# A COMMUNITY-DRIVEN MODEL OF RESEARCH PARTICIPATION: THE JACKSON HEART STUDY PARTICIPANT RECRUITMENT AND RETENTION STUDY

Sharon B. Wyatt, RN, CANP, PhD; Nancy Diekelmann, RN, PhD;
Frances Henderson, RN, EdD; Michael E. Andrew, PhD;
Gloria Billingsley, PhD; Sherry H. Felder, RN, MSN;
Sonja Fuqua, RN, MSN; Priscilla B. Jackson, RN, MSN, CFNP

Recruiting African Americans for research participation is a recognized challenge. The aim of the Jackson Heart Study (JHS) is to recruit and retain 6,500 African-American participants to examine the risk factors and causes of heart disease in this ethnic group. A multi-method Participant Recruitment and Retention Study was conducted prior to initiating the JHS as a basis for designing a culture-specific plan for recruitment, retention, and adherence of participants. Probability and purposive sampling were used to select African-American adults aged 35–84 from the Jackson area. Data were collected using a structured survey ($N=125$) and in-depth interviews ($N=31$ individual; 10 group). Data were analyzed and interpreted using inferential statistics and interpretive phenomenology to identify participatory barriers and facilitators, and to uncover the meaning of taking part in research. Findings generated an emerging Community-Driven Model, which has potential to enlighten researchers about effective strategies for recruiting and retaining African Americans for research participation. (*Ethn Dis.* 2003;13:438–455)

**Key Words:** Adherence, African Americans, Community-Driven Model, Heideggerian Hermeneutics, Interpretive Phenomenology, Jackson Heart Study, Recruitment, Retention

From the School of Nursing (SW), School of Medicine (SW, SF), and the Examination Center, Jackson Heart Study (SW, SF, formerly MA, PJ), University of Mississippi Medical Center, Jackson; Department of Public Policy and Administration (GB) and the Coordinating Center, Jackson Heart Study (formerly GB), Jackson State University, Jackson; Center for Educational Research and Evaluation, University of Mississippi, Oxford (SHF); Jefferson Comprehensive Health Center, Fayette (PJ), School of Nursing, Alcorn State University, Natchez (FH), Mississippi; School of Nursing, University of Wisconsin-Madison, Madison, Wisconsin (ND); Division of Occupational Health and Safety, Centers for Disease Control, Morgantown, West Virginia (MA).

Address correspondence and reprint requests to Sharon B. Wyatt, RN, PhD; School of Nursing; University of Mississippi Medical Center; 2500 North State Street; Jackson, MS 39216-4505; 601-984-6249; 601-815-4124 (fax); swyatt@son.umsmed.edu

## INTRODUCTION

Data from multiple studies confirms that African Americans are under represented in research on all the major conditions that affect their health and do not readily participate in medical research. Many barriers to research participation account for this lack of participation,[1–7] most notably distrust of research stemming from prior abuses.[8–12] The challenge of recruiting adequate participation is well recognized and pessimism about the potential for successful research is a commonly held view.[13,14] Recent literature[15–26] stresses that recruitment is difficult necessitating sufficient planning for the development of new models for recruitment and retention. Furthermore, while much can be learned from others, clearly each study has its own unique set of challenges that must be identified and addressed.[27]

The Jackson Heart Study (JHS) is the largest single-site study ever undertaken to examine the risk factors and causes of cardiovascular disease in African Americans. Broadening the research objective from atherosclerotic heart disease in a biracial cohort to cardiovascular disease in an all-African-American cohort, the JHS is a continuation and extension of the Atherosclerosis Risk in Communities (ARIC) study, now in its fifteenth year. The JHS undertook a Participant Recruitment and Retention Study (PRRS) looking at the potential study population prior to initiating enrollment to plan for recruitment and identify study-specific challenges. The specific aims of the PRRS study were to:

- determine factors promoting and inhibiting full participation in the Jackson ARIC cohort.
- determine similar enhancing or impeding factors for the Jackson community, particularly for those persons who fall within the younger and older ranges anticipated for the JHS.
- describe the common experiences of participating or refraining from participation in this type of research protocol.

Together, these 3 aims guided a multi-method quantitative and qualitative study designed to foster the development of a comprehensive recruitment plan for the JHS. A Community-Driven Model of recruitment and retention was generated by findings from both methods, but was most clearly articulated from the interpretations of in-depth interviews with potential JHS participants. This paper will focus on the age appropriate, culturally sensitive, and site-specific Community-Driven Model of research participation. This emerging model has the potential to enlighten researchers about effective strategies for recruiting and retaining African-American research participation.

## BACKGROUND

Study enrollment began in September 2000 and will continue through March 2004. The JHS is similar to the Framingham study and aims to recruit and retain 6,500 African-American adults residing in the Jackson Metropolitan Statistical Area (MSA), includ-

*Many barriers to research participation account for lack of participation,[1–7] most notably distrust of research stemming from prior abuses.[8–12]*

ing those who continue to participate in the ARIC study. Completion of an initial home interview, a baseline and cyclical clinic examinations every several years, as well as annual follow-up telephone interviews and ascertainment of clinical events were listed as objectives of the JHS study, which is described elsewhere in greater detail.[28,29]

The ARIC study is a longitudinal, observational epidemiological study examining the etiology and natural history of atherosclerosis and atherosclerotic disease conducted in 4 communities across the United States.[30] Each community recruited a population-based sample of approximately 4000 persons who have completed an initial home interview, a series of clinical examinations every third year, and an annual telephone follow-up interview. In addition, a surveillance team continuously collects cardiovascular morbidity and mortality events data in each community. Of the 4 communities, Jackson, Mississippi has been the site of the only all-African-American cohort.

African Americans have a higher cardiovascular morbidity and mortality than European Americans and Mississippi African Americans exceed the national average.[31] Determining the manifestations, natural history, and risk factors of cardiovascular disease for African Americans is imperative. Explanations for this well-recognized excessive cardiovascular disease burden can be obtained only if adequate numbers of African Americans can be recruited for further research. The success of the JHS depends on effective recruitment and retention of participants as well as participant completion of study protocols.

The city of Jackson lagged behind other ARIC sites in recruitment and retention of eligible participants. Initial household enumeration was lower in Jackson than in the other sites combined. In Jackson, 20% fewer residents completing their initial home interview continued in the study compared to the other sites. The overall response rate for Jackson was 47% and even fewer participants returned for each subsequent clinic visit in Jackson. Approximately 60% of the initial cohort participants completed the fourth examination (Jackson, 1996). In addition, fewer Jackson participants completed the entire protocol at each successive visit. Though these statistics reflect the challenge of recruiting and retaining African Americans for participation in Jackson, reasons for participation and non-participation were not specifically investigated in ARIC. A PRRS was undertaken to identify the barriers and facilitators to research participation in the African-American ARIC cohort, as well as other residents of the Jackson metropolitan area who were not ARIC participants. Findings from the PRRS were intended to provide a basis for planning the recruitment, retention and adherence to study protocol (RRA) for the JHS.

## THEORETICAL PERSPECTIVES

A convergence of theoretical approaches best described as "communitarian research"[32] underlies this research. This body of research values the connections that form between researchers and participants viewing participants as associates or comrades in the scientific endeavor. This multi-method research design is consistent with the study's intention to center the JHS in the community as a specific approach to increasing recruitment, retention and adherence to study protocol. A friendly, cooperative "relationality" defines such inquiry. As Lincoln observes, "Relationality is the major characteristic of research that is neighborly." This research is rooted in "community, shared governance, . . . and neighborliness."[33,34] It represents care-based ethics that presume dialogue, values, personal experience and builds bonds of mutuality, in contrast to contractual arrangements, within local communities.[35] This sense of neighborliness implies that research serves the community and includes the "community in which it is carried out, rather than the community of knowledge producers and policymakers."[33(p280)] The effectiveness of this research is judged by its authenticity, its fairness, and its ability to provoke transformations and changes in the public and private spheres of everyday life—transformations that ultimately speak to conditions of oppression.[33,36] Thus the approach taken in this research emphasizes collaboration, narration, dialogue and transformation, which are reflected in the Community-Driven Model that is emerging.

Two specific perspectives were addressed which, when taken together, express the communitarian research point of view. One perspective, the POPCI model, specified key elements of *p*articipant, *o*rganizational, *p*rotocol and *c*ommunity *i*nvolvement defined from the research literature. The POPCI model also included extensive key informant interviews with investigators of major NHLBI-funded studies of heart and kidney disease with significant African-American enrollment.[37] The other, the community-driven approach, was one in which partnerships were made during interpretive interviews, and participants were included in the analysis, write up, and ongoing development, implementation, and evaluation of a RRA plan.

# METHODS

## Study Design

To provide insights from both theoretical perspectives, a multi-method design was employed. Data for the PRRS was collected using a structured survey and in-depth interviews.[38] Quantitative (survey) methods allowed comparisons between ARIC participants and dropouts, and the Jackson MSA non-ARIC community to provide a meaningful understanding of POPCI predictors of RRA. The structured questionnaire interview was developed to capture the key participant, organizational, protocol and community involvement factors identified in the POPCI framework. Qualitative (interpretive) methods enriched the description of these predictors and delineated the dynamic interpersonal and community-driven aspects of RRA that could not be quantified. The unstructured interpretive interview was designed to uncover the meaning of taking part in research.

