

# Recruiting Intergenerational African American Males for Biomedical Research Studies: A Major Research Challenge

Goldie S. Byrd, PhD; Christopher L. Edwards, PhD; Vinaya A. Kelkar, Ph.D; Ruth G. Phillips, MD; Jennifer R. Byrd, BS; Dora Som Pim-Pong, MS; Takiyah D. Starks, MS; Ashleigh L. Taylor, MS; Raechel E. Mckinley; Yi-Ju Li; Margaret Pericak-Vance, PhD

**Funding/Support:** This study was supported by the National Center on Minority Health and Health Disparities/National Institutes of Health grant P20 DM000546.

The health and well-being of all individuals, independent of race, ethnicity, or gender, is a significant public health concern. Despite many improvements in the status of minority health, African American males continue to have the highest age-adjusted mortality rate of any race-sex group in the United States. Such disparities are accounted for by deaths from a number of diseases such as diabetes, human immunodeficiency virus (HIV), cancer, and cardiovascular disease, as well as by many historical and present social and cultural constructs that present as obstacles to better health outcomes. Distrust of the medical community, inadequate education, low socioeconomic status, social deprivation, and underutilized primary health care services all contribute to disproportionate health and health care outcomes among African Americans compared to their Caucasian counterparts. Results of clinical research on diseases that disproportionately affect African American males are often limited in their reliability due to common sampling errors existing in the majority of biomedical research studies and clinical trials. There are many reasons for underrepresentation of African American males in clinical trials, including their common recollection and interpretation of relevant historical of biomedical events where minorities were abused or exposed to racial discrimination or racist provocation.<sup>1</sup> In addition, African American males continue to be less educated and more disenfranchised from the majority in society than Caucasian males and females and their African American female counterparts. As such, understanding their perceptions, even in early developmental years, about health and obstacles to involvement in research is important. In an effort to understand perspectives about their level of participation, motivation for participation, impact of education, and engagement in research, this study was designed to explore factors that impact their willingness to participate. Our research suggests that: (1) African Ameri-

can males across all ages are willing to participate in several types of research studies, even those that require human samples; (2) their level of participation is significantly influenced by education level; and (3) their decision to participate in research studies is motivated by civic duty, monetary compensation, and whether they or a relative has had the disease of interest. However, African American males, across all age groups, continue to report a lack of trust as a primary reason for their unwillingness to participate in biomedical research. There is an ongoing need to continue to seek advice, improve communication, and design research studies that garner trust and improve participation among African American males as a targeted underrepresented population. Such communication and dialogues should occur at all age levels of research development to assess current attitudes and behaviors of African American males around participation.

**Keywords:** African American ■ men's health ■ racial disparities

*J Natl Med Assoc.* 2011;103:480-487

**Author Affiliations:** Department of Biology (Drs Byrd, Kelkar, and Phillips and Mss Byrd, Pim-Pong, Starks, Taylor, and Mckinley), North Carolina A&T State University, Greensboro; Duke Pain and Palliative Care Center (Dr Edwards), Department of Psychiatry (Dr Edwards), Duke Center for Human Genetics (Dr Pericak-Vance), and Department of Medicine, Duke University Medical Center (Dr Edwards), Durham, North Carolina; Miami Institute for Human Genomics, University of Miami, Florida (Mr Li and Dr Pericak-Vance).

**Correspondence:** Goldie S. Byrd, PhD, Professor of Biology, Dean for the College of Arts & Sciences, A411 General Classroom Bldg, North Carolina A&T State University, 1601 E Market St, Greensboro, NC 27411 (gsbyrd@ncat.edu).

