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African American Participation in Health-Related Research Studies: Indicators for Effective Recruitment

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Abstract

Objective: To elucidate factors that influence African American willingness to participate in health-related research studies.

Methods: The African American Alzheimer disease research study group at North Carolina A&T State University designed an in-person questionnaire and surveyed more than 700 African American adults on their willingness to participate in health-related research studies. The questionnaire was distributed and collected in a nonclinical setting during the years 2008 and 2009. This study was approved by the North Carolina A&T State University Institutional Review Board.

Results: Of the 733 valid respondents, 16% had previously participated in a health-related research study. Of these, more than 90% were willing to participate again in future research studies. Of the 614 who had never participated in a research study, more than 70% expressed willingness to participate. The majority (75%) of experienced research study participants (RSP) were older than 40 years compared with 45% of non-research study participants. Experienced research participants were also twice as likely to have a college degree compared with non-research study participants. Seventy-three percent of non-research study participants were willing to participate in research studies in the future. The factors that were probable impediments to participation included lack of time and trust. Men with knowledge of the Tuskegee Syphilis Study

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were 50% less likely to be willing to participate compared with those who had not heard of Tuskegee Syphilis Study.

Conclusions: African Americans are willing to participate in health-related research studies. Several factors such as the appropriate incentives, community trust building, outreach, and community partnership creation are necessary for engaging minority participants. Incorporating factors that target African American enrollment in research design and implementation, such as increased training of minority health ambassadors and African American researchers and public health specialists, are needed to better engage minorities across generations, in research.

Keywords

African American; health-related research studies; recruitment

African Americans and other minorities continue to be underrepresented in clinical research studies. The long-term goal of this study is to offer more information on designing and implementing research studies that will increase participation of minorities in health-related research studies (HRRS).

Inclusion of African Americans and other minorities in clinical research studies was mandated by the National Institutes of Health Revitalization Act of 1993.[1] Previous studies on the topic of recruitment have shown that recruitment and retention of African Americans in clinical research trials is a major challenge, and as a consequence, such research trials rarely represent this segment of the population.[2,3] Several studies have documented that African American participation in clinical research trials is especially low among older persons.[4–10] Recognized barriers shown to contribute to African Americans' reluctance to participate in clinical trials include cultural differences, economic limitations, less access to health care, disparate care, less access to research facilities, perceived exclusion from and lack of trust in research.[8,11–19]

In spite of the numerous causes for mistrust of the health care system and research environments by African Americans (lack of access to care, historical research atrocities, racial segregation, and low numbers of minority health care professionals) some studies show that African Americans are just as willing to participate in clinical research studies and HRRS as their white counterparts.[20,21] While evaluating minority recruitment efforts of the health and retirement study, Ofstedal and Weir[22] observed that there was not a significant difference in interview and survey response rates by African Americans as compared with whites and Hispanics, when recruitment of minorities accurately represented the population. As evidenced by the previously mentioned studies, African American participation is not confined to noninvasive studies such as surveys and focus group activities. In a recent Alzheimer research study, African Americans had 39% and 43% participation rates for studies involving invasive procedures such as lumbar puncture and emission tomography, respectively.[13] It is important to mention that a study by Katz et al[23] found low willingness to participate in research studies involving invasive procedures, across 3 racial groups (white, African American, Hispanic). However, more than 50% of respondents were willing to give a biological sample or undergo a noninvasive procedure for research purposes.[23] These findings suggest that low rates of participation for some types of studies are not

unique to African Americans. The failure of some research groups to actively recruit minorities or African Americans accounts for low participation rates in these studies. A 2006 review of recruitment activities in clinical research studies reported a significant difference in race and ethnicity of the number of individuals invited to participate in HRRS.[15] The authors found that in many instances, Hispanics and African Americans were not actively recruited for participation. For example, nonwhite minorities comprised less than 1% of the total number of participants in several of the clinical registries that were reviewed.[15] These results highlight the need for increased support for minority recruitment, participation, and retention in studies to further improve the implementation of HRRS and the accuracy of these results.

Our study is one of the first to capture the differences in African American attitudes toward and willingness to participate in health-related research in otherwise healthy people in a nonclinical, community setting. The results of this study provide a list of factors that promote the willingness of minorities to participate in HRRS and substantiate behavioral intentions along with actual research participation. This study surveyed African Americans in the Greensboro, High Point, and Winston-Salem, North Carolina metropolitan area (the Triad), and included those with previous research participation experience, those without previous research experience but who were willing to participate in future research studies, and those who were not willing to participate. Our goal for this study is to offer specific strategies for designing and implementing research studies in a manner that will increase participation of minorities in HRRS.