### *Sample*

The PRRS was methodologically designed to collect data as comparable to the ARIC study cohort as possible. In addition, the design allowed for data collection from a Jackson community sample comparable to that to be included in the JHS (aged 35–84 from the 3 county Jackson MSA). Information was collected from: 1) ARIC participants and dropouts; and 2) non-ARIC persons aged 35 to 84. The non-ARIC group was further subdivided into 3 target subsets: those persons in the ARIC age-eligible range (ie, 55–74) who lived outside the sampling area for the ARIC study (ie, Jackson city limits), non-ARIC persons aged 35–54, and non-ARIC persons aged 75–84. ARIC participants and dropouts were identified from the ARIC database. Non-ARIC persons between ages 35 and 84 were identified using the Mississippi Department of Public Safety list of persons for the 3 study counties comprising the Jackson MSA who either held a drivers license in Mississippi or a Mississippi Identification Card.

### *Structured Interview*

Probability sampling was used to select both ARIC and non-ARIC Jackson MSA women and men in each of 3 distinct age groups: 35–54, 55–74, and 75–84 for inclusion in the structured questionnaire component of the study. The PRRS was a pilot survey intended to provide a general description of the sample population for purposes of planning recruitment and retention strategies; a total sample size of 125 individuals was identified as adequate to provide a meaningful description of the sub-populations of interest. After obtaining informed consent, 3 African-American interviewers trained in survey techniques completed interviews with 25 ARIC participants, 25 ARIC dropouts (defined as participants completing at least one, but not all ARIC examination visits), and 75 community participants equally divided among the 3 age groups. Additional detail on the methods and findings from the structured interview component of the PRRS are described in a separate publication.[39]

### *In-depth Interview*

Purposive sampling, using maximum variability and key informant strategies,[40] was used to recruit individual participants for the interpretive in-depth interviews from the set of ARIC participants, dropouts, and Jackson MSA community residents. The randomly generated list from each of the defined sub samples used for the probability sample was used as a starting point. Persons were selected from the list to assure maximum variability on several demographic variables (eg, age, gender, occupation, SES) as well as extent and experience of research participation. A key informant sampling strategy was used to identify group participants representing several categories of persons anticipated to be difficult to recruit. In addition to these interpretive interviews with individuals and groups, one group interview was conducted with 7 ARIC participants and individual interpretive interviews were conducted with all ARIC clinic staff during the plenary stage of this research. Adequate sample size for studies using interpretive methods lies in the quality of the information obtained rather than their actual number.[41,42] Data quality is judged by its textual richness and ability to evoke thinking in the reader.

After granting informed consent, a total of 31 persons participated in 34 individual interviews. Three interpretive interviews were completed with one person and 2 with another. A total of 84 persons participated in 10 group interviews. Group size ranged from 6 to 11 with an average of 8 participants per group. Individual interviews were conducted by telephone by 2 interviewers, one an experienced interpretive interviewer and the other an African-American doctoral student trained in interpretive techniques. Group interviews were conducted by a biracial team of trained interpretive interviewers in churches, community centers, and other similar locations that were convenient for the participants. ARIC participants and dropouts were asked the following:

> "As you think about your experiences in the ARIC study, please tell me in your own words what being in ARIC was like for you. Describe a time, one that stands out for you because it reminds you what it means to be an ARIC participant, or it reflects an experience that is remembered because of its commonness—the average things that happen just by participating in research. Include as much detail as possible and stay in the telling of your experience, rather than stepping back and analyzing it or describing it from afar. After giving the details of your experience, please tell me why this experience is important and what it means to you."

Jackson area community participants were asked:

> "Thinking about your understanding of the JHS and any experiences you may have had with medical or other research, please tell me in your own words what

**Table 1. Interpretive interview: additional questions and probes**

When you think about taking part in something like the JHS, how would you go about deciding to take part? From your life experiences, what would you need to know? Who would you need to talk to? What personal or other issues come to mind that would help or hinder your participation—make it easy or hard? What fears or concerns would you want to talk about?

And if you were going to tell a neighbor or a friend about the JHS, what would you tell them? How would you go about helping them decide whether to take part or not?

The JHS is a long-term study, lasting perhaps indefinitely. How would you decide about staying in the study year after year? How would you talk with a friend or neighbor about staying in a study like this year after year?

There are many issues of trust for African Americans that may make a difference in whether persons take part in a study like this. Do you have any experiences from your life to share about how you might trust enough to take part in a research study like the JHS? How would you trust. . .the Medical Center?. . .the government sponsorship?. . .in light of the Tuskegee Study?. . .that there were sufficient benefits for African Americans from this study?

What about your entire family—your parents, brothers or sisters, and your children—if they were asked to take part in order to learn something about inheritance or passing things on in families? Do you have a story, a life experience, to share about family participation?

And what if you were asked for permission to store genetic material, that is DNA, in order to look at some of these family patterns in heart disease at a later date when we know more about genes? Would that be OK? If so, why? If not, why not? Have you any stories or experiences from your life to tell us about concerns like this?

> you think would be important to your participating or not in such a study. Describe a time that stands out for you because it reflects a memorable experience that reminds you of issues that are similar to those which come to your mind with the JHS—perhaps not exactly medical research, but a similar request to be a part of something that will last for some time to come. Include as much detail as possible and stay in the telling of your experience, rather than stepping back and analyzing it or describing it from afar. After giving the details of your experience, please tell me why this experience is important and what it means to you."

Other questions or probes were used as necessary and are enumerated in Table 1.

An African-American transcriptionist, experienced in interpretive research and listening to cultural speech patterns, transcribed each audio taped interview. All identifying information, such as names and places, were deleted at the time of transcription from the text and replaced with pseudonyms that were utilized throughout the data analysis. Tables 2 and 3 describe the characteristics of the participants in the individual and group interpretive interviews. Both individual and group participants were mostly female (58% and 61%, respectively). Most individual participants were between 55–74 years of age (69%), while group interview participants were between 35–54 (66%) as younger participants were anticipated to be more difficult to reach. Most group participants had high school education or less (49%), though 39% had 13–16 years of schooling and 12% had completed postbaccalaureate education. Most individual participants had a high school education or less (71%).

**Table 2. Characteristics of Jackson Heart Study Participant Recruitment Study individual interpretive sample by type of respondent**

| | ARIC Participants | ARIC Drop Outs | Community | Total |
|---|---|---|---|---|
| Gender | | | | |
| Male | 4 | 4 | 5 | 13 (41%) |
| Female | 6 | 5 | 7 | 18 (58%) |
| Education | | | | |
| ≤High school | 6 | 9 | 7 | 22 (71%) |
| Some college | 1 | — | 5 | 6 (19%) |
| College+ | 2 | — | — | 2 (6%) |
| Age | | | | |
| 35–54 | — | — | 5 | 5 (16%) |
| 55–74 | 10 | 9 | 3 | 22 (69%) |
| 75–84 | — | — | 4 | 4 (13%) |
| Total | 10 (32%) | 9 (29%) | 12 (39%) | 31 (100%) |

The remainder of this paper will focus on the hermeneutical analyses and findings from the interpretive interview component of the PRRS. While findings from the structured survey were complementary, the interpretive interview component most fully articulated the emerging Community-Driven Model of recruitment and retention.

## HERMENEUTIC ANALYSES

The background for the interpretive interview component of the study was interpretive phenomenology, specifically Heideggerian hermeneutic phenomenology. Hermeneutics is an approach to analyzing texts for common practices and meanings (themes) and is often used with minority and disadvantaged populations to give voice to their meanings and experiences.[35,43–45] Interpretive phenomenology acknowledges that both the researcher and the participant bring prior meanings to the research interaction arising from their experiences and location in historical time. Thus meanings are always situated or contextual and historical. The work of the interpretive phenomenologist moves beyond traditional logical structures of understanding in order to reveal and explicate otherwise hidden relationships of mean-

**Table 3. Characteristics of group interview respondents by group type: The Jackson Heart Study Participant Recruitment**

| | Nontraditional Religious (*N*=10) | Elderly (*N*=11) | Homeless (*N*=8) | Transitional (*N*=6) | Inner City (*N*=7) | Rural (*N*=7) | Medically Indigent (*N*=7) | Homogenous (*N*=9) | Nonprofessional Males (*N*=10) | Disenfranchised Community (*N*=10) | Total (*N*=84) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Gender | | | | | | | | | | | |
| Male | 4 | 2 | 8 | 0 | 1 | 2 | 1 | 4 | 5 | 3 | 33 |
| Female | 6 | 9 | 0 | 6 | 6 | 5 | 6 | 5 | 1 | 7 | 51 |
| Age | | | | | | | | | | | |
| 35–54 | 9 | 1 | 8 | 6 | 7 | 6 | 4 | 9 | 9 | 3 | 56 |
| 55–74 | 1 | 5 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 4 | 11 |
| 75–84 | 0 | 5 | 0 | 0 | 0 | 1 | 2 | 0 | 0 | 0 | 8 |
| Education | | | | | | | | | | | |
| ≤High school | 2 | 6 | 5 | 0 | 2 | 4 | 4 | 1 | 8 | 9 | 41 |
| Some college | 6 | 5 | 3 | 4 | 5 | 3 | 0 | 5 | 1 | 1 | 33 |
| College+ | 2 | 0 | 0 | 2 | 0 | 0 | 3 | 3 | 0 | 0 | 10 |
| Marital status | | | | | | | | | | | |
| Married | 9 | 3 | 1 | 3 | 4 | 3 | 4 | 6 | 6 | 1 | 40 |
| Divorced | 1 | 3 | 1 | 2 | 1 | 0 | 0 | 1 | 1 | 3 | 13 |
| Separated | 0 | 1 | 0 | 0 | 1 | 1 | 1 | 0 | 0 | 3 | 7 |
| Widowed | 0 | 4 | 0 | 0 | 0 | 2 | 1 | 0 | 0 | 1 | 8 |
| Never married | 0 | 0 | 6 | 1 | 0 | 1 | 1 | 2 | 2 | 1 | 14 |
| Income | | | | | | | | | | | |
| <$5,000 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 0 | 5 | 9 |
| $5,000–7,999 | 0 | 4 | 2 | 1 | 0 | 0 | 2 | 0 | 0 | 1 | 10 |
| $8,000–11,999 | 0 | 1 | 2 | 0 | 0 | 2 | 1 | 0 | 0 | 0 | 6 |
| $12,000–15,999 | 1 | 1 | 2 | 0 | 0 | 1 | 1 | 0 | 2 | 0 | 8 |
| $16,000–24,999 | 4 | 4 | 1 | 0 | 0 | 0 | 1 | 2 | 7 | 3 | 24 |
| $25,000–34,999 | 2 | 0 | 1 | 2 | 2 | 0 | 1 | 3 | 0 | 0 | 14 |
| $35,000–49,999 | 1 | 0 | 0 | 0 | 3 | 0 | 0 | 1 | 0 | 0 | 6 |
| $50,000+ | 2 | 0 | 0 | 3 | 0 | 3 | 1 | 2 | 0 | 0 | 13 |