## INTRODUCTION

Including large numbers of African American males in research is critical, especially given their disproportionate burden associated with many chronic diseases. Despite much improvement over the past several decades, African American males in the United States continue to have disproportionately higher age-adjusted,

all-cause mortality rates as compared to white males and females and even in comparison to African American female counterparts.<sup>2</sup> Such disparity contributes to their disproportionate reduction in life expectancy. Several reasons have been published that account for wide gaps in health status in African American males that include: low socioeconomic status, lack of health insurance, low education attainment, racism, discrimination, and low access to primary health care.<sup>3,4</sup>

In addition to high disease burden and lower life expectancy, African American males as well as many other historically disenfranchised populations continue to be underrepresented in research studies and clinical trials.<sup>5-8</sup> Because of these historical differences, the National Institutes of Health published the 1993 Revitalization Act (revised in 1994 and amended in 2001), which mandated that minorities and women be included as participants in research, and that trials be designed in a way that takes into consideration racial differences.<sup>9-11</sup> Despite these governmental guidelines, African Americans remain underrepresented at all levels of clinical trials and biomedical research relative to their share of disease burdens.<sup>12,13</sup> Only 5% of the persons who participate in clinical trials are persons of color collectively.<sup>14,15</sup>

In addition to the individual- and investigator-level barriers listed above, several system-level barriers have been identified that may account for the lack of participation of African Americans in research. These barriers include the lack of sensitivity of researchers to issues of distrust and lack of cultural specificity and sensitivities of black men.<sup>16-20</sup> They also include individual issues such as a lack of time and lack of education and understanding of the research process. Distrust of the health care system and of health-related research also negatively impacts enrollment in research studies and clinical trials.<sup>21</sup> As a consequence, standard open enrollment practices for subject ascertainment lead to fewer African American participants and especially African American males. Other barriers to recruitment include: (1) lack of experimental designs that specifically target minorities, (2) lack of awareness in minorities, (3) lack of integrity in experimental design by researchers, (4) lack of research done by minority investigators, and (5) fear of past research atrocities such as the Tuskegee Syphilis Study (TSS).<sup>22-28</sup>

In order to improve generalization of research trial results, it remains important for investigators to set specific and consequential recruitment goals that include adequate representation of ethnic groups driven in part by culturally sensitive recruitment materials in the context of community receptive researchers and research institutions. This is particularly significant for minority groups, such as African American males, who continue to be disproportionately burdened by acute and chronic disease, limited access to health care, and poor health outcomes.

Reminders of research atrocities such as the TSS and

even of research biases and misrepresentations of more recent studies collectively influence minorities' mistrust of medicine and research.<sup>29</sup> The TSS is widely known for the abuses on African American males, who were subjects in a study to assess the effects of untreated syphilis.<sup>27</sup> The influence of the 40-year government-supported study is widely viewed as a major factor in African Americans' unwillingness to participate in research.<sup>30</sup> Recent investigators have begun to challenge the impact of the Tuskegee study in accounting for the research participatory behaviors of African Americans.<sup>31,32</sup> These investigators suggest—and we concur—that knowledge of the TSS is not necessarily inhibitory; there are general issues of trust among African Americans that stem from a history of unequal treatment in major social and political constructs. Other investigators have also shown that African Americans are just as willing as whites to participate in studies.<sup>33</sup> Yet, African American males remain underrepresented in research studies and clinical trials.

A recent report indicated that men of color are among the most understudied populations and that they suffer the poorest overall health outcomes.<sup>34</sup> The author suggests that collectively and within research and clinical settings there is an increasing understanding that cultural beliefs and perceptions about health and health-related research are important and have significant influences on health behaviors. Studies that explore males' perceptions of health-related research and behaviors are scarce and often poorly executed.<sup>35</sup> However, closing the health disparities gap among African American males will not only require intentionality on the part of researchers, but it will also require continuous dialogue/inquiry with African American males and an understanding of current issues, perceptions, and attitudes about their willingness to participate in studies and improve health outcomes. We posit that closing the gap will also require early intervention with young African American males who are making decisions about their careers in research and health-related fields, and about their health and possibly that of their parents and grandparents.

Several models of best practices have been reported that provide guidance on recruiting and retaining diverse populations by incorporating trust and community relations into the algorithm of subject ascertainment.<sup>36-40</sup> These programs focus on interpersonal and psychosocial processes that promote trust and understanding of the research process. Though much attention has been given to African Americans in general, attention to the nuances of male participation in research is still a major challenge for most studies. Understanding their specific perceptions about research participation as a distinct group is novel and important. The goal of this study was to understand the perceptions of intergenerational African American males, as a special group, about participating in research studies. We have

sought the perceptions of African American males across generations from 18 years of age to more than 70 years of age and across education levels. African American males aged 18 to 24 years are the age group among African American males with the lowest amount of health insurance and lowest exposure to health care providers. Their perceptions, at this age, are important in their health-related and participatory-related decisions.

