

Research Series

Factors Affecting Research Participation in African American College Students

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Background and Objectives: *African American participation in research trials must increase. This study evaluates factors affecting participation of African American college students in medical research. Methods:* A total of 200 students attending South Carolina State University (SCSU), a historically black college, completed surveys evaluating the likelihood of participation within 6 months in three types of noninvasive research studies (surveys with or without questions regarding sensitive information and collection of DNA with a buccal swab). Likelihood of participation by investigator's race (African American, white, Asian) or institution (SCSU, historically black college, predominantly white college, government) was compared with Wilcoxon signed-rank tests. Logistic regressions evaluating likelihood of participation included gender, Trust in Medical Researchers Scale score, prior participation, and family/friend participation. **Results:** Fewer respondents would participate in a survey asking about sensitive information than would provide DNA. Respondents were more likely to participate in a study if conducted by a historically black college or African American investigator. Respondents with more trust and without prior participation were more likely to participate. Just more than half of respondents (52.0%) stated that their physician's encouragement would increase their likelihood of participation. **Conclusions:** Collaboration with African American investigators, historically black colleges, and community physicians may improve African American participation. Trust in researchers and participant's past research experience should also be considered.

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The National Institutes of Health requires the inclusion of underrepresented minorities in medical research.¹ Despite this requirement, there continues to be a lack of African American representation in research trials. For instance, studies have shown that African American participants comprise only 6% of cancer clinical trials, and low African American participation is also seen within other types of trials.²⁻⁶ This lack of participation limits the ability of researchers to generalize data from clinical trials to African Americans and may ultimately contribute to the presence of health disparities in this population.

The lack of African American participants in research trials is often attributed to investigators' difficulties in recruitment and retainment of minority subjects.⁷⁻⁹ Studies demonstrate African Americans may be more difficult to recruit and have a variety of

barriers to participation and retainment in research trials.⁹⁻¹¹ This highlights the need to develop culturally appropriate, effective recruitment strategies. Such strategies may need to address factors such as a lack of minority investigators and mistrust, which are well-established barriers to participation.^{9,11,12} Other factors, such as socioeconomic status, ease of participation, physician encouragement, and the intervention being studied may also influence research participation.^{9,12-14}

Few studies have evaluated the above factors in a college-age African American population. Evaluating this population is important, however, because individuals in this group may be the most amenable to participation due to their age and education level. Further, these are the individuals who will be recruited for future research trials. Thus, the specific aim of this study is to evaluate, in African American college students, previously identified factors known to influence research participation. This information may be used to develop and improve recruitment strategies for involving African Americans in future clinical research projects.

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Methods

Sample

A survey was administered to 200 students at South Carolina State University (SCSU), which is a historically black college in South Carolina. Self-identified African American students 18 years or older were recruited from summer classes. No students refused to participate. This study was determined to be exempt from formal review by the Institutional Review Boards at the Medical University of South Carolina (MUSC) and SCSU. No financial incentives were provided for participation.

Survey Description

To develop the survey, we first undertook a literature review of studies that focused on African American participation in medical research. This review identified the specific items and scales considered for possible inclusion. Cognitive interviews were conducted for clarity, understanding, and flow with five students from a historically black university, the target population for this survey. Amendments to the survey were made based on consensus recommendations from three independent investigators who reviewed these interviews. This resulted in a 47-item survey.

The survey included questions regarding participant demographics and previous experience with medical research. Likelihood of participation based on encouragement from family/friends, physician, or community leaders was evaluated using a 5-point Likert scale. Trust was evaluated using the previously developed Trust in Medical Researchers Scale (TMRS).¹⁵ The TMRS is a 12-item scale that results in scores ranging from 0 to 48. The higher the score, the greater the trust in medical researchers.

Three relatively uninvasive study types were evaluated: a confidential survey regarding study habits (not considered sensitive information), a confidential survey regarding sexual behaviors and drug use (considered sensitive), and DNA collection using a buccal swab (considered sensitive), which was described to subjects as “swabbing the inside of your mouth to collect your genes/DNA.”

Likelihood of participation in these studies was assessed using the same questions for each study type. Each of the questions started with “How likely would you be to participate in this medical research study (in the next 6 months) if . . .” and then varied regarding the institution conducting the study (SCSU, a historically black college, a predominately white college, a government/federal agency) or the race of the investigator (African American, Asian, white). Responses were scored as very likely=3, somewhat likely=2, and not likely at all=1.

Analysis

Percentages stratified by gender for the demographic variables, prior experience with medical research, and likelihood of participation in each research study were compared using Chi-square statistic. Mean score on the TMRS was compared by gender using Student's *t* test. To evaluate differences in likelihood of participation based on the investigator or institution conducting the study, Wilcoxon signed-rank tests were performed comparing each institution to a historically black college and African American investigators to white or Asian investigators. A *P* value of <.05 was considered significant.