ings. The descriptions of what *is,* are interpreted to show what *could be.* Common practices are described that are often at hand, familiar and yet out of sight. While calling attention to these common human practices and experiences, hermeneutics does not put forward a political or psychological framework, nor does the interpretive phenomenologist attempt to hypothesize, explain, or reconcile an underlying cause of a particular experience.[46–48] Rather, the description of the common experiences is intended to reveal, enhance, or extend understanding of the human situation as it is lived. The purpose of hermeneutics is to evoke thinking in the reader concerning the matter at hand; specifically, the life experiences of the participants as they unfold in the context of the time, their history, and their social relationships in their respective worlds.

While the thinking that accompanies hermeneutical scholarship is reflective, reflexive, and circular in nature, describing the process of hermeneutical analyses may suggest a linearity and structure that belies the seamless, fluid nature of this approach to inquiry. Although a brief summary of the hermeneutical analyses utilized in this study is described here, adapted from Diekelmann,[46] the reader is referred to several authors—Benner,[49] Diekelmann and Ironside,[50] Gadamer,[51] Grondin,[52] and Palmer[53]—who discuss hermeneutical methodology in more detail.

What follows is a description of one application of the interpretive method referenced above. Study investigators, who functioned as an interpretive team, read each interview to obtain a general understanding of the text. During each of a series of research meetings over an 18-month period, common themes were identified within each interview and each investigator shared her or his written interpretations with the team. Dialogue among team members clarified the analyses. As the investigators analyzed subsequent interviews, each text was read against those that preceded it while comparing and contrasting themes. Thus, new themes were allowed to emerge, and previous themes were continuously refined, expanded, and incorporated in other themes or determined unwarranted. During the process, the investigators clarified any discrepancies in interpretations by returning to the interview text or by re-interviewing participants for clarification. Three re-interviews were conducted to clarify meanings. Phenomena were not reduced to differences or similarities, but rather, the investigators worked together to explicate the practices of identifying the seemingly simple and overlooked intent.

Looking at interview texts in parallel, the investigators worked to identify and explore recurring themes that cut across interview texts. During this process, the investigators reread and studied interpretations generated previously to see if similar or contradictory interpretations were present in various interviews. Although an underlying assumption of hermeneutical analyses presumes that no single correct interpretation exists, the investigators' continuous examination of the whole and the parts of the texts with constant reference back to the participants ensured that interpretations were focused and warranted. Including the reader in the interpretation is an important aspect of hermeneutic analyses. During weekly meetings, the investigators read and exchanged written interpretations and discussed how excerpts and interpretations supported or did not support the author's interpretations. Whenever conflicts arose between interpretations of the interviews, the investigators returned to the text and provided extensive documentation to support the interpretations.

Reading across texts from African-American scholarship and literature on African-American health issues, the investigators worked to remain open to potential difficulties in the identification and interpretation of common themes while bringing them into conversation with the existing literature. The purpose of this procedure was to conduct critical learning using other interpretive approaches to extend, support, or overcome the themes identified using hermeneutics. In this way, analyses proceeded in cycles in which understanding, interpreting, and critiquing are in the center of the dialogues and discourses pursued.[54] Like the hermeneutic circle, interpretations were considered complete but never-ending.[47]

The hermeneutical approach provided the opportunity for investigators working on this interpretive study, and for non-JHS interpretive researchers, to review the entire analyses for plausibility, coherence, and comprehensiveness. In addition, some participants in the study were asked to read interpretations of their interviews as well as the interviews of other participants to confirm, extend, or challenge the analyses. Others, not included in the analyses but likely to be readers of this study, reviewed the written interpretations. This review process exposed unsubstantiated and unwarranted interpretations. In the final research report sufficient excerpts from the interviews were used to allow the reader to participate in the analyses. The purpose of the research report is to draw the reader into the interpretations of the texts by providing a wide range of verbatim, unedited, explicated text and multiple interpretations. After this step, the reader can then recognize the sources of the common practices or themes reflected in the actual texts. The reader is then free to agree or disagree with the interpretations offered.

## RESULTS

The interpretive phase results describe patterns and themes that the researchers derived from hermeneutic analyses of transcripts of individual (34) and group (10) interpretive interviews. In the course of reporting the themes and patterns, a model was developed for use in recruitment. These patterns and themes reflect a process model for mobilizing community support and participation for the JHS using insights and understanding of community members themselves. In addition, an extensive research report was written that included all quantitative and qualitative findings.[55] The report became the manual for preparing and training recruiters for enacting the Community-Driven Model in recruiting for the JHS and will provide the basis for its ongoing evaluation throughout the process of RRA.

Derived from the analyses of participant interviews and the findings of the qualitative part of the study, this model, in contrast to a community-based model, includes the key constituents in new ways. For example, in a Community-Driven Model, strategies for recruiting and retaining participants specifically include community members as co-investigators. Community members become caring participants using their wisdom and knowledge to assist in creating a space and place in the community for the JHS. Together they help in overcoming barriers to participation. In addition, hermeneutical analyses of interviews pointed to the strategies for language and study protocol that are culturally appropriate and sensitive to safeguarding community concerns identified and described in the interviews. Three patterns emerged reflecting all the themes of common experiences of Jackson African Americans regarding participation in the JHS. They are:

1. Interpreting the Concerns of the JHS Family: Safeguarding Political and Moral Concerns
2. Gathering the JHS Family: A Community-Driven Model for Recruiting and Retaining Research Participation
3. Friends of the JHS: Growing, Cultivating, and Building Community Partnerships

"Gathering the JHS Family" will be presented with key issues and principles of a Community-Driven Model, including patterns, themes, and further explications of how the emerging model overcomes barriers to participation identified by participants. Selected strategies are presented that reflect the emerging Community-Driven Model.

## A COMMUNITY DRIVEN MODEL OF RECRUITMENT AND RETENTION: KEY ISSUES AND PRINCIPLES

To be optimally effective, the JHS will require attention to *both* the demands of good science and the demand for co-participation and inclusion of the Jackson area African-American community. A Community-Driven Model of research co-participation offers possibilities for enacting a research approach which respects each side of the research enterprise—the researchers and the research participants. Individuals outside the mainstream of academic sciences who do not share the same access to social or economic resources and who have little voice in shaping scientific agendas or social policies are admitted to new partnerships with the research community. This way of thinking about research requires a shift in perspective on the part of the researcher—a shift that incorporates a view of study participants as "knowers and knowledge workers." Study participants have knowledge or information relevant to themselves, as well as the study. Participants harbor a different yet valid set of values, worldviews, and ways of carrying out their lives within the context of the study.[56] This shift also requires a willingness to understand and accept participant values, knowledge, and traditions as a foundation to conducting the study as well as a commitment to meaningful action. Such action involves members of the community in planning, implementing, and evaluating research studies as "resource collaborators"—that is as partners and central participants rather than as ancillary reactors to an already developed idea or plan.[57] The JHS consent form, jointly developed with community members, incorporates the notion of researcher-participant reciprocity by including a mutual pledge of participation emphasizing the relational principle of co-investigation.

In some ways, this community-driven approach used in the PRRS is not new. Community-based approaches for health research have become increasingly popular among scientists as a step toward resolving the potential conflicts between science and community needs and addressing the problems of implementing the research early on.[58] Such models vary in the level of participatory involvement in the research process. Consultative or collaborative models are most common centering on involving the community in planning and conducting the research, identifying topics of importance to the community, and providing feedback to the community. Such approaches provide a valuable vehicle for effective health research participation. Community-based approaches are particularly effective in studies with health screenings, illness identification, referrals and assistance with behavioral changes.[59] The issue, though, is not just community participation (community-based models) but co-participation in all aspects of the research program (Community-Driven Model).