The purpose of our study was to explore and clarify motivations and barriers specific to African American men, across age ranges, regarding their participation in research studies.

## METHODS

Survey development included designing and pre-testing a content-validated 46-item survey that assessed key constructs related to recruiting African American men and women for research studies. For this analysis, only responses from male participants were included. We recruited participants primarily from North Carolina and surrounding areas to complete the survey. The volunteers included: (1) individuals from area churches, (2) individuals attending health education conferences and caregiver conferences, (3) individuals living and working in coed senior homes, and (4) patrons of barber and beauty shops in the African American community. This study was approved by North Carolina A&T State University’s institutional review board. No monetary or in-kind incentives were offered to respondents for completing the survey.

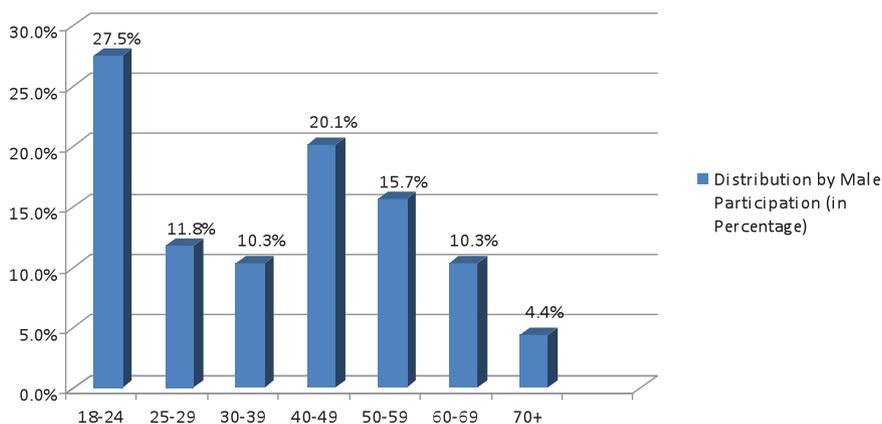
Statistical analyses included  $\chi^2$  tests and bivariate correlations to determine if a statistically significant relationship was observed between survey variables. The test variables were stratified by gender, age range, years of education, level of past participation, and willingness to participate in future studies.

## MEASURES

The measures that were included in the survey were: (1) previous knowledge of the TSS and other clinical research trials, (2) previous research participation, (3) willingness to participate in clinical research trials, (4) types of studies willing to participate in, (5) types of samples willing to give for research, (6) motivation for participating in research, and (7) reasons for not participating in research studies.

All participants were asked a yes/no question to determine if they had previous knowledge of a recent research studies related to health or a disease/disorder in their city or county. They were then asked a more specific question to assess knowledge of the TSS. We asked, “Have you heard about any of the following health-related research studies?” The TSS was one of the choices, along with the Sister Study, Women’s Health Initiative, and the Farmington Heart Study. The choice of “other” was included so that the participant could add a response if necessary. Two yes/no questions were used to determine if participants had previous experience in a research trial and their willingness to participate in a research trial. If the answer to the former was no, then the next questions were designed to determine if a participant was willing to participate or not. If the participant answered yes to “Have you ever participated in a health-related research study?” then the next set of questions were designed to obtain more information about the participant’s experience in a research trial. In order to determine the reasons for research participation, we asked, “What motivated you to participate in the study?” The answer choices were: (a) relative with disease, (b) I have/had the disease, (c) monetary compensation, (d) civic duty, and (e) other. Each participant was also asked the types of studies they were willing to participate in and if they were willing to give a sample—if so, what type of sample(s) would they give to a research study?

**Figure.** Distribution of Survey Participants Who Shared Age



Participants were also asked to give a reason for being unwilling to participate in a research trial.

