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

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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 marketing[16] 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 methods[17] 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 sites[18]—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

from Jackson, Mississippi. Initial household enumeration of potentially eligible persons was lower in Jackson (81%) than in all other sites combined (88%). While each ARIC field center had a similar proportion of completed initial home interviews, 20% fewer Jacksonians who completed the initial home interview continued in the study, compared to each of the other sites.[20] At the time of the baseline examination of the Jackson ARIC study during 1987–1990, a total of 3728 participants completed visit 1 (47% response rate). Relatively fewer participants returned to each subsequent clinic visit (84% visit 2; 70% visit 3) in Jackson. Approximately 60% (n=2,368) of the initial cohort participated in examinations at the completion of visit 4; 3371 (90.4%) were still living.

To address additional challenges that might arise from the expansion of the study area and the age range beyond that of ARIC, a preliminary study of factors influencing African-American research participation in the three-county Jackson Metropolitan Statistical Area (MSA) was undertaken as part of the feasibility phase (1997–1999) of the JHS.

The design for the participant recruitment study (PRS) was informed by a comprehensive review of existing literature on recruiting and retaining research participants; in-depth interviews with other NIH researchers who were actively recruiting African Americans in other studies; and in-depth interviews with ARIC staff responsible for initial recruiting, ongoing retention, and enacting the ARIC protocol for data collection. These three pivotal information sources provided the background for developing an innovative conceptual model of key participant, organization, protocol, and community involvement (POPCI) factors thought to influence recruitment and retention.[12] Participant factors were defined by social and personal demographics. Organization factors included continuity of interaction between participants and research staff/investigators, commitment to study purpose, and compatibility, such as cultural sensitivity and ethnic match, between participants and staff. Protocol factors were defined by aspects of study design, accommodation to participant needs, and quality assurance and control, including feedback to participants and staff. Community involvement was defined as community mobilization, community partnership, and trust.

The interviewer-administered survey to assess the relationship of selected POPCI factors to potential participation in the JHS both as individual and family was based on a previously used instrument.[21] The PRS survey sample of 126 African-American participants between the ages of 35 and 84 years and residing in the JHS study area was selected at random by using the intended sampling frame for the JHS random sample—continuing Jackson-ARIC participants and the Mississippi Department of Transportation Driver's License and Identification List of race- and age-eligible persons. In-home interviews were completed by a team of three trained African-American interviewers from June to August 1999. The PRS survey allowed investigators the opportunity to pilot test the realities of locating and contacting participants and gain experience in conducting home interviews while collecting data to inform subsequent recruitment efforts. For example, we tested the effectiveness of including a JHS magnet in the initial contact letter and providing cash or non-cash payment for interview completion. The most efficient number of contact attempts prior to "closing" a file from further contact and methods of tracing persons no longer at the available address were also tested.

As described in prior publications,[12,22] the PRS used an interpretive phenomenologic approach to address questions regarding the common experiences and meaning of research participation. Findings from the PRS were used to identify site-specific barriers and facilitators of research participation, develop explicit strategies for recruiting and retaining the continuing participation of ARIC cohort members in the JHS, and suggest practical methods for recruiting and retaining the larger JHS cohort.

Survey findings provided information on POPCI predictors of participation. For example, participant age, health status, and quality of life, as well as positive family history of chronic illness were all predictors of participation. Those POPCI predictors targeted by JHS recruitment strategies included participant-staff compatibility, completing examinations within the promised time, not losing pay from work, positive information in the media, healthcare provider support, and community trust that no harm would come to them.

Interpretive interview findings contributed to a community-driven model for recruitment and retention. Community members became partners in creating community awareness of the JHS toward overcoming barriers to participation. The PRS participants advised that for the study to succeed in recruiting, the JHS must become a "family," with researchers and participants joining together on a journey of collegial learning. Just as in their own families, the JHS family described by PRS participants valued elders to provide a supportive presence for newcomers, personal contact, and respect for all members for what they could offer. These new research partnerships between researchers and researched, between Blacks and Whites, revolved around community, reciprocity, and caring. Specific strategies for recruiting were uncovered that included creating a home for the JHS within the examination clinic. A Council of Elders was formed; members were ARIC participants who provided their wisdom and experience in research participation to researchers and participants alike.

Participating in all phases of the study including protocol review, hiring and training staff, overview of study progress, and participation in quality control site visits, elders provided a supportive presence for staff, investigators, and community alike. Details of enacting these strategies are described in Recruitment Protocol, below.

Recruitment strategies were built on a foundation of community partnerships that assured possibilities for community-wide benefit and participation in JHS activities, regardless of individual inclusion in the JHS cohort. The PRS participants described strategies for growing, cultivating, and building community partnerships that included JHS community seminars and forums, lay health advisor training, and alliances with businesses to support local participation. The JHS Partnership for Health Education and Awareness implemented community outreach activities that built on these findings as they mobilized the community. These strategies, including community membership on JHS committees and voting membership on the steering committee, will be described in a future publication.

Participant recruitment study (PRS) interviews also illuminated culturally appropriate language and study protocol sensitive to safeguarding community concerns. Protocol working groups assured community participation in advancing key scientific questions, developing and testing data collection instruments,[23] and developing the consent form used to describe the study to the participants.