A Community-Driven Model expands a community-based model to one characterized by collegial relations. In a Community-Driven Model, researchers and participants work together—co-participating and offering different skills in a process of mutual learning. Therefore, the issue is not one of community or researcher control, rather there are examples throughout the research program where both the researcher and the community make a major contribution. Though the other is always involved, at the end of the day, the researcher and the community are co-equals.[60,61] Community-driven research is critically distinctive from other forms of research because it emphasizes conducting research with the active engagement of the community as a social and cultural entity vs conducting research in a community simply as a setting to conduct research.[58] Key principles of this Community-Driven Model have been synthesized from the existing literature and include:

- Appreciating the Black community as a unit of identity; this concept is not the same as geographic or demographic clusters of predominately Black persons. In this model, community incorporates *both* the geographic boundaries as well as the sense of cultural identity shaped by shared values, social and political experience, and common fate. Heterogeneity is recognized. In particular, this model reflects a basic assumption of the African-American culture—communal essence or groups of persons organized around the notion of "persons-in-relation."[62]
- Building on community strengths and assets, and networks of trusting relationships to support and expand social processes of working together.
- Creating collegial partnerships among researchers and researched with each participating and sharing influence across all components of the research process.
- Committing to tangible community benefits resulting from the research conducted.
- Developing processes of co-learning and empowerment that attend to social inequalities. A Community-Driven Model fosters reciprocal transfer of knowledge, skills, capacity, and power among all participants. Learning from the "local theories,"[63] practical knowledge and shared wisdom of the community, researchers and participants alike engage in co-generative learning[64] which explicitly attends to the ways in which inequality shapes co-participation.
- Engaging in a cyclical and iterative process of building and maintaining partnerships, across all phases and components of the research process. The research design and operational procedures enact scientific protocol informed by the experiences and knowledge of those who will be studied.
- Fostering wide dissemination of research findings as well as knowledge gained through community-driven processes to all partners. This principle of dissemination includes participant consultation and collaboration prior to submission of articles for publication, acknowledging contributions of participants, and, wherever possible, developing co-authored publications.

Challenges, conflicts, and barriers are inherent in such a model. Identifying who represents the community will be an early barrier to overcome in order to avoid conflicts among participant groups. The lack of mutual trust and respect among the proposed partners is well documented in the research and clinical literature. Once established, trust cannot be taken for granted and will require constant vigilance by all. The continued presence of inequitable distribution of power among the community, researchers, and health professionals makes shared control a difficult ideal. Researchers are likely to encounter institutional as well as historical and individual barriers to accomplishing shared control. Conflicts over meanings, language, values and beliefs, assumptions and priorities are inevitable, necessitating conjoint development of operational norms. Such a model of research will be time-consuming and will represent a substantive revisioning toward a multi-method inclusive science. Significant time is required to establish and maintain trusting relationships among the research as well as the participant community. This expenditure of resources and time is often viewed as tangential to the purpose of the research. Unless such an investment is made in both populations, historical evidence supports the theory that recruitment using this approach will be difficult, potentially diminishing and threatening the results of the study.

When the key issues and principles of the emerging Community-Driven Model are incorporated with unique pattern and themes, this model is a promising example of a new and potentially successful approach to recruitment and retention of African-American research participation.[65]

## A COMMUNITY-DRIVEN MODEL: PATTERN AND THEMES

### Pattern: Gathering the JHS Family—A Community-Driven Model of Recruitment and Retention

The pattern "Gathering the JHS Family: A Community-Driven Model for Recruitment and Retention" is reflected in 2 of the 3 key themes: "Participants and Community as Co-investigators: Inviting Participation"; and "Welcoming and Staying: Creating Space and Place." The JHS is a family study. Yet, more than simply a "family study," the JHS is also about becoming a family, African and European Americans together. Family is not an entity that can be "recruited"; families can only be gathered together over the course of time. Similarly, continuing membership in a family is not about "retention"; but about varying ways and levels of participation over time. Reinterpreting the traditional language of "recruiting and retaining" to become "creating family, gathering, and participating" allows researchers to ask different questions. One important question for recruiting and retaining persons as part of this study becomes: How can we gather and participate as a family as researchers and participants? This question is seldom considered in designing research studies. Rather, investigators, often in isolation from the community they intend to study, develop the details of the research expecting that participants will recognize the importance of the scientific contributions and join in as subjects. A very different approach is required when researchers are dealing with a group, a community that has been *used* in research. Researchers must refrain from designing studies in isolation from the community they intend to study; something must pull them back from this stance. One "something" is the possibility for a new research comportment* that turns on a Community-Driven Model of recruitment and retention. Such a model envelops participants and community as co-investigators by listening and joining together to invite research participation.

## Theme: Participants and Community as Co-Investigators

One of the most striking findings of this research was the extent to which the participants in the PRRS came forward to express their interest and intent to be involved in this study in a meaningful way. For example, only 8.7% of the respondents to the PRRS structured survey indicated they would not likely participate in the JHS. The participants' stories challenged the interpretive team to reflect on the potential for the JHS. The challenge involved finding new solutions for age-old health problems while dispelling age-old suspicions in creating the JHS family. One participant offered the following advice:

> ". . . a study of this kind, what it can do by *those of us who are African Americans becoming a part of the solution to this problem* . . . to help alleviate the problem [among our people] by sharing with the purpose, the problem, the purpose of the study and what this will result, possibly result in, I think that will help a lot in resting or retiring or resigning certain possible suspicions about what people might fear."

In conventional research, participants are considered subjects for investigative study. Certain controls must be in place between the researcher and the researched. However, this relationship is being challenged and dangers explicated. For example, the word "subject" can connote subjugation and allegiance to the power or dominion of another, in this case, the researcher. Epidemiological studies, especially longitudinal cohort studies where research participation extends over time, have modified that traditional researcher-researched relationship to consider persons who are studied as "participants." This denotation opens the possibility for shared involvement. The participants in this study suggest yet another possibility—researchers and participants as learners and co-investigators. The meaning of co-investigator is a relationship of partnership and sharing of power, "shar[ing] with the problem, the purpose . . . and what this will result, possibly result in." In interpretive research, participants become co-investigators as they converse and ask questions that are meaningful. These participants-*as*-co-investigators suggest myriad ways for new research partnerships that include collaborating in the design of the study as well as in its ongoing evolution and monitoring. Researchers become learners and participants become teachers.

Learning together is offered as one possibility for this new partnership as is keeping open the possibility for undiscovered learning and novel ways of thinking:

> "Well, studies that lend themselves toward genetic type conclusions . . . I don't quite feel comfortable . . . if a person is going into a study with a preconceived notion that something is genetic, that really it's not genetic, I think that it colors it in a way that doesn't really let you get the full benefit of what the findings are. Because, I think because you are African-American you [are] gonna have a higher incidence of heart disease or high incidence of stroke or whatever, just because you are African-American is a myth. That is not a good conclusion. What, what I would like for the study to do is to come up for the reason, with the reasons why. Not say that, . . . if . . . I am born African-American, but . . . if you took the condition of my heart, and compared it to any other race of person that has the same kind of care of the body, you know, exercise, attitude, environment of love and all that, I've got a feeling those hearts [would] be functioning just about the same way. So, [it is important for the JHS] to look at what's happening in the, in the Black community . . . then if we find if a conclusive statement that [environment] has less to do with it than genetics, then ok, that's the finding of this study . . . But I think that probably I would need to . . . hear, just *hear,* . . . that we go into this (JHS) looking at the disease in relationship to what . . . to lifestyle, [stress, discrimination, living situation], and that kind of talk I think would be the thing that would convince me that we're not saying: 'Born Black you're going to die earlier with heart disease,' you know, instead of saying that 'they could be.' . . . And if I'm a part of a study that can help make that happen for my people, I'd be happy to be a part of something . . . that lets [us all] look at what the truth is . . . But that's what I want my people to do is look at the reason why. That's what I want. And to be a little part of that, that is the way to go. Looking at the truth, that's where we gotta go, to the truth, not make excuses."

This participant's story warns of the importance of studying genetics exclusively: don't tell us it is our race that matters most without a broad-based study that includes the realities of our daily lives. The participant reminds us that our preconceptions of what might be involved are necessary but not sufficient and can limit understanding. She calls us to keep open a future of possibilities that transcend race or genetics or even environment In addition, this individual cautions us to assure that uncovering the practical wisdom and insights of participants continues as a part of ongoing research. Friere[66] elaborates further:

---

* Comportment, in this study, refers to a way of behaving that brings to bear the situated context and the actions of persons. In other words, comportment is more than externally observed manner or behavior. It is a kind of behavior that is shaped by the context-specific concerns, purposes, goals, and commitments and allows what matters to show up. Comportment is constituted by our interpretive understanding.

> "The truth is, however, that the oppressed are not 'marginals,' are not people living 'outside' society. They have always been 'inside'-inside the structure that made them "beings for others." The solution is not to "integrate" them into the structure of oppression, but to transform that structure so that they can become 'beings for themselves.' "

These participants call us to think together, as researchers and participants, in new ways to uncover innovative ways of thinking. Thinking is a central practice of all researchers and scholars. Thinking is also a common, day-to-day lived (embodied) experience of being human. Thinking-as-lived, or the embodiment of our life experiences, is often reflected as problem solving in which the unknown becomes known, questions are asked and answered. Participants can be included in many ways by researchers. In this study, by engaging the community in interpretive scholarship during this PRRS, the JHS has already taken the first step toward creating a new vision of relationships between researchers and participants, opening the possibility for participants and community to share the role as co-investigator. As one participant said, "So we are kind of serving as ones who are helping to develop the study . . . without [our] participation, there won't be a study!" What might these new possibilities mean for the JHS? What are the lessons of a Community-Driven Model that will lead the researchers to consider different approaches so that the community concerns of being guinea pigs, treated like rats, and the legacy of Tuskegee are addressed? How will researchers comport themselves? How will they shift and share power with each other and the participants? How will researchers and participants reach out initiating different approaches to know and connect with one another?

As the interpretive investigators listened to how involved these participants wanted to become, they were struck by the possibilities for co-participation by community representatives at *all* levels of the study. Community co-participation on the Recruitment Committee was already assured within the JHS organizational structure; but, what might occur if co-representation was extended to assure that community voices were present at the highest level of the study? These structural changes might mean, for example:

- Reconfiguring the Steering Committee to include voting community members.
- Including community members as co-authors on papers that report study findings.
- Holding open-site visits by representatives from the sponsoring institute announced to the community and scheduled in locations to accommodate community attendance.
- Co-writing the Manual of Operations for examinations and interviews as well as training manuals for recruiters and clinic staff.
- Developing an Oversight and Evaluation Committee comprised of community members that meets bi-annually to review the evaluations from the study participants and suggest ways to improve or change interactions with co-participants regarding the conduct of the study.

