

## THE JACKSON HEART STUDY: AN OVERVIEW

Herman A. Taylor, Jr, MD, MPH

*The future health of the nation will be determined to a large extent by how effectively we work with communities to reduce and eliminate health disparities between non-minority and minority populations experiencing disproportionate burdens of disease, disability, and premature death.*

~ Guiding Principle for Improving Minority Health, Centers for Disease Control and Prevention

This issue of *Ethnicity and Disease* focuses on a major effort of scientists, a community at risk, and the National Institutes of Health to change the current course of the cardiovascular disease (CVD) epidemic, particularly as it affects African Americans. That effort is the Jackson Heart Study (JHS).

The JHS is an ambitious and unique undertaking. In it, compelling scientific objectives are coupled with creative initiatives to build capacity for research in minority health at key institutions in Mississippi (the state with the nation's worst CVD statistics). Furthermore, programs to train minority students (as young as 14 years old) in the sciences of public health have been conceived and launched as a part of the study. Perhaps most novel is the unique and evolving relationship with the community from which the JHS participants are drawn—the Jackson metropolitan statistical area (MSA) African-American adults. In the JHS, community/lay input into a scientific enterprise has been elevated to a uniquely high priority.

The scientific questions and the population on which the JHS focuses make it a study for our time. The capacity building, minority training, and community engagement aspects of the JHS are features that set it apart and

make it more than a study. It is possibly an evolving model for community-centered research into public health problems, a platform suitable for use in other communities, other populations, and other geographies. It is one answer to the call to action—by the Centers for Disease Control and Prevention, the National Institutes of Health, and the American people—to address disparities in cardiovascular health among American populations.

### METHODS IN THE JACKSON HEART STUDY

Given its complexity and the novelty of some of its approaches, a detailed accounting of the methods of the JHS is presented herein. The issue begins with an overview<sup>1</sup> that serves as an executive summary of the methods employed in the study and the setting in which the study takes place. The academic setting is a three-way collaboration of diverse institutions with proud and separate histories of scholarship and service: Jackson State University, a large, public institution with the second highest number of PhDs awarded annually among historically Black colleges and universities nationally (home of the JHS Coordinating Center); Tougaloo College, a private undergraduate institution, historically Black and renowned for producing a surprisingly large share of leaders in the scientific, medical, and civic arenas (home of the Undergraduate Training Center); and the University of Mississippi Medical Center, the state's only medical university, scholarly home of the late master physiologist Arthur Guyton and the Cardiorenal

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From the Coordinating Center at Jackson State University; the Undergraduate Training Center at Tougaloo College; and the Examination Center at the School of Medicine, University of Mississippi Medical Center (HAT); Jackson, Mississippi.

Address correspondence and reprint requests to Herman A. Taylor, MD, MPH; University of Mississippi Medical Center; 2500 North State Street; Jackson, MS 39216-4505; 601-368-4644; 601-368-4651 (fax); htaylor@medicine.umsmed.edu

Center of Excellence he founded, as well as the local site for the landmark Atherosclerosis Risk in Communities (ARIC) study (home of the Examination Center). Like the institutions forming the research partnership that is the JHS, the Jackson MSA is itself a study in internal contrasts: it is large (>2,300 square miles), urban and rural, rich and poor (and in between), aware of its troublesome social history while justifiably proud of its current and future opportunity. The capital of the state with the worst CVD statistics in the nation and the largest percentage of African Americans, Jackson is a compelling backdrop for a modern, community-based assessment of the determinants of the CVD epidemic. The overall methods paper also describes the specific components of the home interview and the clinic examination. (A prior publication<sup>2</sup> gives additional detail on results' and specimen handling by the multiple reading centers subcontracted to the study.) The final size and general description of the cohort are detailed in this paper as well. The overall methods paper is intended to cover the broad sweep of topics, while subsequent papers offer detailed and practical descriptions, and in some instances theoretical models, useful to specialists in the respective disciplines that collaborate to make a study like JHS work.

### Recruitment Methods

Recruitment is challenging for most modern research studies. Recruitment among a southern, African-American community, given the traditionally strained relationship between African Americans and academic medical centers and the suspicion of research and researchers, was daunting. The huge area for recruitment in metropolitan Jackson, an area 20% larger than Delaware, compounded the difficulty. Fuqua and colleagues<sup>3</sup> describe the evolution of a multitude of approaches, but a singular underlying theme guided most of the team's actions: the solution to problems within the community can

be found through the wisdom of community residents. This paper describes the insights provided by Jackson residents before the start of recruitment, their participation in the selection of recruiters, the use of their insights as a curriculum for the recruiters, and the outcomes of the iterative process of developing best practices in recruiting for this population. A prior publication<sup>4</sup> gives additional relevant detail. A future paper will detail the concerted effort to make the JHS a study of the community, with the community, and for the community stressing the concept of the community monitoring board—a pioneering effort at transparency, accountability, and responsiveness to the community by investigators conducting a population-based study.