JHS RECRUITMENT METHODS

Sampling Plan

The population for the JHS was all noninstitutionalized African-American adults between the ages of 35 and 84 residing in the Jackson MSA (n=76,420). This age range extended that of the ARIC study (45–64 at the time of recruitment) to include younger (35–45) and older (75–84) persons. Only persons who otherwise met study criteria but were deemed to be physically or mentally incompetent by trained recruiters were excluded from study eligibility. A total sample size of 6500 was identified as the target at the inception of the study but was subsequently reduced to 5500, as power analyses confirmed that all scientific questions could be addressed with this lower number. At the conclusion of enrollment, the 6500 participants were expected to be distributed as follows: 2000 persons from the ARIC sample along with age-eligible individuals living in ARIC households (<100 expected); 2500 persons from the random sample; and 2000 persons from the family sample. These expectations were proportionally decreased when the targeted sample was reduced to 5500.

Figure 1 summarizes the derivation of the JHS sample. Initially, three sampling frames were identified to provide participants from either an ARIC, random, or family sample. A fourth sample group was added in 2002 to include volunteers who matched the age, sex, and socioeconomic distribution of the total population. The volunteer sample was not anticipated to exceed 1250 (reduced to 1063 with reduction in target cohort size). As indicated, each of the four components of the JHS sample has notable and unique attributes.

The sampling frame for each sample type provided the name of an eligible householder, and the household served as the sampling unit. A household was potentially eligible if the householder from the sampling list was living in the household or if the householder was deceased but the surviving spouse lived in the household. With the exception of the volunteer sample where the individual was the only householder considered eligible, all age- and race-eligible household members were enumerated as potential study participants.

ARIC Sample

Living participants in the ARIC study made up the sampling frame for the ARIC component of the JHS. A total of 3371 participants were alive at the initiation of the JHS, and their attained ages were 57–76 years. A complete list of ARIC participants was generated from the Jackson ARIC field site data and sorted according to the date of recruitment into the ARIC study. The sample list was released by the JHS Coordinating Center to the Examination Center every three months until the ARIC list was exhausted in January 2003. Because of continuing attrition from ARIC cohort deaths, a total of 3027 participant names were ultimately eligible for JHS recruitment.

Community Random Sample

The sampling frame for the community random sample plan was originally intended to replicate that used in the ARIC study,[18] thus providing direct correspondence between the derivation of the two samples. The ARIC study used the Mississippi Driver's License and Identification List that provided information on age, sex, and ethnicity for residents of the city of Jackson. This list, used for the PRS as a trial, was intended for use by the JHS to randomly select individuals as representatives of households in the three-county Jackson MSA. Approximately six months before the JHS was to begin, an amendment to the federal Driver's Privacy Protection Act was passed that changed the level of consent for public release of personal information from driver's license lists from an "opt out" to an "opt in" basis. The Mississippi Highway Patrol was no longer able to release a complete listing of all persons with driver's licenses or state identification cards, which prevented its use in the JHS.

As an alternative, multiple commercially available lists were scrutinized to assure adequate coverage of the area. The Accudata® list was deemed to provide the most complete count of