The Community-Driven Model encourages and develops substantive or subtle new standards for conducting research in a variety of racial and ethnic communities. Revoking the modernist image of inquiry that turns humans into objects and gives researchers power over them, this community-driven approach encourages the development of new collaborative relationships characterized by reciprocal, trusting, and non-oppressive interactions between researchers and those studied.[67] The most profound legacy of the JHS and the emerging Community Driven Model may be providing an opening to think together—researchers and participants—about these ideas and other possibilities, as well. New insights into an inclusive approach for recruiting and retaining participation in medical and other research have resulted from the emerging Community Driven Model.

## Theme: Welcoming and Staying: Creating Space and Place for the Jackson Heart Study

How physical space and welcoming practices influence participation was a common theme for the JHS. The space and place for the JHS is the Jackson Medical Mall. Newly remodeled and developed from an almost abandoned shopping mall in central Jackson, it offers a "one-stop shopping" approach to medical care including the Public Health Department, the outpatient clinics of the University of Mississippi Medical Center as well as numerous medical support facilities and health education services. The JHS location is in an economically challenged section of the city; and, the Jackson Medical Mall brings the potential to unite and revitalize this particular community. The JHS family identifies the JHS facility, located in the Jackson Medical mall, as a setting which offers them a warm welcome, and a hospitable sense of communal belonging and identity. ARIC staff introduced the interpretive team to the important concept of place and belonging: "it has to be sensible to their needs."

The ARIC staff suggested that many participants were lost to follow-up because of the rundown appearance, inhospitable location and predominance of White employees in the old study space.

> "The accommodations that they [JHS] have for people, it's gonna make all the difference in the world whether or not these people are gonna wanna come back. When they come in, they should be comfortable, and have enough people like them, or working with them, to make them feel comfortable, and more will continue to participate . . . I think we need to make a note of this and pay more attention to them . . . We need to be more sensible to their needs . . . that's

> what's gonna get more of the participants to participate."

This problem may have the appearance of being "solved" since the JHS has a new building, which is well appointed and hospitably located within the African-American community with an African-American staff. Yet, these ARIC staff urged the team to evaluate more than simply the space where clinic examinations occur. Team members called the team to look at the "heart" of the JHS as a home. Similar to the analogy of house and home, a house can be bought and sold, but a home can only be created. Home is a place where persons come to be safe and feel nurtured, a meaningful place of true community where supportive presence, rather than distrust abounds.[68] The staff's attention to consistently keeping the clinic space clean and tidy is reflective of caring and creating a sense of hospitality. How staff dress communicates to the public an image of professionalism, confidence, and welcoming and encourages persons to return to the clinic. The following excerpt from one of the participants describes the changing experience of "home" in the ARIC clinic and highlights concerns of space and caring:

> "When you first start out in a place and it's all spic and span, but down through the time, if it's not really kept up, you know, tidy, it would go down. . . . in the first beginning it seemed like it may have been in a little better kept up. More like a clinic or like in a hospital or something . . . Also some of the folks that was in there was dressed different from . . . the beginning because at first they all, everybody with uniforms on. I feel like in a clinic or anything dealing with people, the way I was taught when I was going to school . . . is you need to be dressed properly and everything to keep down germs . . . And just something about a uniform, it's different from just plain old work clothes, sweaters and jeans and stuff like that. It just sounded like at the clinic to me . . . [it] just made a difference to a lot of people . . . if you're dealing with people health wise, giving tests and doing exams on people, I feel like you need to be dressed like a nurse."

As a medical establishment, the JHS also brings with it the potential for impersonal, inhospitable treatment. Participants in the PRRS told stories exemplifying a failure to connect with staff and the erosion of trust that occurred as a result of these practices.[5] Most often these stories portrayed hurried clinician-researchers who, albeit doing their "job" well, did not take time with participants. These staff failed to visit, converse, go beyond straightforward instructions or provide reassurance to participants. One participant tells of her experience in being recruited to enroll her son, recently diagnosed with sickle cell disease, in a research study. An uncaring and poorly timed request to take part in a study eroded her trust in the information and ended in her refusal to take part:

> "There was another study going on for sickle cell and I wasn't sure if, what she, what they were trying to do in the long run would benefit me or hurt me. She really didn't explain it very well . . . And she basically said, 'Well we got this study going on and I think you should participate in it and we'll give you $25 for coming every month and here, read this, sign it and mail it back' and I, you know, I had doubts. When she said, you know, rattled off all this misinformation I had, I immediately had doubts . . . because of the way she presented it . . . I didn't think she was very caring, not that I didn't trust her but I just had some doubts about her method and what she was trying to do. . . . I didn't partake in the study. She didn't follow-up to call, she never called me to say 'Well, did you read that information? What do you think? Do you have any questions?' She never did that. Nor did I volunteer to call her and ask her any questions, because I just didn't feel a connection at all with her."

Knowing whether participation will benefit or harm relies on both good information and a caring presentation. Both of these fundamental principles are necessary for individuals to assess the risks and benefits of participation. This exemplar story reminded the team that *comportment speaks*. This moving story also reminded the team that attention to the *small acts of caring* that can provide assurances of good will despite the impossibility of absolute protection from harm or security is essential to welcoming the JHS family of researchers and participants alike. Reflecting on the subtle practices through ongoing storytelling and interpretive sessions is central in the Community-Driven Model.

ARIC participants also reminded the interpretive team of how small acts influence retention and continued participation in the research study. Participants told of times when they were greeted with "kind, gentle words," transportation was provided for them, or they received a letter from the study staff. In addition, the individuals stressed how these seemingly simple acts sustained their participation, got them "involved in the study . . . [made them] feel worthy . . . [and] let the people know that this is not a business or professional thing, this is a personal thing; that we care." Few would disagree that space and welcoming practices influence participation. This theme made staff mindful from the beginning of the importance of these often taken-for-granted practices. Sessions with recruiters and all staff to share their experiences of both connecting and breakdown keep attention focused on small acts.

What it takes to show trust through "walking the talk" is revealed in the "small acts" that are familiar. These simple times cannot be predicated or planned, but they are not insignificant.[69] An ARIC participant, who had never owned one before, saw the simple gift of an umbrella as "pretty special." What makes these times so significant for healthcare professionals and clients? The small acts described in this study appear meaningful to participants and are central to the success of the study. In their simplicity, small acts offer hope for a caring world. Dressing to please others, remembering a name, or sending a letter when one is not legally required all speak to "walking the talk" of engendering community and through small acts creating the JHS family in caring ways. Small simple acts are remembered and their meanings are inexhaustible.[70] From a community-driven perspective, staff activities can enhance the value of these small acts by planning staff activities that reflect these gestures:

- Engaging in small acts of caring and recognition in all phases of the study—respectful recognition of personhood including direct eye contact, calling by name including salutations, and never assuming the familiar.
- Involving *all* the researchers in recruiting by having at least one night a month where researchers accompany the recruitment team in making home visits to invite participation.
- Staff sharing in meals and other planned community activities to nurture connections.
- Making time and opportunity for researchers and staff for listening to community stories, such as tales of family and daily happenings.
- Sending birthday, Kwanzaa, or other holiday cards to all study participants each year as a remembrance during special times of the year.
- Scheduling recruiters to spend time in the clinic each week welcoming participants they have recruited and providing a continuing connection.
- Taking every opportunity to recognize and offer tangible incentives in appreciation for their participation that remind persons of their membership in the study.
- Providing each participant with a certificate of membership in the JHS cohort that is suitable for framing.

Some of these activities are common, familiar and successful recruitment strategies. However, in the emerging Community-Driven Model, these small acts are privileged, even when they are viewed as time consuming and resources are scarce. In the Community-Driven Model, these small acts are preserved as hallmarks of a central commitment to engendering community. As humans we live in community; the issue is *how* we live. Communities can be caring and connected as they welcome and gather people together or they may be isolated places only emphasizing individuals. Because humans are social beings by nature, community is a necessary utility. The community "as" gathering and staying lays forth a commitment to creating and recreating new communities. Consequently, the possibility for anything to emerge is preserved. Such could be the case for the JHS. From the hymn, *The Ister River,*

> "It is useful for the rock to have shafts,
> And for the earth, furrows
> It would be without welcoming, without stay."

Does attending to these subtle practices of welcoming and gathering make a difference in recruitment and retention? In this passage, the "useful" designates an essential community of rock and shaft, earth and furrow. This essential community is in turn determined by the nature of welcoming and staying practices.[71] Perhaps it will be the small acts of caring that will make the welcoming and staying practices of the JHS community of researchers and participants a new platform for biomedical research that is inclusive and overcomes disparities which like rock is solid and like earth, fertile.

The multi-method approach to interpreting the interview data collected in the PRRS contributed to an understanding of new approaches to recruitment and retention from multiple perspectives. Important community practices such as welcoming and staying, and engaging the community as co-investigators were identified in the service of creating a new model for overcoming barriers to research participation.

## A COMMUNITY-DRIVEN MODEL: OVERCOMING BARRIERS OF RESEARCH PARTICIPATION

Participant narratives consistently identified issues of trust as a significant barrier to research participation. No guarantees of participation are certain even when trust building strategies are implemented. Interviews and examinations may be seen as an imposition, even when the study is known and interviewers are of the same ethnic and social group. Participation in research studies may not have high priority for persons with many competing demands on time and problems in their lives. Caring for minor children and other relatives and the need to work at multiple jobs are just some of the competing barriers to taking part among otherwise willing individuals. Despite individuals' desires and best intentions, it is not always possible to fit participation in a research study in among the demands of life.