**RESULTS**

Of the 583 persons who completed the survey, 360 were females (62%) and 223 (38%) were males. Of the 223 males that responded, 19 did not give their education and were excluded (Figure). Of the 204 male participants who provided complete data, 27.5% were between the ages of 18 and 24 years, 11.8% were aged 25 to 29 years, 10.3% were aged 30 to 39 years, 20.1% were aged 40 to 49 years, 15.7% were aged 50 to 59 years, 10.3% were aged 60 to 69 years, and 4.4% were aged 70 years or older (Figure). Although 100% of respondents indicated having a family member that suffered with at least 3 of the top 10 health disparities, only 13% of the males had ever participated in a related research study or clinical trial.

Nearly 50% of male respondents had received a high school diploma or General Education Development as their highest educational achievement. As shown in Table 1, 5.5% had no high school diploma and 19.4% had at least a bachelor's degree. Nine percent of males had a master's degree and 4.6% had a terminal degree.

We assessed past participation in research studies relative to education level and gender (Table 2). Only 13% of the male respondents had ever participated in any type of research study, and the likelihood of participation increased with increased education ( $\chi^2 = 13.9, p = .016$ ). Collectively, participation was related to education ( $\chi^2 = 16.95, p < .01$ ).

As shown in Table 3, the majority of males (83.6%) had not participated in any type of research study. The number of males who had participated in biomedical research studies increased as age increased in general, but participation generally clustered around ages 40 to 69 years (primarily baby boomers). Those in the young-adult category (18-24 years) had past participation as well. Levels of previous participation ranged from 8.9% for 18- to 24-year-olds to 28.6% among 60- to 69-year-olds. All categories had at least some respondents who had participated in research studies, even the young-adult category (18-24 years).

Among the men who had never participated in a research study, 74% of respondents indicated a willingness to participate (Table 4). Within the age groups, 86.3% of those aged 18 to 24 years indicated a willingness to participate in future studies. The lowest enthusiasm for participating in research was in the 30- to 39-year age group (63%), the 40- to 49-year age group (68%), the 60- to 69-year age group (64.3%), and those aged 70 years and older (66.6%). The second highest was in the 50- to 59-year age group. At least 63% across all age groups indicated a willingness to participate in future studies.

Further, male respondents were willing to participate in several types of research studies, including surveys, focus groups, clinical trials, and genetic studies. The types of studies that males were willing to participate in varied across the age range (Table 5). In every age group, survey studies were clearly the preferred type of research study. For persons in the 18- to 24-year age range, the

**Table 1.** Educational Attainment Among Male and Female Survey Participants

	No High School Diploma	High School or General Education Development	Associate's Degree	Bachelor's Degree	Master's Degree	Doctor of Philosophy or Doctoral Degree
No. of males						
Within gender, %	12 (5.5%)	108 (49.8%)	25 (11.5%)	42 (19.4%)	20 (9.2%)	10 (4.6%)
No. of females						
Within gender, %	2 (0.6%)	133 (38.3%)	28 (8.1%)	103 (29.7%)	66 (19.0%)	15 (4.3%)
% of Total	14 (2.5%)	241 (42.7%)	52 (9.4%)	145 (25.7%)	86 (15.2%)	25 (4.4%)

**Table 2.** No. of Males That Have Participated in Research Studies at Each Education Level

Gender	Education Level <sup>a</sup>						Total
	0	1	2	3	4	5	
Male participation	10	96	24	38	14	6	188
N count	83.3%	88.9%	96.0%	90.5%	70.0%	60.0%	86.6%
Within education level, %							
Y count	2	12	1	4	6	4	29
Within education level, %	16.7%	11.1%	4.0%	9.5%	30.0%	40.0%	13.4%

<sup>a</sup> 0, ≤ high school; 1, high school or General Education Development; 2, associate's degree; 3, bachelor's degree; 4, master's degree; 5, terminal or doctorate degree.

number 2 choice was genetic studies, and the least desirable study types were clinical trials and focus group studies. For middle-aged men, the second most preferred study type was focus group research, and the least preferred was genetic studies; and among those aged 70 years and older, the responses were almost equal among study types. In every age group, except for the 40- to 49-year age group, clinical trials were the least preferred study to participate in, while genetics studies were the second least preferred category. Among the males who had never participated in a research study, 74% indicated a willingness to participate. Whether or not a biological sample had to be taken from the participant did not deter participation, as 72% of the cohort stated that they would participate even if a sample had to be given with the agreement to participate remaining constant across the age groups.