Methods

Procedures

A survey instrument was developed to document the perceptions and attitudes of African Americans toward research participation. The survey consisted of 20 common questions for both groups, research study participants (RSP) and non-research study participants (NRSP), with an additional 15 questions only for those who had participated in a clinical research study or an HRRS and 11 additional questions for those who had not participated in a HRRS. The questionnaire was designed at the middle school reading level and the reading level was verified using online readability measuring tools and field tested for those with less than a high school diploma.[24] The survey instrument was also pilot tested and modified accordingly to increase internal validity of the results.

The term “health-related research study” will be referred to as HRRS, and survey respondents with prior HRRS participation will be referred to as RSP and those with no HRRS participation experience as NRSP, for the remainder of this article.

Study population and procedures—The study focused on African American adults, aged 18 years and older across gender and socioeconomic status, in the Triad region of North Carolina. To reach the demographic of interest in a nonclinical setting, the African American adults in hospitals, health clinics, or physician’s offices were excluded from this study. To reach a wider range of the African American community, defined groups representing different demographic clusters with respect to age, gender, and education

were identified. Clusters included academic: faculty, staff at historically black colleges and universities, African American sororities and fraternities; community: congregations from random samples of primarily African American churches; beauty parlors and barber shops with African American clienteles, community centers with African American participants at health fairs, civic organizations' meetings and other community events attended predominantly by African American adults. Surveys were administered by an interdisciplinary team of trained African American public health specialists that were community stakeholders with experience in facilitating educational and outreach activities in these communities. Participants completed the survey forms independently; however, administrators were available to answer any questions regarding the survey instrument or study. Study participants were not given incentives or reimbursements for completing the survey. This study was approved by the North Carolina A&T State University's Institutional Review Board.

Measures

Data were collected in a deidentified state for all subjects surveyed. Demographic data collected included age, gender, level of education, and place of residence. For those who reported previous research participation (RSP), questions assessed the following: (1) knowledge, if any, of well-known health studies (such as the Tuskegee Syphilis Study [TSS], Framingham Heart Study [FHS], Women's Health Initiative [WHI.); (2) willingness to participate again in the future; (3) type of study in which they had participated; (4) disease associated with the study; (5) participation experience; and (6) motivation for participation.

For those who did not report previous participation (NRSP) in research studies, subsequent questions assessed the following: (1) knowledge, if any, of well-known health studies including the TSS, the FHS, the WHI, and so on; (2) willingness to participate in future HRRS; (3) the types of studies in which they were willing to participate; (4) their willingness to give clinical samples if necessary; (5) their knowledge of and willingness to participate with informed consent (IC) protocol; and (6) motivation for participation.

Statistical analysis

Data collected from the surveys were entered into Microsoft Excel, and analyzed using IBM SPSS (vl9; IBM Corp., Armonk, New York). Statistical analyses included both descriptive and inferential. Data for this study were analyzed using multivariate statistical methods because the goal of this study was to understand the role (if any) of multiple variables (including demographic and others) on participation of African Americans in HRRS. Logistic regression models and odds ratios (OR) were appropriate for these analyses because the dependent variables (participation [yes/no] or the willingness to participate) were categorical. Log odds were used to obtain the odds of participation (yes/no binary outcome) in HRRS under differing independent variable conditions.

Results

Demographics

The final study sample consisted of 733 residents of North Carolina, primarily from the Triad region of Central North Carolina. A total of 855 complete or partially complete surveys were received out of 1000 that were distributed for a response rate of 85%. Out of the 855 surveys received, 17 were excluded for lack of critical demographic or other information. Another 105 were excluded because of the following: (1) 102 were residents of other states (Florida, South Carolina, Virginia, or Texas) and (2) 3 surveys did not give residential information. Those surveys missing only 1 demographic variable (age, gender, or education) information but had other necessary information were included in the analyses.

