

## Cardiovascular Disease in African Americans: Innovative Community Engagement for Research Recruitment and Impact

Herman A. Taylor, Frances Henderson, Ahmed Abbasi, and Gari Clifford



Historical events and the illumination of unequal treatment of cardiovascular and other diseases among African Americans and their white counterparts have suppressed African Americans' participation in research. Approaches that bring scientific professionals into actual partnership with affected communities show promise for overcoming this reluctance. Two examples are the Jackson Heart Study (JHS) and the emerging Moyo Health Network (MOYO). JHS uses layers of community engagement, including a pioneering effort to develop future health scientists and practitioners, the JHS Undergraduate Training and Education Center (UTEC). JHS-UTEC focuses on preparing young adults and teenagers (mostly African Americans) for rigorous higher-level learning and careers in health research and practice. MOYO is a mobile platform for health research to examine factors contributing to the development of disparities in the young while creating channels to disseminate interventions. Community trust in MOYO is substantially enhanced through its education and training program, which offers engaging ideation events along with app development and coding training opportunities to young people. Participants impart their cultural insights while using newly acquired technology skills to help with the community-focused design and launch of the network. The JHS and MOYO provide models for addressing cardiovascular health disparities by fostering community partnerships.

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### Introduction

Stemming the tide of cardiovascular disease (CVD) among African Americans requires attention to multiple aspects of the CVD epidemic.<sup>1</sup> In addition to directing attention to prevalence rates of traditional CVD risk factors, understanding the individual and combined potency of those factors is critical. Persistent differences in access to care, from primary prevention to tertiary intervention, continue to frustrate attempts to improve health status of the subpopulation. A web of social determinants—how and where people live, work, and play (and pray)—is increasingly recognized as central to the trajectory of the CVD epidemic,<sup>2,3</sup> a trajectory that has for so long vectored only sluggishly (if at all) toward better health for African Americans relative to their white counterparts.<sup>4</sup>

Widespread knowledge among African Americans of historical research abuses, compounded by the illumination of current inequities in medical care between African Americans and their white counterparts,<sup>5,6</sup> have negatively affected African Americans' willingness to participate in biomedical research.<sup>7</sup> Our American health enterprise appears simultaneously anxious to enroll minority participants in research, but anemic in terms of advocating for and facilitating health care for marginalized groups.<sup>8</sup> This perception impedes the development of trust, a basic requirement for recruitment of participants into potentially life-saving studies.

Overcoming these and other barriers to health research in African Americans is a complex undertaking that has generated a large literature. Among the most promising approaches described are those that aim to bring scientific professionals into partnership with affected communities.

After briefly reviewing the current challenges faced by the African American population for CVD, we discuss examples of community engagement that are meeting with some success. We conclude by distilling 7 principles that should be considered by researchers to more effectively partner with priority communities.

### Clear and Present Concerns

Though still the leading cause of death, CVD mortality has declined significantly during the last several decades, a result of improved understanding and control of risk factors (such as smoking and high blood pressure), break-through pharmaceuticals (such as  $\beta$ -blockers and statins), surgical and quasi-surgical interventions (such as revascularization therapies), and systems of care (such as coronary care units and protocol-driven acute care).<sup>9</sup> However, the advances have not resulted in equal results for all Americans. African Americans have had substantially higher CVD mortality throughout this Golden Age of cardiology<sup>10</sup> and substantially fewer large-scale research initiatives.

This era of seminal studies on CVD was therefore also largely an era of missed opportunity for comprehensively assessing the determinants of high risk among African Americans, a group that was for most of US history the largest minority population in the United States. This was a problem of both research professionals' routine practice of recruiting homogeneous samples and reluctance among African Americans to participate in "experiments." This fear was fed by fact. The "US Public Health Study of Untreated Syphilis in the Negro Male (1932-1972)"<sup>11</sup> popularly, and unfortunately, known as "The Tuskegee Study," is infamous. The Henrietta Lacks story,<sup>12</sup> the subject of a best-selling book and

a television movie, relates to how the important HeLa cell line derived from the cervix of a dying African American woman enriched (monetarily) thousands and helped improve the lives of millions, all while doing little for Ms Lacks or her family, is regarded by many as similarly egregious. The lack of trust fostered by these big national stories is sustained by smaller anecdotes close to home, relating disrespect, mistreatment, or worse at the hands of hospitals, medical centers, and providers.