African American males were willing to provide an array of biological samples for research. More than 50% of the respondents were willing to provide blood, saliva, hair, urine or feces, blood pressure, weight, or height (Table 6). Fewer were willing to provide other types of samples such as body tissues (19.4%), results from memory tests (44%), or magnetic resonance imaging (26.6%). Having a relative with the disease, use of minority study personnel, and monetary compensation were the most powerful incentives for participation in research.

Participants were also asked what would motivate them to participate in studies. Respondents had 4 choices, which were: (1) “I have a relative with the disease,” (2) “I have or had the disease,” (3) monetary compensation, or (4) “It is my civic duty.” Having a relative with the disease was the most likely motivator (40%); monetary compensation was the second most likely motivator and civic duty was the third (Table 7). The least common answer was that of having the disease themselves. When compared across age groups, having a relative with disease was also the primary motivation. Monetary compensation was the second most selected reason for participation by all age groups except those between the ages of 40 and 59 years. In this age group, monetary compensation was the least motivator. In these 2 age groups, having the disease themselves was second, and monetary compensation was last. Civic duty was second in the 60- to 69-year age group only (and tied for second in the 50- to 59-year age group) and tied for second with “I have the disease” in the 50- to 59-year age group.

Twenty-eight percent of respondents who had never participated in a research study indicated an unwillingness to participate in studies. Table 8 shows the distribution of responses from the 35 males who were unwilling to participate in future studies.

Those who had not participated in a research study were then asked if they would be willing to participate in

**Table 3.** Previous Research Participation Among Different Age Groups of Participants

Previous Participation	18-24 y	25-29 y	30-39 y	40-49 y	50-59 y	60-69 y	≥70 y	Total
Yes	5 (8.9%)	4 (16.7%)	2 (9.5%)	6 (14.6%)	3 (9.4%)	6 (28.6%)	2 (22.2%)	28 (13.7%)
No	51 (91.1%)	20 (83.3%)	19 (90.5%)	35 (85.4%)	29 (90.6%)	15 (71.4%)	7 (77.8%)	176 (86.3%)
Total	56	24	21	41	32	21	9	204 <sup>a</sup>

<sup>a</sup> Nineteen male participants did not list their age.

**Table 4.** Percentage of Males Willing to Participate in Research Studies in Each Age Group

Willingness to Participate	18-24 y	25-29 y	30-39 y	40-49 y	50-59 y	60-69 y	≥70 y	Total
Yes	44 (86.3%)	14 (70%)	12 (63.2%)	24 (68.6%)	22 (75.9%)	9 (64.3%)	4 (66.6%)	129 (74%)
No	7 (13.7%)	6 (30%)	7 (36.8%)	11* (31.4%)	7 (24.1%)	5 (35.7%)	2 (33.3%)	45 (26%)
Total	51	20	19	35	29	14	6	174

**Table 5.** No. of Participants Willing to be Recruited Into Different Types of Research Studies per Age Range

Willingness to Participate	Age Range							Total <sup>a</sup>
	18-24y	25-29 y	30-39 y	40-49 y	50-59 y	60-69 y	≥70 y	
Survey	33 (40.2%)	12 (37.5%)	10 (47.6%)	20 (48.7%)	15 (38.5%)	6 (54.5%)	1 (16.7%)	97 (41.8%)
Focus group	13 (15.6%)	5 (15.6%)	2 (9.5%)	9 (22%)	8 (20.5%)	1 (9.1%)	2 (33.3%)	40 (17.2%)
Clinical trial	12 (14.6%)	5 (15.6%)	4 (19.1%)	9 (22%)	6 (15.4%)	2 (18.2%)	1 (16.7%)	39 (16.8%)
Genetic studies	24 (29.3%)	10 (31.3%)	5 (23.8%)	3 (7.3%)	10 (25.6%)	2 (18.2%)	2 (33.3%)	56 (24.1%)