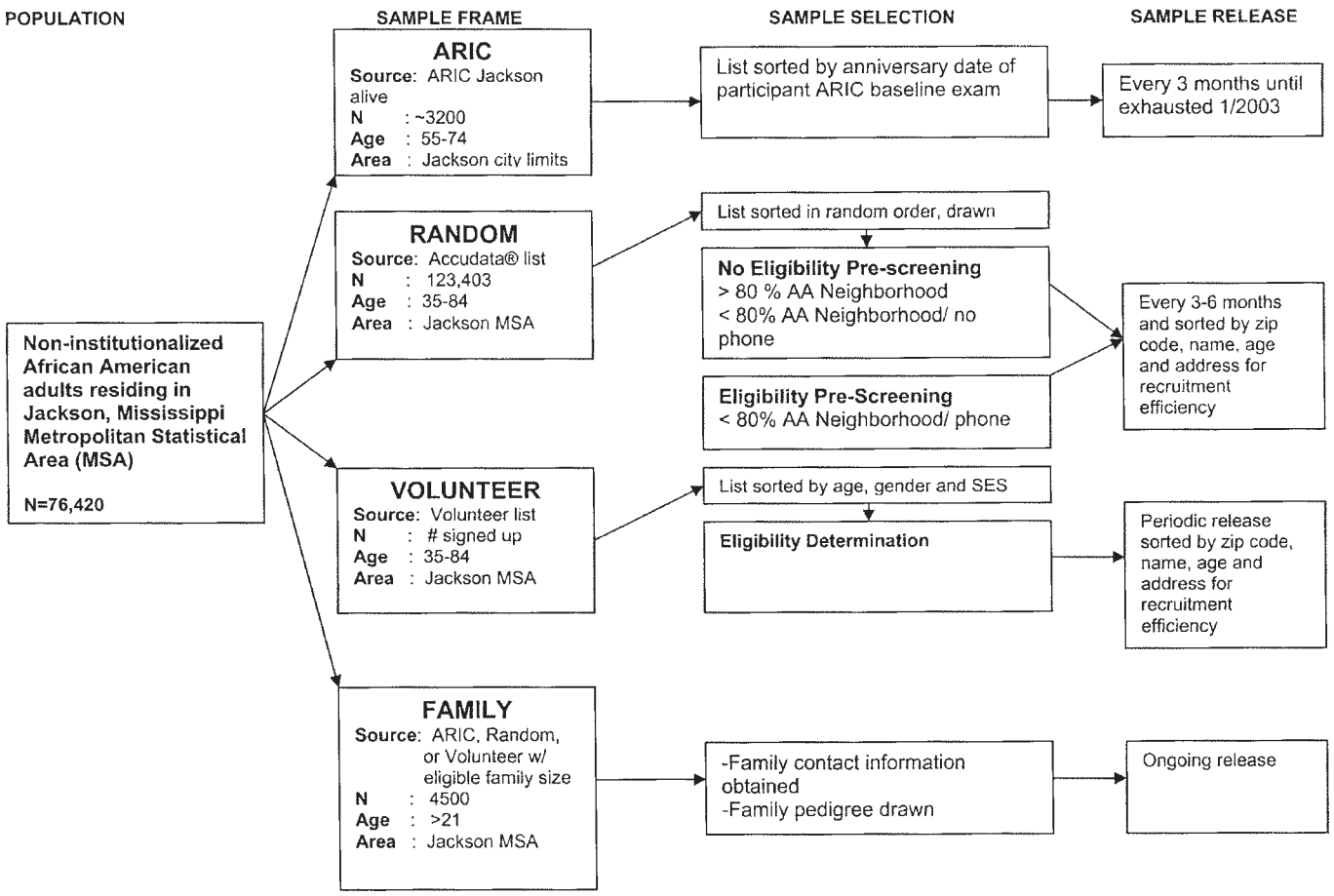

Fig 1. Sampling protocol

households for individuals aged ≥35 years in the Jackson MSA and included 123,403 householders in the JHS age range. While this list did not identify ethnicity of the householders, it included the age group in decades and the address. By linking the list with the 1990 Census data (updated to 2000 Census data when it became available), information on the density of African Americans in a given locale was identified by comparing with the percent White population. Persons living in neighborhoods of <30% African Americans were deleted from the total list because the cost of eligibility prescreening in these areas was prohibitive. The list was sorted in random order, and households were drawn from the top down until the cohort selection was completed. After the random sample was generated, an eligibility prescreening process was implemented to reduce the ineligible number of persons in the list. The JHS Scholars from the Undergraduate Training Center conducted tracing to identify missing telephone numbers. A commercial survey firm completed a telephone eligibility interview to identify persons living in 30%–79% African-American Census areas who had a phone number. Five contact attempts at varying times of day and days of the week were made for each householder and, when contacted, a short survey was administered. All eligible or uncontacted householders were retained in the random list for field recruitment. Random selections were made every three to six months, sorted by zip code, name, age, and address for recruitment efficiency.

Volunteer Sample

In 2002, enrollment was opened to volunteers who met census-derived age, sex, and socioeconomic status (SES) eligibility criteria for the Jackson MSA. A community volunteers list maintained by the Community Partnership Office provided the sampling frame. An enrollment algorithm based on census data for each county specified anticipated recruitment for each cell. Median income for each zip code served as an SES proxy. Each potential volunteer was classified as either having a high (above the median) or a low (at or below the median) income. The resulting 20 strata per county were filled on a first-come basis. The completion of baseline interviews in each recruitment cell for random and volunteer samples was constantly compared to assure that no

cell was exceeded and that the designated number of volunteers was not surpassed.

Family Sample

The sampling frame for the family study was a participant in any one of the ARIC, random, or volunteer samples whose family size met eligibility requirements. Eligibility included having at least two full siblings and four first-degree relatives (parents, siblings, children over the age of 21) who lived in the Jackson MSA and were willing to participate in the study. No upper age limit was placed on the family sample. Known contact information was obtained during the baseline clinic examination from the index family member with a verbal pedigree format to identify name(s), age(s), address(es), and telephone number(s). Once all contact information was complete, a pedigree was drawn with Progeny® and the family listing was released to the JHS Examination Center by the Coordinating Center. Recruiters extended pedigrees during field recruitment, and this information was added to the Progeny® database. Additional detail regarding the JHS family study is discussed by Wilson and colleagues in this issue.[24]

Recruiter Selection and Training

Recruiters' ability to engender trust by hearing and responding to participant concerns and employ multiple community-driven recruiting strategies was central to JHS recruitment success.

Recruiter Selection

Using principles and themes of "finding common ground" from the PRS,[12] a group of community residents were selected for the JHS. Age, gender, ethnicity, and personal characteristics of recruiters (honest, friendly, sincere, personable, caring, passionate about JHS potential, informed, and convincing) were emphasized. Recruiter selection interviews served to discern these characteristics and included a roleplay in which applicants conducted a mock recruitment interview with a member of a Council of Elders to assess their interpersonal skills.