To investigate the relative likelihood of an individual participating in a research study if conducted by an African American or white investigator, we conducted logistic regression analyses incorporating the following independent variables: gender, TMRS score stratified into tertiles, prior participation in a research study (yes/no), and having a friend or family member who has participated in a research program (yes/no). Given the type of study and the race of the principal investigator, we calculated the relative likelihood of participants indicating that they would be somewhat or very likely to participate (as opposed to not likely at all).

Results

Of the 200 respondents, 58% were male and 42% were female. Other demographic data are presented in Table 1.

When asked whose encouragement would increase their likelihood of participation, 52.0% responded their physician, 42.5% a family member/friend, and 32.5% a community leader. More women than men reported being asked to participate and participating in medical research in the past. Women also had a higher mean score on the TMRS.

Table 2 presents the percent of respondents likely to participate in a medical research study within the next 6 months by type of trial. As expected, more respondents would be likely to participate in a trial consisting of a survey asking about study habits, which is generally not considered sensitive information, versus one that asked about sexual behavior and drug use or one that involved DNA collection. More respondents would participate in a study collecting DNA information with a buccal swab than a survey asking about sexual behavior or drug use. Women were less likely to participate than men in surveys from SCSU regarding sensitive information and were also less likely to participate in a study that involved collection of DNA if the study was run by a predominantly white college or a white investigator.

Results from Wilcoxon signed-rank tests presented in Table 3 show that respondents generally were more likely to participate in future medical research if performed by their own institution or a historically black

Table 1

Respondent Demographics and Research Participation Experience

		Total (n=200)	Male (n=116)	Female (n=84)
		%	%	%
Age group*	18–19	31.0	33.6	27.4
	20–21	47.0	41.4	54.8
	22–23	17.5	22.4	10.7
	≥ 24	4.5	2.6	7.1
Class	Freshman	23.5	26.7	19.1
	Sophomore	5.5	6.9	3.6
	Junior	18.5	14.7	23.8
	Senior	52.5	51.7	53.6
Prior participation in medical research*		31.0	19.0	47.6
Asked to participate in the past*		37.0	24.1	54.8
Family member/friend has participated in medical research		48.0	49.1	46.4
Mean trust score†		26.5	25.4	28.1

* χ^2 distribution $P < .05$ for comparison of male and female
 † t test comparison $P < .05$ for comparison of male and female

college. They were also more likely to participate if the investigator was African American.

Table 4 presents results from logistic regressions evaluating likelihood of participation for each study type if conducted by a white investigator. This category was evaluated since white investigators are the most prevalent in medical research. Participants with higher trust in medical researchers and those who had not participated before were more likely to participate in the future. Results were similar when logistic regressions were performed for studies conducted by African American investigators (data not shown).

Discussion

The low level of participation by African Americans in clinical studies is a substantial limitation to the furthering of scientific knowledge. The National Institutes of Health (NIH) requires inclusion of minorities in NIH-funded studies. Moreover, some data suggest that different racial/ethnic groups may respond differently to the same treatments.¹⁶ Consequently, improving knowledge of barriers and concomitant strategies to overcome barriers to

Table 2

Percent of Respondents Who Responded That They Would Be Somewhat or Very Likely to Participate in a Research Project by Type of Trial

	Survey About Study Habits			Survey About Sexual Behavior and Drug Use			DNA Information From Buccal Swab		
	Total	Male	Female	Total	Male	Female	Total	Male	Female
Sample size	200	116	84	200	116	84	200	116	84
Institution									
Historically black college	82.5	81.0	84.5	58.0	59.5	56.0	75.0	78.5	70.2
South Carolina State University	84.0	81.9	86.9	65.0	71.6*	56.0*	68.0	69.8	65.5
Predominately white college	78.0	77.6	78.6	58.5	62.1	53.6	76.5	86.2*	63.1*
Government	78.0	74.1	83.3	53.5	53.5	53.6	63.0	62.9	63.1
Investigator									
African American	80.5	78.5	83.3	66.0	70.7	59.5	65.0	63.8	66.7
White	76.0	75.0	77.4	55.0	60.3	47.6	70.0	75.9*	61.9*
Asian	77.0	75.9	78.6	53.5	56.0	50.0	58.0	56.0	60.7

* χ^2 distribution $P < .05$ for comparison of male and female

Table 3
Results from Wilcoxon Signed-Rank Test

		<i>Survey About Study Habits</i>		<i>Survey About Sexual Behavior and Drug Use</i>		<i>DNA Information From Buccal Swab</i>	
		<i>Preference</i>	<i>P Value</i>	<i>Preference</i>	<i>P Value</i>	<i>Preference</i>	<i>P Value</i>
Comparison versus HBC	SCSU	—	.55	SCSU	.02	HBC	.03
	Predominately white college	HBC	.002	—	.66	HBC	.04
	Government	HBC	.001	HBC	.03	HBC	<.001
Comparison versus AA investigator	White	AA	.002	AA	.01	AA	.002
	Asian	AA	.02	AA	.004	AA	.009

HBC—historically black college
SCSU—South Carolina State University
AA—African American

Table 4

Likelihood (OR and 95% CI) of Participating in a Study if Led by a White Investigator

