

RECRUITING AFRICAN-AMERICAN RESEARCH PARTICIPATION IN THE JACKSON HEART STUDY: METHODS, RESPONSE RATES, AND SAMPLE DESCRIPTION

Objective: The sampling and recruitment methods, response rate, and cohort description for the all-African-American Jackson Heart Study (JHS) are detailed.

Methods: Four subsamples of participants residing in the Jackson, Mississippi metropolitan statistical area (MSA) were included: random, volunteer, ARIC (continuing from Atherosclerosis Risk in Communities study), and family. A community-driven recruitment model was developed, and community representatives guided recruitment.

Results: 96% ($n=5,302$) of target enrollment was achieved with diversity in sex, education, and income. The JHS cohort provides a sample of African-American adults for longitudinal investigation.

Discussion: Cohort recruitment was challenging. The JHS experiences provide useful lessons for observational epidemiological studies recruiting African-American research participation. Co-participation of researchers and researched in study design and realistic evidence of community benefit were crucial to recruitment success. (*Ethn Dis.* 2005;15[suppl 6]:S6-18–S6-29)

Key Words: African Americans, Cardiovascular Disease, Jackson Heart Study, Longitudinal Study, Recruitment

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INTRODUCTION

Subsequent to the 1994 National Institutes of Health mandate for more diversity in research populations,¹ increased emphasis has been placed on recruiting African Americans and other ethnoracial minorities into research studies. Past race relations and historical experiences with the research and medical community have been identified as a major barrier to effective recruitment, particularly for African Americans. The long-standing mistrust of research, suspicion of the motives and practices of researchers, and fear of exploitation and negative stereotyping as a result of research findings are well chronicled.^{2–6} Numerous reviews have highlighted strategies that may be effective in addressing these issues^{7–11} while attending to other barriers to participation, including factors unique to participants, study organization and protocols, and community involvement.¹² Participatory action,¹³ researcher-researched contextual matching,^{14,15} and social marketing¹⁶ models have been proposed as frameworks for generating recruitment strategies. No one set of approaches has emerged as superior in producing results, and the literature now stresses the importance of developing study-specific methods¹⁷ to address the unique cultural, structural, and community barriers and concerns regarding trust and disease burden.

The Jackson Heart Study was an outgrowth of the Atherosclerosis Risk in Communities (ARIC) study, seeking to secure new and continuing participation of 5302 African Americans for long-term observation of cardiovascular risk

factors. The JHS aimed at enrolling a representative, population-based cohort of self-defined African-American persons aged 35–84 years, with an embedded collection of families for genetic study. Recruitment involved ARIC participants, random selections, and volunteers from three counties surrounding Jackson, Mississippi, as well as first-degree relatives of index participants. Before the JHS, the Jackson site of the ARIC study—one of this study's four sites¹⁸—represented the largest historical effort to recruit African-American research participation from a single place.

The purpose of this paper is to describe the recruitment model developed in concert with community representatives; the sampling plan; the recruitment protocol including staff hiring, training, and certification; participant contact procedures; enrollment that used a home induction interview; and the recruitment results.

JHS RECRUITMENT MODEL

African Americans are under-represented in research on the major diseases in which health disparities are evident. The excessive cardiovascular disease (CVD) burden among African Americans may be remedied, in part, by participation in studies like the JHS, which are designed to address potential contributing factors. Yet research participation among this population is low, ranging from 3%–20%,¹⁹ and often difficult to obtain. The experiences of the ARIC study reflected the challenge of recruiting African-American adults

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