<sup>a</sup> The total is higher because participants made multiple selections.

a health-related research study, with response being yes/no. If they answered no, they were asked why not. The number 1 reason for their unwillingness to participate was lack of trust. Lack of time was the second most given reason and “other” was the third. Actual responses included “too busy,” “because I have issue with historical treatment of black people,” “because I don’t trust that research,” “health issues,” or “not interested.” These responses were categorized as follows: (1) lack of time, (2) lack of trust, (3) health reasons, and (4) other. Table 8 shows the distribution of responses from the 35 males who were unwilling to participate in future studies. “Health reasons” was the least used response. Lack of trust was the most used response, and lack of time was the second most used answer.

### CONCLUSIONS

Inclusion of African Americans in research studies remains an important challenge in eliminating health disparities and creating scientific literature that is more responsive to and representative of the ultimate consumers of that knowledge. While there are many reasons for the seeming absence of African Americans in research and clinical trials, this study shows that with appropriate education and rapport (trust), African American male representation could be increased. Those who have post-secondary levels of education are more likely to participate in research studies than those with less education,

and initial efforts may focus on those more educated populations. As increasing numbers of African Americans are participating, models of participation become the new normal, and an increasingly diverse group of African Americans, including those with lower levels of education, participate.

We also assert that as researchers and the general public learn more about motivators and barriers for African American male participation in research, more-efficient study protocols will be devised and the general community may become more receptive to recruitment efforts. A more diverse study population assists with eliminating the need to generalize about a population that is underrepresented.

Our results are consistent with several studies that indicate that African Americans are willing to participate in research studies. While knowledge of the “legacy” of the TSS is reported to not have an impact on research participation among African Americans, results from this study show that trust remains a primary barrier to research participation in African American males. This barrier is significant across all age groups that participated in this study. Such results indicate a need to continue extended community-based conversations with African American males to assure that trusting relationships are established between researchers and potential participants.

In order to close health disparities gaps for African American males, there is a great need to assist African

**Table 6.** Number of participants That Are Willing or Not Willing to Provide Different Samples for Research

Willingness	Study Samples								
	Tissue	Blood	Saliva	Hair	Urine/ Feces	Blood Pressure	Weight/ Height	Memory Test	Magnetic Resonance Imaging
Yes	28 (19%)	97 (68%)	89 (62%)	89 (62%)	88 (61%)	92 (64%)	88 (61%)	63 (44%)	38 (27%)
No	116 (81%)	46 (32%)	55 (38%)	55 (38%)	56 (39%)	52 (36%)	56 (39%)	80 (56%)	105 (73%)
Total who responded	144	143	144	144	144	144	144	143	143

**Table 7.** Reasons and Responses of Nonparticipants Willing to Participate in Research<sup>a</sup>

Motivation	Age Range, y						
	18-24	25-29	30-39	40-49	50-59	60-69	≥70
Relative with disease I have/had the disease	32 (39.5%)	11 (32.3%)	10 (35.7%)	14 (41.2%)	16 (50%)	7 (41.2%)	4 (44.4%)
Monetary compensation	14 (7.3%)	7 (20.6%)	4 (14.3%)	7 (20.6%)	6 (18.8%)	1 (5.9%)	2 (22.2%)
Civic duty	20 (24.7%)	11 (32.4%)	6 (21.4%)	6 (17.6%)	4 (12.5%)	3 (17.6%)	3 (33.3%)
	15 (18.5%)	5 (14.7%)	8 (28.6%)	7 (20.6%)	6 (18.8%)	6 (35.3%)	0 (0%)

<sup>a</sup> The total is higher because participants made multiple selections.