Variables		<i>Survey About Study Habits</i>	<i>Survey About Sexual Behavior and Drug Use</i>	<i>DNA Information From Buccal Swab</i>
		<i>OR (95% CI)</i>	<i>OR (95% CI)</i>	<i>OR (95% CI)</i>
Gender (male)*		1.70 (0.68–4.24)	1.82 (0.97–3.43)	1.86 (0.81–4.31)
Trust score	Moderate**	3.15 (1.49–6.67)	0.73 (0.35–1.52)	1.71 (0.79–3.70)
	High**	131.92 (9.01–1931.95)	2.70 (1.23–5.94)	5.37 (1.65–17.47)
Previous participation†		0.27 (0.10–0.79)	0.32 (0.14–0.75)	0.15 (0.05–0.41)
Family/friend has participated***		1.05 (0.45–2.44)	0.95 (0.50–1.82)	2.09 (0.91–4.77)

OR—odds ratio
CI—confidence interval
* Compared to females
** Compared to individuals with low trust scores
*** Compared to individuals who answered “no”

recruitment of minorities is paramount to addressing health disparities.

Our study is novel in that it evaluates several factors that might affect participation in medical research by an African American college-age population. It is necessary to understand the attitudes and beliefs of this population because of their potential for future participation in studies.

The results of the study show that for African American college students, the study’s research design influences the likelihood of participation. Fewer respondents were willing to participate in a confidential survey regarding sexual behavior and drug use than were willing to provide a sample of DNA using a non-invasive method. This suggests that in this population there is more concern regarding the use of private information

than the use of DNA in an unethical fashion. Since most respondents were willing to participate in a survey that did not include sensitive information, clinical trials should minimize the use of sensitive information and reassure subjects regarding the confidentiality of their information.

Racial Concordance

An important, although not unexpected, finding was that participation is also affected by the race of the investigator or perceived racial culture of the institution conducting the study. The results of this study thus reiterate the finding from studies of other African American populations showing preference for participation in studies conducted by African American investigators and historically black colleges. We found this preference even in a young, well-educated population, and it indicates that racial concordance will be a continuing issue in African American recruitment. This finding emphasizes the need to develop strategies to increase the number of minority investigators and historically black colleges conducting clinical trials.

These findings suggest the need for predominantly white colleges, federal agencies, and non-African American investigators to increase their collaboration with African American investigators and institutions. Such collaborations proved beneficial in our study. We increased our recruiting success by having an African American student from a historically black college recruit African American young adults. Collaboration with community members, especially physicians, may also be helpful, since more than half of respondents stated that their physician's encouragement would increase their likelihood of participation in medical research. Further research is necessary to evaluate what physician factors, such as continuity, race concordance, and/or trust in medical researchers, are relevant to the effects of their encouragement on participation.

Gender

Several gender differences were apparent in bivariate comparisons. More than twice as many women had been asked to participate in medical research than men. Similarly, more than twice as many women reported having participated in medical research. Although women had a higher mean TMRS score than men, both means were over 24. Based on previous literature, respondents who score at least 24 on the TMRS are more likely to say they will volunteer to participate in a research program than those who score less than 24.¹⁵ Thus, the gender difference in mean TMRS score may be only statistically significant and not reflect a difference that affects future behaviors. Also, it may reflect differences in previous participation and not inherent gender differences. Women may be recruited more heavily for research studies if they are seen as being more likely to participate by investigators and

thus end up participating more than men. Further studies are necessary to evaluate whether the reasons for the gender differences identified in this study require improved recruitment strategies for men or are simply based on coincidental differential exposure to medical research.

Other Relationships

In adjusted relationships evaluating the likelihood of participating in medical research within the next 6 months, both the TMRS and past participation in research were significant. As expected, respondents with higher TMRS scores were more likely to participate in the future. Respondents who reported past participation in medical research were less likely to participate. Explanations for this finding could include the possibility that respondents had negative experiences during their past participation or that they felt they had fulfilled their civic duty by participating once and thus do not need to participate again. Future research is necessary to evaluate these hypotheses, since the population of African Americans willing to participate in research studies will decline if past participation leads to decreased future participation.

Limitations

Several limitations should be considered in the interpretation of our findings. First, the sample was limited to African American college students who attend a historically black university. Although these individuals should be more likely to report future participation in research than many other African Americans based on their age and education, their choice of attending a historically black university may reflect an underlying cultural centrality that makes them more comfortable with African American investigators. However, this sample was selected not to be representative of the general demographics of the US population but instead to reflect a group that is less likely to participate in research and represents future recruitment potential.

Second, the survey focuses on the likelihood of future participation, which as a behavioral intention is a valid predictor of future behavior. However, this measure does not measure actual participation under different circumstances. Thus, future behavior may differ from that reported in this survey.

Conclusions

Increasing African American participation in medical research requires an improved understanding of the factors affecting the decision to participate. Attention to sensitivity of information collected and collaboration with African American investigators, historically black colleges, community members, and physicians may improve African American representation in medical research. Trust in medical researchers and past research experience should also be considered.

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