A recruitment director and a team of five interviewers (four female, one male) were selected to recruit the original targeted cohort of 6500 from an area larger than the state of Delaware within three years. Recruiters' responsibilities included locating and contacting participants, conducting home induction interviews with paper forms, scheduling clinic examinations, and data entry. The recruitment director provided oversight and direction to the team. During the first year of recruitment, the need for additional staff to increase respondent contacts and reduce recruiter burden for file preparation and data entry was documented. The additional staff included six recruiters (five female, one male), two recruiter assistants, and a data entry coordinator. The recruiters were African Americans of varying ages with a minimum of a bachelor's degree; three had a master's degree.

Recruiter Training

An extensive training program provided initial and ongoing preparation of the recruitment team. Initial preparation was provided in an eight-week didactic and practical training program accomplished in four phases: orientation to the JHS, orientation to recruitment procedures, inviting research participation, and a field practicum. Each recruiter then underwent a complete home induction interview and baseline clinical examination to gain first-hand experience with the requirements and demands of study participants. A manual of operations was prepared and given to each recruiter.

A unique one-week series focused on inviting research participation and communicating with potential participants. Methods for enhancing listening and trust-building skills, developing interpretive skills, and providing participant support throughout the recruitment and retention processes were stressed. The PRS report served as a textbook, and Council of Elders members co-participated in guiding recruiters through the participant stories and interpretations. Multiple ways of knowing and connecting, and hearing and responding to participant concerns, including fears emanating from past mistreatment or the Tuskegee Syphilis Study, as well as special concerns regarding genetic study were explored. They were also guided in the process of telling and interpreting personal stories to illustrate how their lived and learned experiences prepared them to be interactive listeners.

Recruiters also completed a two-day workshop focused on cultural diversity and the realization of personal sensitivities. Conversation was focused on the complex implications of the "insider/outsider" debate—that is, whether membership in a particular ethnic group makes a person an "insider" to the JHS target population.[25] Recruiters explored personal experiences of being an insider or outsider within their own community and how these might inform community-driven recruitment.

Following the eight-week classroom training, successful completion of a filed practicum was required. Certification for JHS data collection required three acceptable, recruitment director-observed, in-field interviews, successful debriefing with the recruitment director, and a passing score on a written protocol examination. The initial interview was completed with a JHS Council of Elders member, and two subsequent interviews were conducted with potential participants identified in accordance with sampling protocols. Debriefing sessions were held with each recruiter to assess her/his familiarity with and understanding of the intent of the questionnaire items, and overall ability to handle the field experience with confidence, accuracy, and confidentiality. Throughout the field data collection, annual written examinations were required, and the director