### Genetics and the Jackson Heart Study

Determining the role of genetics in health and disease among African Americans is important, especially given the lack of mechanistic explanations for the large disparities in health between African Americans and others in this country. A focus on the genome as key factor in disease does not diminish the influence of environment. Rather, a greater understanding of the relative roles of gene and environment can only be gained by careful analysis of both. Genetic influences need to be identified and not remain the default explanation when residual confounders, often, in fact, environmental, cannot be elucidated. Wilson et al describe methods underlying the genetic studies in the JHS. Of special note are the methods for formulating the Family Study—a nested study of related individuals with important potential to identify genetic and familial influences on cardiovascular health detailed by Wilson and colleagues.<sup>5</sup> The sensitivities within the African-American community surrounding genetic studies are also discussed, along with JHS approaches to address those concerns.

### Sociocultural Methods

Another traditional source of residual confounding in epidemiologic studies is inadequate characterization of the psychosocial and sociocultural influences that may impinge on health. Social and psychological environment are widely believed to be the key determinant in ethnic disparities. The JHS is designed to add considerably to the documentation and understanding of the effects of culture, racism, and discrimination. Payne et al<sup>6</sup> describe the comprehensive battery of surveys, administered in the home or in the clinic, and the theoretical framework that guided the selection of instruments.

### Diet and Physical Activity Methods

Diet was assessed comprehensively for the cohort as a whole. However, an intensive substudy that combined JHS baseline assessments with repetitive (on multiple occasions in differing seasons) 24-hour dietary recalls, 24-hour urine testing, and biomarker measurement, make the JHS unique among African-American health research projects. The paper by Carithers et al<sup>7</sup> provides extensive detail regarding this contribution. Validation/calibration studies may add new tools for assessment of nutrient intake among African Americans that allow for culturally determined differences in food preferences, portions, selection, and preparation. Physical activity was likewise carefully assessed as described by Dubbert et al.<sup>8</sup> Along with questionnaires, pedometer and accelerometers were worn by participants, allowing for multiple, cross-validating means of assessing levels of exercise in the cohort members.

### Events Ascertainment Methods

Critical to longitudinal outcomes assessment, the methods for events ascertainment described by Keku et al<sup>9</sup> form the basis of surveillance activities. These methods borrow heavi-

ly from the ARIC study, the JHS predecessor in Jackson. This similarity is intentional because of the success of the ARIC methods and because of the continuity and comparability it allows. This consistency of methods effectively makes the JHS a longitudinal study at its baseline exam, since many participants in JHS were also ARIC participants. Therefore, approximately one third of JHS participants have up to 18 years of systematically ascertained event data available through ARIC.

### The Undergraduate Training Center

The Undergraduate Training Center (UTC) is a novel component of the study that focuses on preparing young adults and teenagers for rigorous higher-level learning, and ultimate participation in the effort to improve the health status of populations, through research and practice. Applications to the college and high school programs far exceed available, funded spaces. Srinivasan et al's<sup>10</sup> contribution to this issue details the approach to building a future cadre of leaders in science, medicine, and related fields. Another consequence of these highly competitive and coveted positions is the fund of goodwill produced by the study's investment in African-American youth. The Tougaloo programs resonate with many in the Black community because of the high premium the African-American community traditionally places on education.

### SUMMARY

The JHS, therefore, is a response to American health disparities that employs community-driven research strategies that promise impact in the near and the long term. It includes scientific investigations in the tradition of Framingham and other large-scale epidemiologic studies that may confirm or revise our understanding of key factors in the current epidemic. The future health of the nation compels us to produce future cohorts of scientists that are prepared to sustain any gains made and to press on toward the long-term goal of eliminating CVD from all segments of American society. The dearth of scientists from the population most afflicted by CVD means that we must make inclusion of such scientists in the scientific workforce a priority. Through programs described in this issue, the JHS is taking steps toward these goals. Ultimately, the science and the scientists that emerge from the JHS will produce health benefits that transcend geography, ethnicity, and the current era of population research.

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