Table 1 presents the distribution of survey responses for the questions about gender, age, and level of education. The final sample consisted of 60% women and 40% men. This ratio was similar for RSP and NRSP suggesting that both gender groups were equally likely to be RSP or NRSP. To report age, respondents were asked to choose from 7 age categories; these categories were then dichotomized into 2 groups: those aged 40 years and younger and those older than 40 years for binary logistic models. Age 40 was used as a cut point because many researchers believe that important “integration of information processing and emotional self regulation” is achieved during the middle adulthood, which begins at the age of 40 years.[25]

Age 40 was used as a cut point because the TSS trial began about 40 years ago (1973–1974) and it is possible that much of the mistrust of the health establishment among African Americans began with TSS trial.[26] Approximately 50% of survey respondents were older than 40 years. However, RSP were older compared with the NRSP. Almost 75% of RSP were older than forty years as compared to 45% of NRSP. With all 3 demographic variables in the model, the odds of RSP being older than 40 years were 3 times (95% confidence interval [95% Cl], 1.96–4.87) the odds of NRSP being older than 40 years.

Survey participants were asked to report their highest level of educational achievement and were given several categories to choose from. These categories were dichotomized into those with and without a college degree for analyses. It is believed that those with a college education will have increased awareness about the importance of research study participation. When compared across educational levels, 46% of the total sample had a college degree. In comparison, 67% of RSP and only 42% of NRSP had college degrees. Those with a college degree were more than twice as likely (OR = 2.24; 95% Cl, 1.45–3.45) to have participated in a research study compared with those without a college degree.

Willing or Not Willing to Participate?

Survey respondents with no prior research study experience, NRSP, were then asked whether they would be willing to participate in future HRRS. Their responses were categorized into 2 groups: (1) those willing to participate in future HRRS and (2) those not willing to participate in future HRRS. Logistic regression models were used to ascertain whether the demographic characteristics (gender, age, and educational level) would predict the likelihood of respondents’ willingness to participate.

As shown in Table 2,73% were willing and 27% were unwilling to participate in future HRRS. Slightly more men than women were unwilling to participate; however, the difference was not statistically significant. For age-related analyses, respondents' were categorized into 2 groups: younger than 40 years and older than 40 years, as before. Younger respondents (aged <40 years) were more likely to state that they were willing to participate compared with those older than 40 years.

The education level of respondents was similarly categorized into 2 groups: with and without a college degree. Analyses showed that the percent willing to participate was not significantly different between the 2 educational categories. Gender and educational levels were not statistically significant predictors of future research participation. It is possible that the disproportionate distributions of those willing and unwilling could have led to diminished power and contributed to nonsignificance of these 2 factors. However, willingness to participate did vary significantly by age. Those younger than 40 years were 70% more likely to be willing to participate than those above 40 years of age.

Subjects were then asked whether they had knowledge of any well-known national or local HRRS (see Supplemental Digital Content available at http://links.lww.com/JPHMP/A16). Respondents were asked to choose from well-known studies, including TSS, FHS, WHI, Sister Study, and others. Almost 85% of RSP and 58% NRSP had heard of at least one national or local health study. More than 66% of RSP and 50% of NRSP had heard of the TSS.

Non-research study participants who were willing to participate in future research were asked what would motivate them to participate in a research study. As shown in Table 3, overall, more people would be motivated to participate if one of their relatives had the disease than if they had the disease. For women, monetary compensation and having the disease themselves were the next highest motivators, whereas for men, monetary reasons and civic duty were the next 2 choices. For respondents younger than 40 years, a high proportion selected monetary compensation as their motivation for participation followed by "I have the disease." For those aged 40 years and older, the other choices were almost equally selected with civic duty a little more popular than "I have the disease." Comparing across educational levels, respondents with a college degree rated "I have the disease" as a slightly higher motivator than civic duty. Monetary compensation was the second most popular choice for both groups (with and without a college degree). For those without a college degree, the other 2 choices ("I have the disease" and civic duty) were the least motivating.

Those with prior participation experience, RSP, were also asked whether they "would be willing to participate in another research study or clinical trial?" Ninety-four of the 119 participants responded to this question (data not shown). The majority (91.5%) of respondents were willing to participate again. When asked to rate their prior participation experience, 79% rated it better than average with scores ranging between 6 and 10 (on a scale of 1–10, where, 1 = poor, 5 = average, 10 = exceptional).

