining characteristics, such as location and culture of the populations from which research participants are enrolled. Little research has examined the effect of location and cultural competency in adapting clinical trial research for minority and underserved communities on accrual for clinical trials. Utilizing embedded community academic sites, the authors applied cultural competency frameworks to adapt clinical trial research in order to increase minority participation in nontherapeutic cancer clinical trials. This strategy resulted in successful accrual of participants to new clinical research trials, specifically targeting participation from minority and underserved communities in metropolitan Washington, DC. From 2012 to 2014, a total of 559 participants enrolled across six nontherapeutic clinical trials, representing a 62% increase in the enrollment of blacks in clinical research. Embedding cancer prevention programs and research in the community was shown to be yet another important strategy in the arsenal of approaches that can potentially enhance clinical research enrollment and capacity. The analyses showed that the capacity to acquire cultural knowledge about patients—their physical locales, cultural values, and environments in which they live—is essential to recruiting culturally and ethnically diverse population samples.

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## Introduction

Considerable attention[1–4] has focused on the need to increase underserved racial and ethnic populations in clinical research, especially in light of the cancer health disparities that disproportionately plague these groups. Clinical trials are considered the gold standard of evidence about efficacy of cancer prevention, early detection, and treatment interventions.[2,3,5] Clinical trial design and implementation are time-consuming and require a multistep process that is complicated by other factors, including eligibility criteria for clinical trials for underserved racial and ethnic populations, recruitment processes, and patients' misconceptions or lack of information about clinical trials.[6]

A growing body of research suggests a correlation between people's social/structural spaces and their health status.[7,8] Location truly matters in cancer prevention and health disparities.[7–10] Some limited research has explored geographic proximity and racial disparities in cancer clinical trial participation. Among numerous barriers noted in the literature,[4,11,12] two particular factors often cited are lack of transportation to and from the clinical research site and the travel distance to the research site.[13–15] Location of the clinical trial site becomes increasingly important to clinical trial success. Place of residence and race were found to be significant predictors of participation in therapeutic and nontherapeutic clinical trials, although patterns differed somewhat between the types of studies.[14]

The capacity to acquire cultural knowledge about patients and the communities where they live is an essential element of cultural competence indispensable to cancer research and a cancer center's ability to recruit

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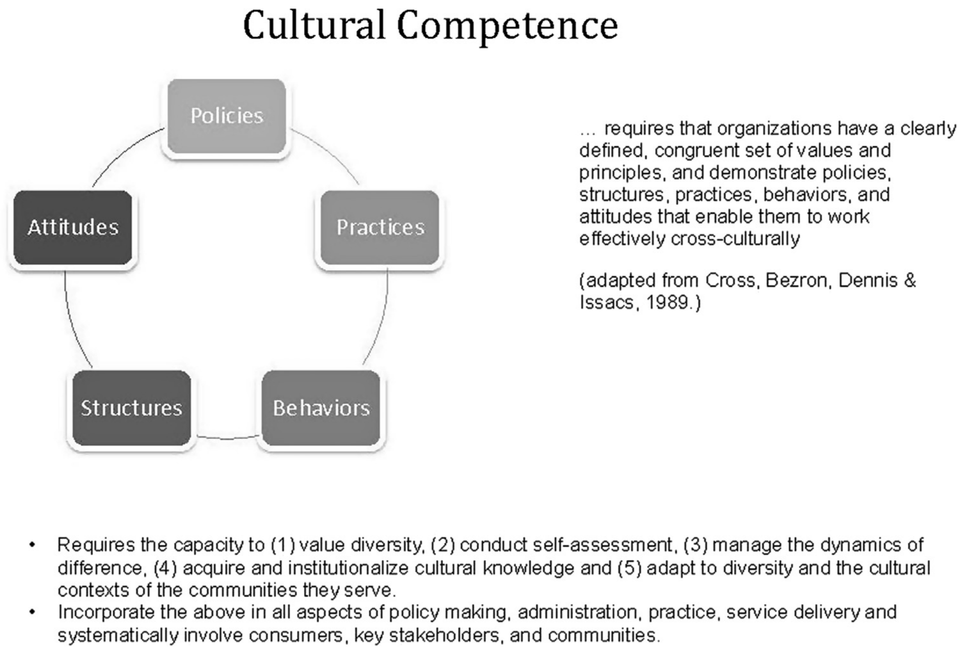

… requires that organizations have a clearly defined, congruent set of values and principles, and demonstrate policies, structures, practices, behaviors, and attitudes that enable them to work effectively cross-culturally

(adapted from Cross, Bezron, Dennis & Issacs, 1989.)

- Requires the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve.
- Incorporate the above in all aspects of policy making, administration, practice, service delivery and systematically involve consumers, key stakeholders, and communities.

**Figure 1.** Cultural Competence Conceptual Model.

racially and ethnically diverse populations successfully.[16] Researchers must make consistent efforts to include members of diverse populations as equal partners in all aspects of the conduct of research, study design, implementation, and evaluation. A major benefit of this research approach is informed patients and communities prepared to effect and sustain change for improved health and well-being.[17]

This approach also draws upon the conceptual framework of cultural competence (Figure 1), an evidence-based approach to deliver health care, reduce health and health-care disparities, and engage diverse communities.[18] Cultural competence requires that organizations, including research centers, have a defined set of values and principles and demonstrate policies, structures, practices, behaviors, and attitudes that enable them to work effectively cross-culturally.[18,19] At the individual level, cultural competence requires a core set of knowledge and skills, the ability to integrate culture and language in health care and in the conduct of research, the capacity to engage in self-assessment and address biases, and a commitment to continued learning over time. Cultural competence responds to the myriad factors that influence diversity among individuals and groups, such as language, nationality, acculturation, age, gender, sexual orientation, education, literacy, SES, religious or spiritual beliefs, and health beliefs and practices.[17] A thorough understanding of these factors and respect for their relevance are necessary to engage diverse individuals, groups, and communities effectively in health disparity interventions. Cultural competence emphasizes reciprocity (i.e., the exchange of information, knowledge, skills, and resources) between academic teams and communities. The authors integrated these philosophical constructs and practices into their community-level, nontherapeutic trials to be responsive to the diversity among individuals who self-identify as African Americans in the Washington, DC metropolitan area.

From 2009 to 2011, prior to the establishment of these sites, nontherapeutic clinical trial enrollment had reached 365. Much of the enrollment was due in part to Georgetown–Lombardi enrollment for the Prostate, Lung, Colorectal, and Ovarian Cancer screening trial. There is a great need to increase clinical trial accrual and ultimately reduce cancer health disparities. Heller and colleagues[20] suggested that multiple, flexible strategies designed for providers and participants at provider sites and within communities are needed to enroll under-represented populations into clinical trials. Thus, the study objective was to demonstrate the importance of an academic, community-embedded office in the recruitment and enrollment of racially and ethnically diverse, underserved individuals in clinical trials. This study addressed the roles of access, influence of cultural competent staff, and engaging African-American populations in clinical research, specifically nontherapeutic trials.

## Methods

### Theoretical Framework

This community-embedded approach to increase participation in clinical trials among racially and ethnically diverse, underserved communities draws upon the tenets of community participatory