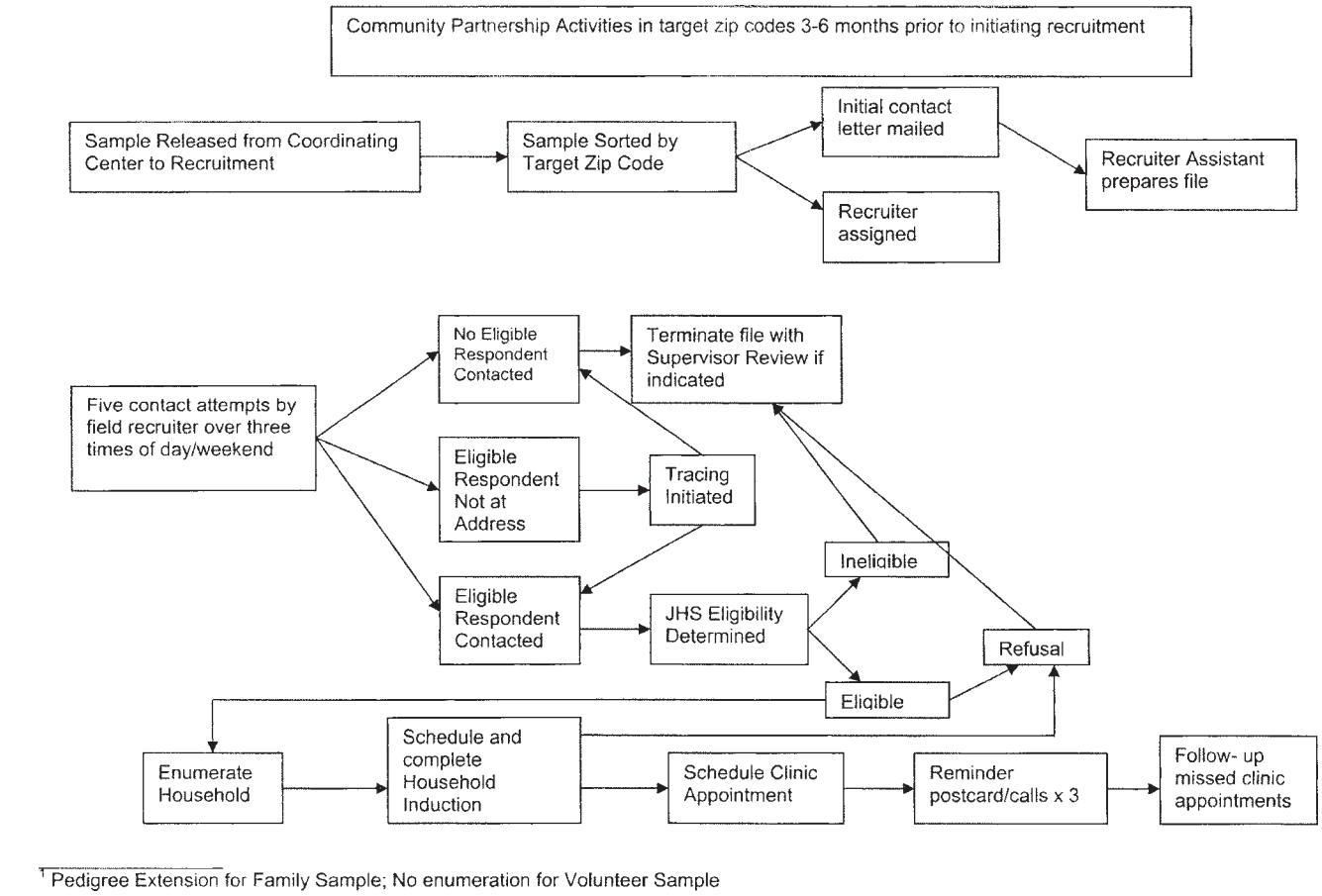

Fig 2. Recruitment protocol

periodically accompanied recruiters on random, selected visits to assess their continued competence and/or to make recommendations for remedial work.

Weekly team meetings included updates and review of study protocols, recruiting strategies, and hearing and interpreting field experiences of the recruiters. This ongoing preparation provided for continuous quality improvement and, coupled with weekly individual oversight by the director, assured that recruiters maintained JHS standards. Periodically, the director made field visits to attempt conversion of hard-to-reach participants and to assist in the overall recruitment effort.

Recruitment Protocol

Figure 2 diagrams the flow of JHS recruitment from community mobilization to scheduling the clinic examination. The first step in recruitment, building trust and credibility in the community, was initiated two years before study start. Recruitment was targeted to one or more particular zip code(s) at a time, and focused community partnership activities were initiated three to six months before initiating recruitment efforts in the given geographic locale.

Participant Contact

The sample was sorted by target zip code, and an introductory letter was mailed to potential participants at the listed address. For the family study, a letter was sent to members of a family identified by the index family member. This letter invited participation, introduced and explained the purpose of the study, and assured confidentiality. The name and contact information for the recruiter was included. With the exception of ARIC participants, for whom research participation was now a common experience, and the volunteer sample, which had requested that their name be placed on a list, all initial contacts were person-to-person in the participant's home. The PRS had signaled the importance of coming into the heart of the community by going to the participant's home as a way of building trust.

All recruiters were identified by a JHS picture name badge as well as magnetic signs affixed to their automobiles to familiarize the study community with the JHS logo and identified recruiters as official JHS representatives. Selected persons were

assigned to a recruiter based on their sample subgroup and geographic area, taking into account each recruiter's unique qualities and expertise, prior experiences, and familiarity with the geographic region. Potential participants were grouped geographically to minimize recruiter travel. If the address listed for the participant was incorrect, phone or internet directories or contacts with neighbors were used to locate the participant.

Initial visits were made to a sample household in the late afternoon or early evening on a weekday or Saturday, as the chance of finding an eligible enumeration respondent (a knowledgeable household member aged ≥16 years) was enhanced at these times. If no eligible enumeration respondent was at home on the first attempt, the recruiter attempted to learn from other household members (eg, child under age 16) or neighbors when an eligible household member was expected to be at home. If no contact was made, a door hanger was left to alert the sample household that a JHS recruiter had attempted to reach them. If a suggested time could not be obtained, the second attempt was made between 5:30–9:00 p.m. on a weekday or on a Saturday morning. At this second call, if no contact was made, a second door hanger and a small seasonal welcoming incentive were left. Additional calls were made, as necessary, with continued efforts to learn from secondary sources when and how to contact an eligible enumeration respondent. Successive attempts were made on varying days of the week and times of the day to increase the probability of finding an adult at home. After unsuccessful home visit attempts, if a phone number was available, household visits were supplemented with telephone contacts. A minimum of five contact attempts—at least one during a weekday, weeknight, and weekend—were required prior to considering a household as a non-contact.

Because of the unique aspect of the family sample, no protocol limit was on the number of contact attempts. Family recruitment progress was reviewed weekly so that decisions could be made regarding the likely yield of additional contact efforts for each individual family.

Eligibility and Household Enumeration

Eligibility determination and household enumeration varied by sample type. Enumeration was the process of completing a household roster to select all potential participant(s). Household members were deemed eligible if they were between the ages 35 through 84 at the time of the interview and self-identified as African-American. For the random and ARIC samples, once the household was contacted, the entire household was enumerated for eligibility. For the family and volunteer samples, no household enumeration was completed. Family members had been identified on the index member family pedigree, and investigators attempted to extend the family pedigree in the home. Volunteers had been selected to fulfill predetermined sampling designations, and no additional household members were eligible.