Survey participants (NRSP) who were unwilling to participate (n = 166) in any future HRRS were asked a subjective question of why they were unwilling. Of the 166 unwilling, 104

responded to this question and the responses were grouped into the following categories: lack of time, lack of trust, health status, lack of interest, and other. As shown in Table 4, overall, the most common responses were lack of time (32.7%), followed by lack of trust (26%) and various other reasons (25%). However, when compared across gender, the primary reason for women's unwillingness to participate was lack of time (34.8%) followed by other reasons (27.5%). For men, lack of trust (37.1%) was the primary reason for unwillingness, followed by lack of time (28.6%). Other written responses included: "knowledge," "I don't want to," "depends," "I've done it before and it doesn't work for me," "don't understand," "I don't know," "too old," and "I would like to think about it." There were no statistically significant differences in responses between the other demographic groups. Lack of time and lack of trust were the most popular responses for both age (<40 and 40+) and educational categories (with or without a college degree). Those younger than 40 years were slightly more likely to mention lack of time (59.3%) compared with those age 40 years or older (40.7%); data not shown.

TSS knowledge

Overall, 62.8% of the 733 survey respondents had heard of at least one HRRS, and about 53% had heard of TSS. When awareness of TSS was compared across gender, education, and age, awareness of TSS significantly differed by education and gender. Awareness among women was 54% compared with men at 44%. Sixty-three percent of those with a college degree were aware of TSS as compared with 40% without a college degree. The difference with respect to age was not statistically significant.

Among the NRSP and the RSP the rates for TSS awareness were 50% and 66.4%, respectively. Further, among the NRSP, we wanted to determine whether knowledge of TSS was related to respondents' willingness to participate in future HRRS. Although not statistically significant, those who had heard of TSS were less likely to be willing to participate in future research studies (OR = 0.77; 95% Cl, 0.54–1.1). When compared across gender, having or not having knowledge of TSS did not seem to affect women's willingness to participate (OR = 1.0; 95% Cl, 0.64–1.6). However, men who had heard of TSS were half (50%) as likely to be willing to participate as compared with those who had not heard of TSS (OR = 0.5; 95% Cl, 0.28–0.87).

These results were further validated, when reasons for nonparticipation (or unwillingness to participate) as discussed earlier, were categorized by gender and TSS knowledge. Among those who gave "lack of Trust" as a reason for "not willing to participate," 91% had heard of TSS. As seen in Table 5, men who had heard of TSS were more likely to give "lack of trust" (65%) as the primary reason for "not willing to participate" with only 5% giving "lack of time" as their primary reason. Whereas, among men who had not heard of TSS, the primary reason for "not willing to participate" was lack of time (58%), with "lack of trust" a distant second with 17%.

For women, both groups (those who had heard of TSS and those who had not) gave "lack of time" as their primary reason for nonparticipation, 34% and 50%, respectively. "Lack of trust" tied with "other" as the second most frequently mentioned reason (25%) for nonparticipation in the "heard of TSS" group.

Those willing to participate (n = 448) were asked, “In what type of research study would you be willing to participate?” The choices for selection were survey studies, genetic studies, clinical trials, and focus groups. The most popular choice among respondents was survey study, whereas the least popular choice was clinical trials. More women than men chose focus group and this selection showed the largest gender difference (female, 37.5%; male, 27.3%). The smallest gender difference was observed in the selection of clinical trials (female, 28.7%; male, 25.6%).

Survey respondents who were willing to participate (n = 448) were further asked whether they would be willing to give a biological sample (ie, blood, urine, or hair) for a research study. Almost 96% were willing to give a sample for research (data not shown). Next, the NRSP were asked whether they were aware of mandatory IC protocol. Overall, more than 83% knew that all research studies required IC of the participants. This knowledge of IC protocol was similar when compared across gender, age, education, and their willingness to participate in future HRRS.

Non-research study participants were then given a brief definition and explanation for IC and were asked whether they agreed or disagreed with the statement, “I am willing to participate in HRRS now that I know about the requirement for informed consent.” A Likert-type scale was provided to understand their level of willingness to participate in future HRRS (strongly agree = 10, strongly disagree = 1). Although the willingness of participants ranged from *strongly disagree* (1) to *strongly agree* (10), the average score was 6.4 (SD = 3.15). Willingness was also compared across the demographic groups of gender, education, their prior stated willingness to participate and their knowledge of IC. All demographic groups had similar mean and median scores, and the differences were not statistically significant. The only significant difference in “willingness after IC” scores was observed between those who were willing before reading information on IC had a high willingness score (mean = 7.25, SD = 2.8, median score = 7)) and those unwilling before reading information on IC had a low willingness score (mean = 3.95, SD = 2.9, median score = 5). This suggests that the majority of those who were unwilling to participate in HRRS before reading about IC continued to be unwilling even after reading about IC.