Taken together, the history and current social context make the challenge of recruitment among African Americans significant and understandable. They also underscore the imperative that the research community needs to create fresh creative approaches in research, approaches that at once recognize the wisdom of the community, demystify the research process, and produce advocates rather than opponents for research in minority communities.<sup>13</sup>

### The Jackson Heart Study's Community-Driven Model of Community Partnership and Capacity Building

The Jackson Heart Study (JHS) is a population-based observational longitudinal study of CVD risk factors among 5,306 African American men and women aged 35 to 84 years living in 3 contiguous counties in the Jackson, MS, metropolitan statistical area. The primary objective of the JHS is to investigate genetic and environmental risk factors associated with the disproportionate burden of CVD in African Americans. The JHS was funded in 1999 by the National Institutes of Health (NIH), National Heart, Lung and Blood Institute (NHLBI), and the National Center on Minority Health and Health Disparities, now the National Institute on Minority Health and Health Disparities (NIMHD). The JHS addresses community participation through recruitment, retention, and community outreach while simultaneously addressing capacity building through the Community Outreach, Undergraduate, and Graduate Training and Education Centers. Each of these provides unique contributions to models for fostering community partnerships.<sup>14</sup>

One of the challenges facing the initiators of the JHS was how to engage the African American community in a large-scale study given the context described. An interdisciplinary team of researchers found in their review of the literature that an approach to research that values the connections that form between researchers and participants and promotes the practice of viewing participants as associates in planning, conducting, and disseminating research held the greatest potential for success. According to Wyatt et al,<sup>15</sup> the research should serve the community and include the community in which it is carried out and be evaluated by its authenticity, fairness, and ability to transform and change the public and private spheres of everyday life, transformations that will help improve conditions of marginalization.

In 1997 to 1998 (pre-JHS launch), Jackson investigators conducted a Participant Recruitment and Retention Study to gather impressions about research from the Jackson

community. Four domains of facilitators and barriers were identified: participant, organizational, protocol, and community involvement factors. Data upon which to build a recruitment and retention protocol were collected using a structured questionnaire and individual and focus group interviews (see references for details). One perpetually useful outcome of the Participant Recruitment and Retention Study<sup>16</sup> was 90 specific recommendations from the community on facilitators and barriers to recruitment and retention of African Americans in the JHS. We used the recommendations to guide the recruitment, selection, and training of recruiters and clinic staff and the subsequently successful recruitment process. The essence of some of the key recommendations is reflected in the Seven Habits of Highly Successful Research in Special Populations (Box 1). Principles of trust, respect, appreciation, listening, and sharing study results in lay language are a few examples.

### Partnering to Lay Groundwork for a Healthier Future

Although establishment of the longitudinal “Framingham-style” epidemiologic study was one impetus for the JHS, the study’s broader vision was to create “A Legacy of Health.” Perhaps the most innovative and compelling expression of the JHS’ commitment to enduring transgenerational change is the creation of the Undergraduate Training and Education Center (UTEC) at Tougaloo College in Jackson, MS. The UTEC is a component of the JHS that focuses on preparing young adults and teenagers, primarily African American, for rigorous higher-level learning and ultimate participation in the effort to improve the health status of populations through research and practice.<sup>17</sup>

UTEC provides high school students and scholars with classroom and hands-on learning experiences, career guidance, and mentoring that prepares them to successfully complete graduate and professional degrees and enter the public health workforce.<sup>18</sup> This effort is already having an effect on diversifying the biomedical and public health research and practice workforce. As of May 2017, nearly 1,000 high school students have completed 1 or more of the 4-week summer workshops; a total of 134 scholars have graduated from Tougaloo; 31 have gone to medical/dental school; 78, to graduate and other professional schools; and 25 have joined the workforce.<sup>19</sup>

It must be acknowledged that JHS is in many ways one of a kind. The constraints of time and funding faced by most research projects prevent this depth and scale of partnership. However, the study illustrates powerful principles that can be adapted to any size study that seeks community involvement. One emerging example is the Moyo Health Network.