**Table 8.** Reasons Males Will Not Participate in Future Studies

	No Time	Lack of Trust	Health Reasons	Not Interested	Other	Total
Count	10	13	1	4	7	35
Percentage	28.6%	37.1%	2.9%	11.4%	20.0%	100.0%

American males in understanding underlying reasons and expectations for their participation. Such discussions will be needed to put this population at ease by increasing the number and competencies of researchers and staffers who relate well and who put to rest some of the myths around research participation. It is clear that most are willing to participate, but based on this study, there are important motivators (eg, compensation, civic duty, history of disease, and study type) that would encourage their participation at different stages in their lives. It is important for researchers to understand these motivators as well as potential barriers that impact male participation in research studies.

Increasing the number of African American males who attain a college education is associated with a larger number of them who consider participation in research studies. In addition, expanding the number of high-level research projects into institutions that enroll large numbers of African American males is an important mechanism for engaging many young men in health disparities projects at an early age. While addressing African American males' health will require commitments at the levels of community, state, and national governments, it is important that researchers understand the health and trust challenges of African American males.

Researchers must take the time to ensure that this significant group of society is knowledgeable and is included in research studies that address health disparities. Even at the tender age of 18 years, many African American males are entering college and shaping their thoughts about their personal health and also about global health in men. They have first-hand experiences with diseases on the college campus as well as experiences with health and disease in their own families. Thoughts of their inclusion in eliminating health disparities are being shaped.

The results of this study provide insights into African American males' perceptions about participation in health-related studies. Hence multilevel colleges and universities, particularly in science and health-related disciplines, have a special opportunity to include in their course curricula discussions of health disparities and the roles of young African American males in participating in the elimination of health disparities. They must also continue to recruit and retain diverse student bodies and health professionals that are motivated by solving problems related to the public's health. Early exposure to such topics on the college campus, as well as improving college degree attainment in general, provide a framework for preparing the next generation of health-conscious African American males to understand better their role in eliminating health disparities in this important segment of society.

## REFERENCES

- Merritt MM, Bennett GG, Williams RB, et al. Perceived racism and cardiovascular reactivity and recovery to personally-relevant stress. *Health Psych*. 2006;25(3):364-369.
- Rich J, Ro M. A poor man's plight: Uncovering the disparity in men's health. Battle Creek, MI: WK Kellogg Foundation Report; 2002.
- Williams DR, Lavizzo-Mourey R, Warren RC. The concept of race and health status in America. *Public Health Report*. 1994;109:26-41.
- Blane D. The life course, the social gradient, and health. In: Marmot M, Wilkinson RG, eds. *Social Determinants of Health*. Oxford, England: Oxford University Press; 1999:64-80.
- McDougall GJ, Holston EC, Wilke P. Recruiting African Americans into research on cognitive aging. *Ethn Dis*. 2001;11(1):124-133.
- Mohluddin SM, Hilleman DE. Gender and racial bias in clinical pharmacology trials. *Ann Pharmacother*. 1993; 27: 972-973.
- Swanson GM, Ward AJ. Recruiting minorities into clinical trials: toward a participant-friendly system. *J Natl Cancer Inst*. 1995;87:1747-1759.
- Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999;14:537-546.
- NIH Guide. Guidelines on the inclusion of women and minorities as subjects in clinical research; notice. *Fed Reg*. 1994;54:14508-14513.
- NIH Policy and Guidelines on the Inclusion of Women and Minorities as subjects in Clinical Research, NIH Guide for Grants and contracts, amended 2001.
- National Institutes of Health. Sex/gender and minority inclusion in clinical research. What investigators need to know. [http://grants.nih.gov/grants/funding/women\\_min/training/sld017.htm](http://grants.nih.gov/grants/funding/women_min/training/sld017.htm). Accessed January 2011.
- Department of Health and Human Services National Institutes of Health 2010 Report. *Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities as Subjects in Clinical Research: Comprehensive Report: Tracking of human subjects research as reported in fiscal year 2008 and fiscal year 2009*.
- Svenson CK. Representation of American blacks in clinical trials of new drugs. *JAMA*. 1989;261:263-265.
- Stone J. *Conducting Clinical Research: A Practical Guide for Physicians, Nurses, study coordinators and investigators*. Cumberland, MD: Mountainside MD Press; 2006.
- Brawley OW, Tejeda H. Minority inclusion in clinical trials issues and potential strategies. *J Natl Canc Inst Monogr*. 1995;17:55-57.
- Durant RW, Davis RB, St George DM, Williams IC, Blumenthal C, Corbie-Smith GM. Participation in Research Studies: Factors Associated with Failing to Meet Minority Recruitment Goals.
- Corbie-Smith G, Thomas SB, St George DM. 2002. Distrust, race and research. *Arch Intern Med*. 2002;162:2458-2464.
- Saunders E. Recruitment of African-American patients for clinical trials—the ALLHAY challenges antihypertensive and lipid-lowering trial to prevent heart attack. *J Natl Med Assoc*. 1995;87:627-629.
- James SA, Keenan NL, Strogatz DS, et al. Socioeconomic status, John Henryism and blood pressure in Black adults: The Pitt County study. *Am J Epidemiol*. 1992;135:59-67.
- The Integrated Postsecondary Education Data System: Completion Survey by Race, 1996-2006. [www.WebCASPAR.nsf.gov](http://www.WebCASPAR.nsf.gov).
- Gamble V. A legacy of distrust: African Americans and medical research. *Am J Prev Med*. 1993;9:35-38.
- Corbie-Smith G, Thomas SB, St George DM. Distrust, race and research. *Arch Intern Med*. 2002;162:2458-2464.
- Gorelick PB, Harris Y, Burnet B, et al. The recruitment triangle: reasons why African Americans enroll, refuse to enroll, or voluntarily withdraw from a clinical trial. An interim report from the African-American Antiplatelet Stroke Prevention Study (AAASPS). *J Natl Med Assoc*. 1998;90:141-145.
- Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans underrepresented in medical research studies? Impediments to participation. *Ethn Health* 1997;2:31-45.
- Sheikh A. Why are ethnic minorities under-represented in US research studies? *PLoS Med*. 2006;3(2):e49.