Work schedules were commonly cited as a reason for non-participation in ARIC: "it was just my job what really kept me from participation like I could have." For many, taking off a day for the study would set in place a disruptive domino effect in the workplace:

> "Well see the only thing . . . the reason why I want' able to just attend, continue to keep coming is the kind of job I have . . . Where I work at it-it would kind of throw things out of whack if I'm off and they would have to get somebody to work in my place in order to let me off and then there is somebody go'n have to try to get somebody to work in that person's place that is in my place. And it was just hard for me to get off, you know. The only time that I would really be able to just come would maybe round vacation time or something like that, you know. It was just my job was what really kept me from, you know, participating like I could have."

Saturday appointments alleviated some of the scheduling conflicts but PRRS participants suggested that getting special dispensation for workers to be off to come to the study would make it possible to continue participation. Gaining support from the workplace "would make it easier for me and everybody else that wanted to participate. It sure would." Even when participants were "convinced it would be worthwhile enough . . . [the JHS would] have to work around people's schedule . . . give you plenty, plenty time ahead so you can plan or ask to schedule time off . . . but if something arises and I have to reschedule because of work, then I have to do that."

Others simply have no way to get to the study site.

> ". . . transportation I think a lot of people, especially that's elderly . . . a lot of us don't seem to have adequate means to get around and do a lot of things . . . some of us are still poor. I mean not saying, using that as a crutch cause it's a lot of Black people got money. But there's also still some in poverty . . . and I think transportation would be a help. Being that we are doing this from the heart, you know."

The recruiters must use current knowledge about removing barriers, such as transportation, to make it easy for people to participate in the study. In addition, having resources to use in adapting recruitment to respond to individual needs is necessary. Doing this "from the heart" indicates *how* this recruitment strategy is implemented in the emerging Community-Driven Model. Participants tell us that persons would more likely come if this support were provided. Examples include:

- Flexible scheduling to accommodate busy schedules. While the demands of the study protocol (fasting) require early morning times, offering Saturday appointments as well as supporting persons who may have to cancel multiple times before actually completing their visit could make all the difference.
- Providing childcare and transportation.
- Negotiating with employers to provide paid leave policies for employees participating in the JHS.

Fear of receiving troublesome health information is a common concern in many cultures but in the emerging Community-Driven Model common concerns such as these are addressed with participants. Many participants tell of the culturally embedded practices of avoiding routine health care for fear of finding out something is wrong.

> "Well it is, it's some people that are afraid to go to doctors. I don't know why they don't, you know, they just, it's a lady that work down there with me. She don't miss a day from work and I asked her, I said . . . 'Don't you ever have to go for your check-up?' You know, like I have to go, you know, get my check-up and my blood pressure checked and everything . . . 'Naw I don't go, I don't go to no doctor.' I say 'Why don't you go to the doctor?' 'I'm scared they go'n find something.' I said 'Well wouldn't you feel better to know if you, you know, if you go and they do find something maybe they would, it would be better where they could treat you and get you well than to just walk around and not know.' "

And another participant describes:

> "It's a number of barriers . . . we need to look at to overcome fear [of health care] . . . cause especially in the Black community, it's your experience and attitudes about health care . . . I think really fear of the unknown . . . fear of when you go to the doctor you hear that you have something wrong with you. Fear of what's next, so it kinda gets down to that . . . you have to reach people where they are."

Frightened as many may be of discovering health problems, participants also spoke of the difficulties of accessing care for identified conditions. For many, money is a barrier; and, participants raised some of the moral and ethical issues associated with providing health care in an observational study: "It's good to know. But don't find out something and then not offer to do anything about it." The emerging Community-Driven Model is a context-specific model that reflects both the particular study and research population. For example, the voice of Tuskegee is heard again as participants describe these concerns:

> "We think about the Tuskegee (emphasis) research, you know . . . and we tend to think that was a betrayal of sorts and so we are not real anxious about participating in anything that has to do with anything that was a promise to help us get better but in fact it was not."

In contrast to not having healthcare access, another common story is that participants see no need for participation. Individuals may already have basic health care and consequently see no point in going for additional examination when they have no health concerns." Another participant reflects, ". . . that is probably one of the key points why when it comes to medical research in African Americans. They don't participate because of that idea of not really going to the doctor unless they are really sick."

Therefore, for some individuals, coming to a study is not warranted because one might find something wrong and have no options for receiving treatment. For others, participation in a study is viewed as unnecessary without having specific health needs. From either perspective, according to study participants, creating links with healthcare providers is imperative for the success of the study. What is challenged is how future participants in this particular study bring a past concern about diagnostic studies that do not accompany the provision of services. Such assurances of ready access to needed health care for JHS participants are central in the Community-Driven Model to garner support for the study in individual patient relationships. As in business relationships, cultivating a friendship with the community of health professionals such that they know about the JHS, can celebrate its contribution to the health of Jackson and let their patients know of the importance of their participation in this historic study could make a positive contribution to individual response to the study. Other possibilities include:

- Training staff to recognize and connect JHS participants with potential health care or social needs with the JHS social worker.
- Negotiating with health and social care providers to provide special access

for JHS participants ranging from providing a free medical visit to connecting with medical assistance programs to assist in meeting health needs.

- Placing display racks about the JHS and its services in healthcare provider offices.
- Providing opportunities for participants to return to the clinic to discuss the results of their examination once all blood tests and other results are returned.

Despite all these and other efforts, participants also remind us that everyone will not accept the invitation to participate—it takes personal desire:

> ". . . it's just . . . got to come from that individual. It's that individual that's just really got to be the one to want to do this and wants to learn more about their, you know, how their future, how their health is. . . . it's got to come from inside . . . you've got to have that desire. In order to do anything you've got to have that desire to do it. And if you have that desire to do it, you will do it. But it's got to come from within."

Participation cannot be forced, only invited or suggested: it is a choice. In training recruiters, the nuanced practices of inviting individuals, not interviewing them, are stressed.[65] Likewise, becoming aware of the subtle potential for coercion as recruiters and other staff helps to overcome barriers. Building partnerships to provide time off work, transportation and medical care are underscored as ways that participatory barriers can be overcome. Recruiters must take care to balance "making it easy" to participate while respecting personal preferences. Not accepting an invitation to be a study examinee should not be equated with losing favor within the partnering community.

## SUMMARY

This emerging Community-Driven Model of recruitment and retention links all levels of involvement in a seamless partnership which incorporates a sense of shared identification with a group, a shared fate as well as self and collective efficacy.[72] This multilevel model suggests that what occurs at one level is intimately linked with all other levels. The model emphasizes participation, caring, sharing, responsibility to others, and conceives of power as an expanding commodity across recruiting, clinic visits, data analysis and study presentations at professional meetings. Collective action enables this model, it is not "given." The concept of this model relies on storytelling sessions at all levels and on listening to each other in order to hear what is really being said. As Collum[73(p123)] suggests, "the time is ripe for an overarching unity of interests . . . that drops the old model of rich White relinquishment and poor Black empowerment . . . that only creates false division that are irrelevant to the real lives and problems. [Listening] to stories retold . . . project(s) the possibility of a common struggle for common interests."

Thus, a Community-Driven Model accepts that there is a balance between achieving the goals of the research effort and achieving the goals of the community in solving real life problems. For the JHS, this means a model of recruitment and retention that is embedded within new research partnerships calling out the best in us, seeking to answer important research questions while finding new ways to live together that are co-equal. Such partnerships are built on engendering mutual trust and respect, nuanced sensitivity to cultural practices and an openness to creating new affiliations (identities) that attend to bonds formed by inclusion and community building. All the while, rigor in scientific research is maintained as a shared value. Listening to participants' narratives, the "how tos," or practical strategies, of gathering, inviting, welcoming, and staying gives way to an emerging Community-Driven Model for recruiting and retaining participants.

## DISCUSSION

This discussion of the PRRS from the interpretive phase of a multi-methods research design presents knowledge of factors inhibiting and facilitating African-American research participation. Interpretive interviews yielded insights into the development of a process-oriented Community-Driven Model of recruitment and retention. Multiple practical strategies for recruiting and retaining the cohort emerged from the PRRS that informed selection and training of recruiters, methods of entering the field for recruitment and data collection, as well as culture and site-specific strategies for RRA. As a process model, the Community-Driven Model continues to emerge as it is enacted in the JHS. Defining the attributes (themes) and evaluating the success of this model is ongoing. The impact of this model on RRA awaits the culmination of enrollment and the baseline clinic examination, and ultimately the continuation of JHS participation into annual follow-up and future clinic examinations.

To summarize, this emerging Community-Driven Model of recruitment and retention for African Americans in a major biomedical study:

- Guides the selection and training of recruiters, community contacts and clinic staff by:
    1. involving persons from the community in the interviewer selection and training process to assure that the nuances of culturally appropriate communication and discernment practices are woven throughout the training process for all staff.
    2. holding regular collaborative storytelling and feedback sessions among recruiters to share interviewing experiences and strategies that work, which expand their individual skills.
    3. recruiting clinic staff from the

Jackson African-American community that uses storytelling as an approach in which participants feel more at ease in asking questions and expressing concerns about the study.
4. training clinic staff with community input to focus on issues of sensitivity in the consent process and openness to discern the best method of presentation for each participant which could increase participation levels.
5. hiring of recruiters to assure a "good mix" not only of diverse ethnic groups but of age and gender consistent with an emphasis on family and engendering community.
6. hiring persons who are dedicated to the project and its importance—"people persons" who are friendly, sincere, and personable.