When contact was made with an eligible respondent, the recruiter—with name badge in view—introduced her/himself, briefly described the purpose of the visit, and proceeded with enumeration. When contacting an eligible participant, the recruiter explained the purpose and importance of the study. A brochure and letter explaining the study and the examination were given to the participant. The recruiter also shared JHS newsletters and letters of support from community leaders, including local mayors, ministers, and leading civic groups such as the NAACP. The voluntary nature of the study and the confidentiality of the collected data were stressed.

Home Induction Interview/Clinic Exam Scheduling

A home induction interview was completed with all eligible participants identified through the enumeration or pedigree extension process who agreed to participate. Repeat attempts were made to secure the home induction interview if a respondent was not at home at the time of enumeration or missed or canceled an interview appointment. The initial interview lasted between 30–45 minutes and was designed to obtain demographic, sociocultural, and personal and family health information from the participant.[23,26] Upon completion of the interview, an appointment to complete the 4.5-hour baseline examination was scheduled. Any participant questions about the clinic visit or the study in general were clarified. Each participant was provided a comprehensive consent brochure (www.jsums.edu) and the business card for a Council of Elders member, should they wish to discuss the realities of participating in a research study. A videotape of the actual clinic examination was available for home viewing. Written instructions for fasting, bringing all medications, and contacting the clinic were reviewed and left with the participant. Special arrangements for transportation and child or elder adult care were also made, if necessary.

Once home induction was completed, the JHS Examination Center continued similar attempts to reschedule any missed clinic appointments, sending a reminder of missed appointment notice and attempting at least five telephone contacts. Study investigators and the Council of Elders made calls to potential participants to encourage participation and build a sense of family within the JHS. Willing participants were rescheduled for clinic visits at any time throughout the baseline examination cycle.

Upon completing the baseline clinic examination, participants received a personalized thank-you letter from the JHS

principal investigator, a personalized certificate of JHS membership suitable for framing, a JHS cloth tote bag with educational materials and trinkets, reimbursement for transportation, and a $25 appreciation for their time. Monthly raffles selected the name of a clinic attendee who received a special gift recognizing their participation. Selected exam and laboratory findings were sent to the participant and, with permission, her or his healthcare provider. A social worker assisted study participants in locating health care and social resources if needed.

Ongoing contact is maintained with the cohort through an annual JHS family reunion and birthday celebration on the Saturday nearest the anniversary of the first clinical examination, a semiannual newsletter, and cards recognizing participant birthdays, sympathy for family losses, and holidays.

Table 1. JHS recruitment phase responses and rates

Response by Recruitment Phase/Activity	Total *n*
Number of household visits* (total contact attempts)	17,343
Participant contacts (single contact/participant)†	11,669
Age/race ineligible	772
Physically/mentally incompetent	193
Deceased	128
Refused	2,258
Moved (locally and out of area)	123
Terminated‡	1,344
Home induction interview complete	6,181
Baseline clinic exam complete	5,302
Proportions for Recruitment Phase/Activity	**Total %**
Home induction interview (HII complete/single contact)	53.0
Clinic exam yield (clinic exam/HII)	85.9
Clinic exam (clinic exam/single contact)	45.5
Refusal (refusals/single contact)	19.4
Age/race ineligible (ineligibles/single contact)	6.6
Physically/mentally incompetent (incompetent/single contact)	1.6
Deceased (deceased/single contact)	1.1
Moved (moved/single contact)	1.1
Terminated (terminated/single contact)	11.5

* Total contact attempts with or without successful personal contact.
† Personal contact made with participant on one or more occasions.
‡ File closed after at least five unsuccessful contact attempts.
JHS=Jackson Heart Study.

RESULTS

Response Proportions

The numbers of persons and response proportions at each stage of the recruitment process are provided in Table 1. The final cohort enrollment was 5302 (96.4% of the target). A total of 17,343 household visits (or telephone contacts) resulted in 11,669 single contacts. Of those contacted, 772 (6.6%) were age or race ineligible, 193 (1.7%) were deemed physically or mentally incompetent, 123 (1.1%) had moved outside the study area or locally and could not be located, and 128 (1.1%) were deceased. Nineteen percent (n=2258) refused to complete the home interview. Recruiters terminated contact attempts with 1344 persons (11.5%) after five or more unsuccessful contact attempts.

Home induction interviews were completed with 6181 persons; 53% of those contacted completed the initial enrollment interview. Fewer that half of those contacted (45.5%) completed the baseline clinic examination. Of those persons who completed the home induction interview, 85.9% (n=5,302) completed the baseline clinic examination.

Sample Distributions

Table 2 summarizes the distribution of the cohort by sample type and county of residence. The combined random and volunteer samples constitute nearly half of the JHS cohort (n=2491). The volunteer sample (29.6%; n=1570) includes members of ARIC households (n=286) who were not otherwise accounted for in the sampling design, as well as persons identified from the volunteer sampling procedures (n=1284). The random sample (n=921) makes up 17.4% of the cohort. The ARIC-JHS sample (30.7%, n=1,626) represents ≈50% of the living ARIC cohort. The family sample includes secondary family members (index family members are counted in their original sample type) and constitutes 22.4% (n=1185).

