



**Knowledge and Access to Information on
Recruitment of Underrepresented Populations to
Cancer Clinical Trials: Evidence
Report/Technology Assessment Number 122**

U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality

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The burden of cancer falls disproportionately upon the medically underserved, and research studies are essential to improving health care in general, including for medically underserved populations. Clinical trials are used to evaluate efficacious prevention and treatment interventions; however, studies often fail to recruit the planned number of participants. Trials often do not include an adequately diverse population to ensure broad generalizability of results. Recent studies of patients enrolled in cancer treatment trials sponsored by the National Cancer Institute (NCI) have demonstrated that the following populations are underrepresented in terms of their participation in cancer treatment trials: the elderly, those of low socio-economic status, those living in rural areas and Latino/Hispanic, Asian /Pacific Islander and American Indian/Alaska native men and women, as well as African-American men. Since the 1980s cancer prevention trials have been conducted with participants at highest risk for disease to reduce the cancer burden, and as in treatment trials, adequate representation of underserved populations in prevention trials is desirable. Questions remain regarding the appropriate level of inclusion, i.e., whether it might depend on the prevalence of the condition/disease studied in the overall population. This issue has not been addressed adequately in the literature. Moreover, there is substantial uncertainty about what are important barriers and promoters of recruitment of underrepresented populations, and what evidence-based interventions would address them. At the request of and with the financial support of NCI, AHRQ commissioned a systematic review of the existing evidence on the recruitment of underrepresented populations into cancer clinical trials, to be performed by the Johns Hopkins University EPC. Specifically, the EPC investigators were asked to consider six key questions: Key Question 1: What methods (e.g., survey studies, focus groups) have been used to study strategies to recruit underrepresented populations into cancer prevention and treatment trials? We defined underrepresented populations as including the elderly, adolescents, those of low socioeconomic status, those living in rural areas, African Americans, Hispanics/Latinos, Asian Americans, and American Indians. Key Question 2: What measures of success (e.g., proportional representation relative to the U.S. population; proportional representation relative to incidence in a specified population) have been used to evaluate the efficacy and/or effectiveness of strategies for recruitment of underrepresented populations into cancer prevention and treatment trials? Key Questions 3 and 4: Which recruitment strategies (e.g., media appeals, incentives, etc.) have been shown to be efficacious and/or effective in increasing participation of underrepresented populations in cancer treatment and prevention trials? Key Question 5: What are the documented barriers to and promoters of participation of underrepresented populations in cancer prevention and treatment trials? Examples of potential barriers include access, knowledge, attitudes, eligibility, fatalism, religiosity/spirituality and exclusions by design. Examples of potential promoters include attitudes, altruism, advanced disease, financial incentives, and no-cost treatment. Key Question 5a: Do these barriers and promoters differ by age, gender, socioeconomic status or race/ethnicity? Key Question 5b: Are these barriers and promoters modified by cultural factors? Key Question 6: What effects do the attitudes and perceptions of health care providers have on the efficacy/effectiveness of strategies for recruitment of underrepresented populations into cancer prevention and treatment trials? Health care providers were defined as including any health professional or health care organization that provides health services to patients.

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