• Identifies specific strategies of recruiting that enact African-American family values by:

1. using storytelling as a communication strategy and giving voice to the study through story. For example, instead of presenting illustrations or descriptors of a study of hypertension and heart disease, the convincing conversation might be a story about hypertension or heart disease that shows the "bottom line" of health benefits. A recruiter might turn the experiences from interpretive interviews into scripts or "story lines" for use in future recruiting.
2. developing multi-level friendship networks or "extended family units" in neighborhoods, at the work site, in churches and other community settings as well as among researchers and staff to mutually support each other in the study.
3. focusing recruiting in targeted segments of the sampling area for a designated period of time to allow teams of volunteers—students, church members, neighborhood groups and researchers—who are providing a community service to saturate the area with information. Recruiters would follow up within a set time frame to actively recruit the identified sample in that area.
4. sending birthday, Kwanzaa, or other holiday cards to all study participants each year as a remembrance during special times of the year.

• Includes strategies that build and sustain a "home" for the JHS family by:

1. recognizing that a building that reflects the caring of the JHS is a clean, welcoming space that repeatedly is attended to and kept that way over time.
2. initiating an organization that lives up to its promises of respecting the time of participants, researchers, and staff.
3. scheduling recruiters to spend time in the clinic each week welcoming participants they have recruited and providing a continuing connection and clinic staff helping recruiters.
4. providing flexible scheduling to accommodate busy schedules.

• Involves the community in ongoing oversight and monitoring of recruitment and retention activities by:

1. developing a core of ARIC volunteers to serve as the JHS Council of Elders. In addition to advising the recruitment team, they might provide information and emotional support for participants at each phase of the study.
2. placing a "suggestion box" in a prominent location in the clinic so that participants can comment on their visit and staff interactions.
3. following up on study contacts with study satisfaction questionnaires, the content of which is hermeneutically co-designed with the community.
4. providing a study "hot line" where any compliments, complaints, or suggestions can be addressed and advertise it widely to all participants and staff alike.

• Inspires interest in creating alliances and building new paths to participation by:

1. disseminating the community-driven motto that was generated from this study for the JHS, *A Legacy of Health,* throughout the community in written and verbal communication.
2. recognizing businesses as participating "Friends of the Jackson Heart Study." Much as local businesses create partnerships with local schools to support education, the JHS and businesses could work together as partners in creating a legacy of health for the Jackson community.

• Informs culturally appropriate protocols and consent by:

1. including culturally appropriate language that must come from continuing conversations between JHS investigators, the Council of Elders, and the community to improve recruitment, retention, data quality, and completeness.

2. using a video tape or a photo novella consent developed with the community toward improving understanding of the JHS by study participants and leading to higher levels of comfort with participation.
3. including language developed by the Council of Elders, community members, and JHS investigators in consent material that could help improve understanding of the consent process.

- Guides the initiation of strategies to overcome barriers to participation by:
  1. training staff to recognize and connect JHS participants with potential health care or social needs with the JHS social worker. This would ensure that persons in need could be linked with available resources.

Additionally, this emerging Community-Driven Model:

- Recognizes that recruitment and retention, while ostensibly about going out and getting people to come for clinic examinations and continuing with annual follow ups, is really about the processes of gathering and co-creating a family, building reciprocal partnerships which can make a difference in study outcomes.
- Appreciates that the success of the study turns on building trusting relationships "one pebble at a time" with the community and among the researchers. For this to occur, a significant investment in time and resources will be required for the co-investigative team of participants, community, and researchers.
- Recognizes that the issues of diversity that divide the Jackson, Mississippi, population, Black and White, participant and researcher, patient and healthcare provider, are brought together in this study and must be addressed in new ways for the JHS to succeed. Additionally, that creating new partnerships is at the heart of new research comportment that is fair and respectful of individual's similarities and differences while celebrating diversity. As Ghandi cogently reminds us: "We must be the change we want to see in the world."

## IMPLICATIONS

This study respectfully challenges a singular commitment of biomedical research to knowledge generation and explores the undiscovered, untested, and unintended consequences of traditional scientific research. For example, research practices of recruitment may be taken for granted, albeit effective and efficient in mainstream European-American populations. However, these research practices have resulted in low participation for African Americans. This study offers a beginning for creating culture- and site-specific models that address low participation. This emerging Community-Driven Model of recruitment and retention is one such possibility for generating practical knowledge from shared experiences that creates approaches based on new partnerships among researchers, staff and community participants. According to James Baldwin,[74]

> "Everything now, we must assume, is in our hands; we have no right to assume otherwise. If we—and now I mean the relatively conscious Whites and the relatively conscious Blacks, who must, like lovers, insist on, or create, the consciousness of the other—do not falter in our duty now, we may be able, handful that we are, to end the racial nightmare, and achieve our country, and change the history of the world. If we do not now dare everything, the fulfillment of that prophecy, recreated from the Bible in song by a slave, is upon us: God gave Noah the rainbow sign, no more water, the fire next time!"

*This emerging Community-Driven Model of recruitment and retention is one such possibility for generating practical knowledge from shared experiences that creates approaches based on new partnerships among researchers, staff and community participants.*

In the process of identifying informal leaders in the community who will join with researchers as co-investigators to recruit and sustain the involvement of 6,500 JHS participants, these co-investigators, "handful that we are," are challenged to promote the development of grass roots leaders who will be able to cultivate and nourish a genuine harmony among races and cultures. Brought together by their commonness, rather than their differences, these co-investigators can use collective intelligence, imagination, humor, and courage to learn and to teach others a new language of collaboration and cooperation for the good of the community, the nation, and the world. Guided in storytelling and ever increasing cycles of understanding by the participants, researchers and participants can join hands, together moving from cultural awareness, the recognition of cultural differences and relativism, to a post-ethnic community where each culture or subculture is viewed from its own perspective and its practices valued. Such can be the legacy of the Jackson Heart Study.

### ACKNOWLEDGMENTS

We gratefully thank the men and women of the ARIC study and the Jackson MSA community who so graciously shared their experiences and co-participated in this study. We also thank Ramona Strong, RN, MSN and Diane Jones, MA for their assistance in the collection of the data, and Bertha Frazier, BA for data transcription. Further, we thank the JHS Council of Elders for their ongoing co-participation in enacting the Community Driven Model in the JHS. This work was supported by the National Heart Lung and Blood Institute and the National Center for Minority Health and Health Disparities, National Institutes of Health, Bethesda, Maryland, under contract NO1-HC-55021.