Table 3 describes the age, sex, education, and income distribution of the final JHS cohort by sample type. As shown, the overall JHS cohort was mostly within the ARIC age range of 55–74 years (45.6%). Sixty-four percent were female and well educated. Most had more than a high school education (40.1% high school/some college; 39.3% college or higher); 20.6% had less than a high school education. Though most of the cohort had an income ≤$25,000 (38.4%), the proportions with incomes of $25,000–$49,000 and $50,000–$99,000 were similar (27.5% and 26.3%, respectively). Nearly 8% had an income ≥$100,000. Thus, unlike previous studies of African Americans, the broad socioeconomic distribution allows the JHS to examine its role in cardiovascular disease.

Sample Representativeness

Inclusion criteria, initial response proportions, and stability over followup determine the representativeness[27] of the JHS cohort. The unique character-

Table 2. JHS cohort distribution by sample type and county of residence

Sample Type	County of Residence			Sample Type Totals‡
	Hinds	Madison	Rankin	
Random	705	144	31	921
Volunteer*	1,235	168	125	1570
ARIC	1,532	32	13	1185
Family†	938	136	61	1626
County totals	4,409	480	230	5302

* Includes 286 ARIC household members.
† Secondary family members only; index members included in original cohort type.
‡ Where n≠totals, category is unknown, total of 179 unknowns; 4 missing values.
JHS=Jackson Heart Study; ARIC=Atherosclerosis Risk in Communities Study.

istics of the JHS sample (eg, inclusion of ARIC and an embedded family sample) precluded obtaining a population-based cohort based on a probability sample of the reference population. Also, like Framingham, the JHS random sample was ''enriched'' with volunteers from the community who met predefined criteria of age, sex, and socioeconomic status[28] to compensate for the high expense and low response of the random sampling strategies and to maintain community relations. A future paper will address non-response bias. To date, annual follow up of the cohort has been successful, which suggests satisfactory cohort stability.

Table 4 compares the cohort and Jackson MSA distribution of sex, age, education, and income.[29] Some differences exist between the random/volunteer sample and the 2000 Census. While the random/volunteer cohort age distribution is similar to that of the Census data, the distributions for sex, education, and income show higher JHS participation by women, and higher proportions of college graduates and those in the high-income groups.

DISCUSSION

Conducting preliminary research to learn about issues important to the community before initiating a large-scale study in an ethnoracial population afforded key information regarding building trust and designing culturally responsive recruitment strategies that yielded a community-driven model for research recruitment. This model provided guidance to overall study design and implementation as well as the structure and organization of study management.

Having a well-appointed facility with easy access and sufficient parking that was located in the heart of the African-American community made a statement to the community. In addition to the passion, care, and concern of the research team, we believe it was an added benefit that most of the leadership and staff were African-American.

Flexibility and willingness to invest a great amount of effort in completing recruitment with extensive interviewer training and the use of local interviewers

Table 3. Age, sex, education, and income distributions of the JHS cohort by sample type, *N*=5,302

Variable	Sample Type				Total; %
	Random	Volunteer	ARIC	Family	
Total	921	1579	1626	1186	5,302; 100%
Age					
21–34 years	0	0	0	252	252; 4.8%
35–54 years	620	1,062	18	626	2,326; 43.8%
55–74 years	252	458	1,449	258	2,417; 45.6%
75–84 years	48	50	158	36	292; 6.5%
85+ years			1	14	15; 0.3%
Sex					
Female	577	956	1093	769	3395; 64.03%
Male	344	613	533	417	1907; 35.97%
Education					
<HS	159	170	570	194	1094; 20.6%
HS, some college	376	615	526	604	3217; 40.1%
College+	382	784	528	387	2083; 39.3%
Income*					
<$16,000	180	190	423	216	1010; 22.7%
$16,000–24,999	45	169	294	130	700; 15.7%
$25,000–49,999	205	384	389	243	1223; 27.5%
$50,000–99,999	222	439	259	251	1173; 26.3%
≥$100,000	53	148	90	57	348; 7.8%

* Missing data=846.
JHS=Jackson Heart Study; ARIC=Atherosclerosis Risk in Communities Study.

Table 4. Age, sex, education, and income distributions of the total JHS cohort, the JHS volunteer/random subsample, and the 2000 US Census for Jackson MSA

Variable	Total JHS Cohort		Random/Volunteer Only		2000 US Census, Jackson MSA	
	n	%	*n*	%	*n*	%
Age						
21–34 years	254	4.8	—	—	—*	—*
35–54 years	2324	43.9	1527	69.4	53542	70.1
55–74 years	2417	45.6	594	27.0	18898	24.7
75–84 years	292	5.5	81	3.7	3986	5.2
≥85 years	15	0.3	—	—	—*	—*
Sex						
Female	3395	64.0	1332	60.4	106952	53.2
Male	1907	36.0	872	39.6	93949	46.8
Education						
<HS	935	22.2	227	12.9	32023	29.5
HS, some college	1994	47.3	909	51.8	57474	53.0
College+	1286	30.4	620	35.3	18958	17.5
Income†						
<$16,000	1009	22.7	316	17.1	19347	29.4
$16,000–24,999	700	15.7	231	12.5	11409	17.4
$25,000–49,999	1221	27.4	515	27.8	20461	31.1
$50,000–99,999	1171	26.3	603	32.6	12116	18.4
≥$100,000	348	7.8	185	10.0	2410	3.7