Discussion

The Revitalization Act of 1993 (updated in 2001) has further focused attention on the relative absence of minorities, in particular African Americans, in medical and health-related research.[1] Several articles have been published since that time that focus on recruitment successes or failures, but few have investigated a community’s potential participants and evaluated their willingness to participate if asked. We surveyed a cross-sectional sample of healthy African Americans, primarily from North Carolina. Responses of participants who were not residents of North Carolina were not used in the final analyses. Our goal was to better understand this population’s views on research participation and then compare the responses of those who were and those were not willing to participate in the future.

Our results show that significant numbers of African Americans have participated or are willing to participate in HRRS and that gender did not dictate whether a person was willing

to participate in HRRS. Specifically, we show that older participants (aged >40 years) with college degrees were more than twice as likely to have participated as compared to those younger (<40 years) and without college degrees. These results are consistent with other studies that show that older African Americans with higher educational attainment were more likely to actually participate in HRRS and suggest that significant predictors of participation by older African Americans include income, attitudes about fairness, and understanding research as a key to improving health care.[27]

Our study showed that younger African Americans may not have participated in large numbers, but they were very willing to participate. Diaz et al[28] showed that younger African Americans were more likely to participate in a study if conducted by a historically black college or African American investigator. In the same study, respondents with more trust in the research process and without prior research participation experience were more likely to participate. In our study, the most common reason given for nonparticipation was “lack of time” for women and “lack of trust” for men. The “lack of trust” response from men corresponded with the lack of participation or unwillingness by men and knowledge of TSS.[19,28] As several other studies have shown, trust of the medical establishment is still a factor, primarily for African Americans and men in particular.[3,18,29,30] The issue of trust in the African American community substantiates the need to build culturally relevant recruitment methods into study design. One way to accomplish this is by incorporating long-term relationship building models into study design that are structured to address issues of burden and trust within minority communities.[31,32]

In addition, we found that respondents were motivated to participate by having a “relative with disease,” by their sense of “civic duty” and with monetary compensations. Money was the second highest motivator for all groups, except those older than 40 years for whom civic duty was the second highest. These results support using specific recruitment methods and language that emphasize the importance of participation for minority participants. Personalizing a disease, by having risk for their family, and receiving current information about the disease and its effects on health and wellness are likely to prompt interest in research outcomes and thereby increase participation by this population.[21] An interdisciplinary approach that employs a comprehensive outreach model that lowers the costs and increases convenience of participation (addressing “lack of time”) can also be an effective way of recruiting minority participants.[21,33–35] Interventions that incorporate education and address barriers such as racial discrimination, beliefs, and mistrust of clinical trials, as well as economic barriers may have more success in recruiting African Americans.[11,18]

Several studies have found that the most common barriers are related to the lack of opportunity for participation. These opportunity factors involve personal characteristics such as income, minority status, and health conditions.[3] The lack of health insurance, an individual’s age, as well as study design protocol have also been seen as barriers to African American participation.[2,35–37] Therefore, interventions that increase the number of opportunities for participation by eliminating factors or barriers are more likely to increase African Americans’ understanding of the benefits and risks of research participation and ultimately help to populate studies with African American participants. More importantly,

using a multifaceted community-based approach for minority recruitment that builds trust and provides services along with other appropriate incentives is an effective way of increasing minority enrollment in research studies.[19,32,38]

A limitation of this study was that the overall survey response sample may not represent the African American population in the Triad region of North Carolina with respect to educational achievement. However, both groups, those with a college degree and those without, were independent and large enough in the sample to discuss their attitudes toward participation in HRRS.

In conclusion, this study emphasizes the need to use different strategies for addressing time, costs and relevance to improve recruitment of intergenerational African Americans. Providing appropriate incentives to decrease costs of participation, increase convenience, improve information access, and awareness of research opportunities, are some ways to increase willingness of African American participation in HRRS.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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TABLE 1