26. Rogler LH. The meaning of culturally sensitive research in mental health. *Am J Psychiatry*. 1989;146:296-303.
27. Jones JH. *Bad Blood: The Tuskegee Syphilis Experiment*. New York, NY: The Free Press; 1981.
28. Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the Black community. *Public Health Then and Now*. 1991;81:1498-1505.
29. Sieber JE, Stanley B. Ethical and professional dimensions of socially sensitive research. 1988. *Am Psychol*. 1988;43:49-55.
30. Freimuth, VS et al. African Americans' views on research and the Tuskegee Syphilis Study. *Soc Sci Med*. 2001;52(5):797-808.
31. Katz RV, Green L, Kressin NR, et al. The legacy of the Tuskegee Syphilis Study: Its impact on willingness to participate in biomedical research studies. *Health Care Poor Underserved*. 2008;19:1169-1181.
32. Katz RV, Green L, Kressin NR, et al. Exploring the "legacy" of the Tuskegee Syphilis study: A follow-up study from the Tuskegee Legacy Project. *J Natl Med Assoc*. 2009;101(2):179-183.
33. Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2006;19:1-10.
34. Satcher D. Overlooked and underserved: improving the health of men of color. *Am J Public Health*. 2003;93(5):707-709.
35. Saunders E. Recruitment of African-American patients for clinical trials—the ALLHAY challenges Antihypertensive and lipid-lowering trial to prevent heart attack. *J Natl Med Assoc*. 1995;87:627-629.
36. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27:1-28.
37. Dilworth-Anderson P, Thaker S, Burke JMD. Recruitment strategies for studying dementia in later life among diverse cultural groups. *Alzheimer Dis Assoc Disord*. 2005;19(4):256-260.
38. Elish NJ, Scott D, Boyak-Schaler R, et al. Community-based strategies for recruiting older, African Americans into a behavioral intervention study. *J Natl Med Assoc*. 2009;101(11):1104-1111.
39. Taylor J. Recruitment of three generations of African American women into genetics research. *J Transcult Nurs*. 2009;20(2):219-226.
40. Ballard EL, Nash F, Raiford K, Harrell LE. Recruitment of Black elderly for clinical research studies of dementia: the CERAD experience. *Gerontol*. 1993;33:561-565. ■