* Sample truncated to depict JHS age eligible range only.
† Missing data=846.
JHS=Jackson Heart Study; MSA=metropolitan statistical area.

and clinic staff seemed to have been crucial to successful enrollment. Recruitment success was very labor intensive. To improve the response proportion, we had to hire seven additional recruiters and two recruiter assistants. Initial projections underestimated the effort and time required to cover the extensive recruitment area. In addition to personal and telephone contact, express mail options were used to enhance completion of clinic exams. Barriers ranged from overprotective dogs to overt mistrust. Men and those in the younger age ranges were most difficult to contact and recruit; they required innovative, community-driven strategies. Often wives and elder JHS participants supported recruiter efforts. The JHS Council of Elders helped inform potential participants of the realities of research participation.

The lack of availability of an ethnic-specific sampling frame was a serious impediment. This lack led to the need for laborious eligibility prescreening. Opening enrollment to include the volunteer sample reduced the effort required to identify ethnicity from the random sampling frame and contributed to building community trust by avoiding having to turn away significant numbers of participants who had made extensive efforts to become a JHS participant. The inclusion of the volunteer option was well received by the community and may have enhanced overall recruitment response in other sample domains as well.

The commitment of African Americans to improving their well-known health disparities and readiness to contribute to developing new knowledge is an invaluable lesson learned. The JHS baseline protocol was complex and time consuming. Study participation required an initial investment of nearly six hours for completion of the home interview, self-administered questionnaires, clinic examination, and 24-hour studies and an additional 20 minutes each year for annual telephone followup. Participants were urged to stay with the study for an as-yet-undetermined number of subsequent examinations; at least two additional examinations are scheduled. Important to sustaining this commitment is respectful treatment and tangible personal and community benefits.[30,31]

The final JHS cohort uniquely represents African Americans, provides sufficient variability in both cardiovascular risk exposures and outcomes to obtain estimates of relative risk,[27] and is old enough to allow measures of outcomes in the near term. Most participants are middle aged (35–54) and of middle to high socioeconomic status, which is consistent with previous cardiovascular cohort studies in similarly aged majority populations.[32]

The JHS encountered several challenges during the recruitment process. Identifying an alternate sampling frame delayed the start of community recruitment. Too few recruiters at the outset of the study necessitated an additional six months of recruitment and a reduction in sample size. Developing adequate results reporting and tracking mechanisms, as well as negotiating evening staff for following

up on missed appointments and incomplete exams were organizational challenges. Like other studies, we found that consumer-centered methods, while more effective, are more costly in time and effort.[7,33] The complexity of participants' lives—caregiving for grandchildren or other family members, disconnected telephone numbers, multiple jobs, and other stresses—made securing completed clinic examinations difficult. Creative mechanisms included paid time off work from several major employers. Similar to the JHS, other studies, notably the Women's Health Initiative, required more clinical and recruitment staff, extended recruitment time, and incurred higher costs for mailing for recruiting African Americans.[34] We found that face-to-face or home visits tend to be preferred by this segment of the population.

SUMMARY

This paper describes the sampling and recruitment protocol used to recruit 5302 African-American men and women ≥35 years of age of varying educational levels and socioeconomic status from the Jackson MSA to participate in a longitudinal, cohort, clinical epidemiologic study. Recruiting African-American research participation is challenging. The JHS undertook a unique participant recruitment study in advance of initiating study recruitment to identify site- and study-specific strategies to enhance participation. Recruiters were trained to employ recruitment strategies that were built on a foundation of community partnerships that assured multiple paths to participation in the JHS. A Council of Elders composed of ARIC participants provided their wisdom and experience in research participation to investigators and participants alike.

The successful JHS recruitment effort included enhanced community outreach and partnership activities, hiring additional recruitment staff, modifying the sample plan to allow for the inclusion of volunteers who met population distribution characteristics, and reducing the target sample size from 6500 to a more realistic (and adequately powered) 5500 participants recruited over 3.5 rather than three years. In keeping with prior literature, the JHS identified sustained community outreach/partnership with African-American involvement at all levels, sufficient recruitment staff, tailored and flexible recruitment methods, and timely tracking with frequent debriefing sessions as essential elements required to meet the challenge of recruiting African-American research participation.

The longitudinal and observational nature of the JHS introduced particular challenges given the recurrent theme of past exploitation and concerns regarding the potential for repeating Tuskegee. Co-participation of researchers and participants in study design and realistic evidence of community benefit were crucial to the ongoing success of this and future such efforts. Acknowledging the magnitude of the challenge, this paper adds to the modest collection of effective strategies to include African Americans in population-based clinical research through carefully planned and executed community involvement in all phases of research, from pre-grant funding through dissemination of findings to the scientific and lay communities. It also describes the response rates, distribution of sample characteristics, and representativeness of the JHS cohort.

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