### The eCohort Idea: A Mobile Platform for Health Research

Inspired by the JHS, the Cardiovascular Research Institute of Morehouse School of Medicine has partnered with

**Box 1.** Seven Habits of Highly Successful Research in Special Populations

1. **Know the community.** It is critical to appreciate the geographic, demographic, cultural, and even historical distinction of the community.
2. **Trust the community.** Trust is reciprocal, parties in successful partnerships perpetually seek validation of genuineness, authenticity, and follow through on promises made.
3. **Respect the community.** Listen to the community's input and acknowledge to them that it matters; obtain their permission to use the information that they share.
4. **Align with trusted entities and persons with shared goals.** Interface with community-based organizations and institutions that promote visions and missions related to health, education, and service.
5. **Establish present value to the community.** Explain the benefits and risks associated with the research using language that all persons in the community understand.
6. **Affirm future value to the community.** Listen to the community's voice about a legacy of health and the value of study participation to future generations.
7. **Report back to the community.** Provide multiple strategies for presenting study results in lay language, early and often, such as an annual Community Monitoring Board meeting; periodic large group and small group gatherings; and lay summaries of scientific articles.

Emory University School of Medicine's Department of Medical Bioinformatics to launch an "eCohort" to examine factors contributing to the development of cardiovascular health disparities in the young. Dubbed the "Moyo Health Network," the cohort will be linked by cell phones to an extensive and scalable open-source platform that is being designed for collecting, integrating, and processing data in a Big Data cloud environment to create the next generation of crowd-sourced medical data. We will collect data for physiology (blood pressure, blood glucose, heart rate, sleep metrics, weight, and related anthropometrics), validated self-reported questionnaires (such as the Patient Health Questionnaire-9), environmental exposure data (such as local pollution sensors), social networking behavior, and other contextual behavior (such as relative location). Moyo Health will provide a platform for data gathering and for dissemination and implementation of interventions. The central aim of the Mobile Platform for Health Research is to improve health and reduce or prevent disparities by prioritizing engagement with populations of color, who are often the last to benefit from advances in technology.

Like JHS, the eCohort idea is community driven. The term "Moyo" is Kiswahili for "heart." Our message is that "We have heart for the community."<sup>20</sup> The core app *Moyo* began as 3 distinct barebones apps. These elements are being combined and expanded, and the "human-device interface" is being reimagined and designed with heavy input from members of the target community working in

collaboration with physicians, engineers, and public health scientists. Intensive "Health Tech" immersion sessions high energy and are high-output experiences that allow professionals and young community members the opportunity to engage deeply on issues of technology and health while designing apps that would have appeal, relevance, and durability. The result is a series of highly creative exchanges that in addition to improving our approach to developing the cohort, are: (1) building knowledge among lay people about the effect and potential of technology in their personal lives, (2) providing academics with quality encounters with a young often marginalized population through close personal interaction, and (3) building trust between scientists and the community.

Partnerships with governmental, private, and academic entities have created training opportunities in coding and app design for select participants. These students are mostly African Americans from junior colleges and high schools and young adults aged 18 to 29 years who have a high school diploma but no undergraduate degree.<sup>21</sup> Upon completion of their training, they are placed in internships before moving on to jobs in the technology sector. Through their improved career prospects, they can contribute to economic and health advances for themselves, their families, and the community.

## Conclusions

The JHS and Moyo Health provide models for addressing cardiovascular health disparities by fostering community partnerships. Lessons learned in the process of nurturing lasting partnerships between and among communities, academic and vocational institutions, and industry, if applied more broadly, hold great promise for the future of CVD prevention and elimination of health disparities. These novel approaches combine the best attributes of research, education, service, and technology to affect the resolution of CVD disparities for all Americans.

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