## REFERENCES

1. El-Sadr W, Capps L. The challenge of minority recruitment in clinical trials for AIDS. *JAMA.* 1992;267(7):954–957.
2. Kelly PJ, Cordell JR. Recruitment of women into research studies: a nursing perspective. *Clin Nurse Specialist.* 1996;10(1):25–28.
3. McCabe MS, Varricchio CG, Padberg RM. Efforts to recruit the economically disadvantaged to national clinical trials. *Semin Oncol Nurs.* 1994;10:123–129.
4. Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health.* 1997;2(½):31–45.
5. Shavers V, Lynch C, Burmeister L. Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol.* 2002;12(4):248–256.
6. Swanson GM, Ward AJ. Recruiting minorities into clinical trials: toward a participant-friendly system. *J Natl Cancer Inst.* 1995; 87(23):1747–1759.
7. Tell GS, Fried LP, Hermanson B, Manolio TA, Newman AB, Borhani NO. Recruitment of adults 65 years and older as participants in the cardiovascular health study. *Ann Epidemiol.* 1993;3(4):358–366.
8. Freimuth V, Quinn S, Thomas S, Cole G, Zook E, Duncan T. African Americans' views on research and the Tuskegee Syphilis Study. *Soc Sci Med.* 2001;52:797–808.
9. Gamble VA. A legacy of distrust: African Americans and medical research. *Am J Prev Med.* 1993;9:35–38.
10. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health.* 1997;87(11):1773–1778.
11. Harris Y, Gorelick P, Samuels P, Bempong I. Why African Americans may not be participating in clinical trials. *J Natl Med Assoc.* 1996:630–634.
12. Kass N, Sugarman J, Faden R, Schoch-Spana M. Trust: the fragile foundation of contemporary biomedical research. *Hastings Cent Rep.* 1996;26:25–29.
13. Blumenthal DS, Sung J, Coates R, Williams J, Liff J. Mounting research addressing issues of race/ethnicity in health care. *Health Serv Res.* 1995;30(1, part 1):197–205.
14. Morse EV, Simon PM, Besch CL, Walker J. Issues of recruitment, retention, and compliance with community-based trials with traditionally underserved populations. *Appl Nurs Res.* 1995;8(1):8–14.
15. Arean P, Thompson D. Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *J Consult Clin Psychol.* 1996;64(5): 875–880.
16. Gauthier M, Clarke W. Gaining and sustaining minority participation in longitudinal research projects. *Alzheimer Dis Assoc Disord.* 1999;13:S29–S33.
17. Green B, Maisiak R, Wang M, Britt M, Ebeling N. Participation in health education, health promotion, and health research by African Americans: effects of the Tuskegee syphilis experiment. *J Health Educ.* 1997;28(4): 196–201.
18. Grunbaum JA, LaBarthe DR, Ayars C, Harrist R, Nichaman MZ. Recruitment and enrollment for Project Heartbeat! Achieving the goals of minority inclusion. *Ethn Dis.* 1996; 6:203–212.
19. Hill MN, Bone LR, Hilton SC, Roary MC, Kelen GD, Levine DM. A clinical trial to improve high blood pressure care in young urban Black men recruitment, follow-up, and outcomes. *Am J Hypertens.* 1999;12(6):548–554.
20. Lillie-Blanton M, Hoffman SC. Conducting an assessment of health needs and resources in a racial/ethnic minority community. *Health Serv Res.* 1995;30(1):226–237.
21. Markens S, Fox S, Taub B, Gilbert M. Role of Black churches in health promotion programs: lessons from the Los Angeles mammography promotion in churches program. *Am J Public Health.* 2002;92(5):805–810.
22. McDougal G, Holston E, Wilke P. Recruiting African Americans into research on cognitive aging. *Ethn Dis.* 2001;11(Winter):124–133.
23. Royal C, Baffoe-Bonnie A, Kittles R, et al. Recruitment experience in the first phase of the African-American hereditary prostate cancer (AAHPC) study. *Ann Epidemiol.* 2000; 10(suppl 8):S68–S76.
24. Stoy DB, Curtis C, Dameworth KS, et al. The successful recruitment of elderly Black subjects in a clinical trial: the CRISP experience. *J Natl Med Assoc.* 1995;87(4):280–287.
25. Whelton PK, Kusek JW, DeBrugge J, et al. Recruitment experience in the African-American Study of Kidney Disease and Hypertension (AASK) pilot study. *Control Clin Trials.* 1996;16:17S–33S.
26. Yancey A, Miles O, McCarthy W, et al. Differential response to targeted recruitment strategies to fitness promotion research by African-American women of varying body mass index. *Ethn Dis.* 2001;11(Winter):115–123.
27. Borhani NO, Tonascia J, Schlundt DG, Prineas RJ, Jefferys JL. Recruitment in the hypertension prevention trial. *Control Clin Trials.* 1989;10:30S–39S.
28. Sempos CT, Bild DE, Manolio TA. Overview of the Jackson Heart Study: a study of cardiovascular diseases in African-American men and women. *Am J Med Sci.* 1999;317(3): 142–146.
29. Taylor H, Garrison R, Jones D, et al. The Jackson Heart Study—an epidemiological study of cardiovascular disease in African Americans: rationale, objectives, and methodology. In press.
30. The ARIC Investigators. The Atherosclerosis Risk in Communities (ARIC) study: design and objectives. *Am J Epidemiol.* 1989;129(4): 687–702.
31. Penman AD. Cardiovascular mortality in Mississippi: the widening gap between Whites and African Americans. *Mississippi Morb Rep.* 1997;15(12):1–2.
32. Denzin NK. *Interpretive Ethnography: Ethnographic Practices for the 21st Century.* Thousand Oaks, Calif: Sage Publications; 1998.
33. Lincoln Y. Emerging criteria for quality in qualitative and interpretive inquiry. *Qualitative Inquiry.* 1995;1:275–289.
34. Diekelmann N, Diekelmann J. *Schooling, Learning, Teaching: Toward a Narrative Pedagogy.* In press.
35. Kavanagh K, Absalom A, Beil W, Schliessmann L. Societal dimensions of health—connecting and becoming culturally competent: a Lakota example. *Adv Nurs Sci.* 1999;21(3): 9–31.
36. Christians CG, Ferre JP, Fackler PM. *Good News: Social Ethics and the Press.* New York, NY: Oxford University Press; 1993.
37. Wyatt SB, AlFadhli H, Andrew M, Billingsley G, Calvin R, Guiterrez-Mohammed ML. A conceptual framework for recruiting and retaining African-American participation in clinical research, the Jackson Heart Study: the POPCI model. In press.
38. Lincoln YS. Sympathetic connections between qualitative methods and health research. *Qualitative Health Res.* 1992;2(4): 375–391.
39. Wyatt S, Guitterez-Mohamed M, AlFadhli H, et al. Participant, organizational, protocol, and community involvement influences on research participation in African Americans: results of the Jackson Heart Study Participant Recruitment Study. Unpublished manuscript. 1999.
40. Patton MQ. *Qualitative Evaluation and Research Methods.* 2nd ed. Newbury Park, Calif: Sage; 1990.
41. Morse J. Designing funded qualitative research. In: Denzin N, Lincoln Y, eds. *Handbook of Qualitative Research.* Thousand Oaks, Calif: Sage; 1994:220–235.
42. Sandelowski M. Sample size in qualitative research. *Res Nurs Health.* 1995;18:179–183.
43. Baldwin D. A model for describing low-income African-American women's participation in breast and cervical cancer early detection screening. *Adv Nurs Sci.* 1996;19(2):27–42.
44. Byrne M. Uncovering racial bias in nursing

fundamentals textbooks. *Nurs Health Care Perspect.* November/December 2001;22(6): 299–303.
45. Jordan J. Rethinking race and attrition in nursing programs: a hermeneutic inquiry. *J Prof Nurs.* 1996;12(6):382–390.
46. Diekelmann N. Narrative pedagogy: Heideggerian hermeneutical analysis of the lived experiences of students, teachers, and clinicians. *Adv Nurs Sci.* 2001;23(3):53–71.
47. Diekelmann N, Ironside PM. Hermeneutics. In: Fitzpatrick J, ed. *Encyclopedia of Nursing Research.* New York, NY: Springer Publications; 1998:243–245.
48. Diekelmann NL, Ironside PM. Exploring the concernful practices of teaching and learning: preserving writing in doctoral education. *J Adv Nurs.* In press.
49. Benner P. A Heideggerian phenomenological perspective on the concept of a person. In: Benner P, ed. *Interpretive Phenomenology.* Thousand Oaks, Calif: Sage; 1994:43–63.
50. Diekelmann N, Ironside PM. Preserving writing in doctoral education: exploring the concernful practices of schooling, learning, teaching. *J Adv Nurs.* 1998;28(6):1347–1355.
51. Gadamer H. *Truth and Method.* New York, NY: Continuum; 1960/1989.
52. Grondin J. *Sources of Hermeneutics.* Albany, NY: State University of New York Press; 1995.
53. Palmer R. *Hermeneutics: Interpretation in Schleiermacher, Dilthey, Heidegger and Gadamer.* Evanston, Ill: Northwestern University Press; 1969.
54. Benner P, ed. *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness.* Thousand Oaks, Calif: Sage; 1994.
55. Wyatt S, AlFadhli H, Andrew M, et al. *Community-Driven Model of Recruitment: The Jackson Heart Study. A Final Report of the Jackson Heart Study Participant Recruitment and Retention Study.* Washington, DC: National Heart Lung and Blood Institute; 1999.
56. DHHS. *Report of the Secretary's Task Force on Black and Minority Health, IV, Part 1.* Washington, DC: US Department of Human Services; 1986.
57. Tyler FB, Pargament KI, Gatz MA. The resource collaborator role: a model for interaction between change agents and community members. *Am Psychol.* 1983;38:388–398.
58. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19: 173–202.
59. Mittelmark MB, Hunt MK, Heath GW, Schmid TL. Realistic outcomes: lessons from community-based research and demonstration programs for the prevention of cardiovascular diseases. *J Public Health Policy.* 1993; 14(4):437–462.
60. Hatch J, Moss N, Saran A, Presley-Cantrell L, Mallory C. Community research: partnership in Black communities. *Am J Prev Med.* 1993;9(suppl):27–31.
61. Lindsey E, McGuinness L. Significant elements of community involvement in participatory action research: evidence from a community project. *J Adv Nurs.* 1998;28(5): 1106–1114.
62. King TS, Ferguson SA. I am because we are: clinical interpretations of communal experience among African-American women. *Women Ther.* 1996;18:33–45.
63. Eng E, Parker E. Measuring community competence in the Mississippi delta: the interface between program evaluation and empowerment. *Health Educ Q.* 1994;21(2):199–220.
64. Elden M, Levine M. Cogenerative learning. In: Whyte WF, ed. *Participatory Action Research.* Newbury Park, Calif: Sage; 1991:127–142.
65. Wyatt S, Diekelmann N, Henderson F, Andrew M, Rashid S. Inviting not interviewing: the gathering practices of recruiters enacting a community-driven model of recruitment in the Jackson Heart Study. In press.
66. Friere P. *Letter to Christina: Reflections on my Life and Work.* New York, NY: Rutledge; 1996.
67. Ryan KE. Evaluation ethics and issues of social justice: contributions from female moral thinking. In: Denzin NK, ed. *Studies in Symbolic Interactionism: A Research Manual.* Vol 19. Greenwich, CT: JAI; 1995:143–151.
68. Some MP. *Ritual: Power, Healing and Community.* New York, NY: Penguin; 1993.
69. Heidegger M. *Being and Time.* New York, NY: Harper and Row; 1927/1962.
70. Heidegger M. *Poetry, Language, and Thought.* New York, NY: Harper and Row; 1971.
71. Heidegger M. *What is Called Thinking?* New York, NY: Harper and Row; 1968.
72. Israel BA, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Educ Q.* 1994;21(2):149–170.
73. Collum DD. *Black and White Together: The Search for Common Ground.* Maryknoll, NY: Orbis Books; 1996.
74. Baldwin J. *The Fire Next Time.* Modern Library ed. New York, NY: Modern Library; 1963/1955.

## AUTHOR CONTRIBUTIONS

*Design and concept of study:* Wyatt, Diekelmann, Henderson, Billingsley, Andrew
*Acquisition of data:* Wyatt, Diekelmann, Fuqua
*Data analysis and interpretation:* Wyatt, Diekelmann, Henderson, Fuqua, Felder, Jackson, Billingsley, Andrew
*Manuscript draft:* Wyatt, Diekelmann, Henderson, Felder, Andrew
*Statistical expertise:* Andrew
*Acquisition of funding:* Wyatt, Diekelmann, Andrew
*Administrative, technical, or material assistance:* Wyatt, Diekelmann, Henderson, Fuqua, Felder, Jackson, Billingsley, Andrew
*Supervision:* Wyatt, Fuqua