Demographic Characteristics of Research Study RSP and NRSP

	Total Sample	RSP	NRSP	Logistic Regression, OR (95% CI)
Gender	n = 733	n = 119	n = 614	0.98 (0.64–1.52)
Male	39.6%	37.8%	39.9%	
Female	60.4%	62.2%	60.1%	
Age group	n = 716[a]	n = 116[a]	n = 600[a]	3.09[a,b](1.96–4.87) (≤40 or 40+)
18–24	193 (27%)	11 (9.5%)	182 (30.3%)	
25–29	70 (9.8%)	7 (6.0%)	63 (10.5%)	
30–39	96 (13.4%)	12 (10.3%)	84 (14%)	
40–49	119 (16.6%)	28 (24.1%)	91 (15.2%)	
50–59	124 (17.3%)	26 (22.4%)	98 (16.3%)	
60–69	79 (11%)	23 (19.8%)	56 (9.3%)	
70+	35 (4.8%)	9 (7.8%)	26 (4.3%)	
Education	n = 715[c]	n = 119	n = 596[c]	2.24[a,b] (1.45–3.45) (with or without college degree)
<High school	23 (3.2%)	2 (1.7%)	21 (3.4%)	
High school/GED	270 (37.8%)	31 (26.1%)	239 (38.9%)	
AD/some college	92 (12.9%)	6 (5%)	86 (14%)	
bachelor's degree	178 (24.9%)	39 (32.8%)	139 (22.6%)	
Master's degree	117(16.4%)	31 (26.1%)	86 (14%)	
Doctoral or professional	35 (4.9%)	10 (8.4%)	25 (4.1%)	

Abbreviations: AD, associates degree; 95% Cl, 95% confidence interval; NRSP, non-research study participants; OR, odds ratio; RSP, research study participants.

[a]Significant at 5% level of significance.

[b]OR for dichotomized variables.

[c]Some responses were missing age and/or education data.

TABLE 2

Survey Respondents Willing to Participate in Future Research Studies by Gender, Age, and Educational Level

	Willing to Participate	Not Willing to Participate	Logistic Regression OR (95% Cl)
Gender	n = 448	n = 166[a]	1.03(0.70–1.5)
Male	39.3%	41.6%	
Female	60.7%	58.4%	
Age group	n = 435	n = 165[a]	1.7 (1.14–2.44)[b] (≤40 or 40+)
18–24	34.9%	18.3%	
25–29	11.5%	7.9%	
30–39	12.2%	18.9%	
40–49	12.9%	21.2%	
50–59	16.1%	17.1%	
60–69	8.3%	12.2%	
70+	4.1%	4.9%	
Education	n = 433	n = 163[a]	1.03(0.7–1.51) (with or without college degree)
<High school	3.0%	4.9%	
High school/GED	41.3%	37.0%	
Some college	13.9%	16.0%	
BA/BS	22.6%	25.3%	
Master	14.3%	14.7%	
Doctoral or professional	4.8%	2.5%	

Abbreviations: 95% Cl, 95% confidence interval; OR, odds ratio.

[a]includes “not sure” (1 person).

[b]Significant at 5% level of significance.

TABLE 3

Respondents' Motivations for Future Research Study Participation

Motivation	Relative Has the Disease, %	I Have the Disease, %	Monetary, %	Civic Duty, %
Overall (willing)[a]	48.4	24.6	31.9	23.5
Gender				
Male	53.9	24	35.9	31.3
Female	59.6	32.8	39.1	25.2
Age				
Less than 40	57.9	32.2	45.5	27.4
40+	56.4	25.2	27.1	29.4
Educational level				
Less than college degree	55.8	23.5	35.7	24.8
College degree or higher	58.7	35.8	41.8	31.3

[a]Percents do not add to 100 because more than 1 choice could be selected.

TABLE 4

Reasons for Unwillingness to participate in Health-Related Research Studies by Gender

	Reasons for Unwillingness to participate					
Gender	**Lack of Time**	**Lack of Trust**	**Health Status**	**No Interest**	**Other**	**Total**
Female	24 (34.8%)	14 (20.3%)	2 (2.9%)	10 (14.5%)	19 (27.5%)	69
Male	10 (28.6%)	13 (37.1%)	1 (2.9%)	4 (11.4%)	7 (20%)	35
Total	34 (32.7%)	27 (26.0%)	3 (2.9%)	14 (13.5%)	26 (25.0%)	104 (100%)

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TABLE 5

Survey Participant Reasons for "Not Willing" to Participate in Health-Related Research Studies by Gender and TSS Knowledge

	Males		Females	
Reasons of "Not Willing to Participate"	**Heard of TSS**	**Not Heard of TSS**	**Heard of TSS**	**Not Heard of TSS**
Lack of time	5%	58%	34%	50%
Lack of trust	65%	17%	25%	0%
Not interested	15%	8%	16%	6%
Other	15%	17%	25%	44%

Abbreviation: TSS, Tuskegee Syphilis Study.