Awareness of the Tuskegee Syphilis Study and the US Presidential Apology and Their Influence on Minority Participation in Biomedical Research

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Objectives. We compared the influence of awareness of the Tuskegee Syphilis Study and the presidential apology for that study on the willingness of Blacks, non-Hispanic Whites, and Hispanics to participate in biomedical research.

Methods. The Tuskegee Legacy Project Questionnaire was administered to 1133 adults in 4 US cities. This 60-item questionnaire addressed issues related to the recruitment of minorities into biomedical studies.

Results. Adjusted multivariate analysis showed that, compared with Whites, Blacks were nearly 4 times as likely to have heard of the Tuskegee Syphilis Study, more than twice as likely to have correctly named Clinton as the president who made the apology, and 2 to 3 times more likely to have been willing to participate in biomedical studies despite having heard about the Tuskegee Syphilis Study (odds ratio [OR] = 2.9; 95% confidence interval [CI] = 1.4, 6.2) or the presidential apology (OR = 2.3; 95% CI = 1.4, 3.9).

Conclusions. These marked differences likely reflect the cultural reality in the Black community, which has been accustomed to increased risks in many activities. For Whites, this type of information may have been more shocking and at odds with their expectations and, thus, led to a stronger negative impact. (*Am J Public Health.* 2008;98:1137–1142. doi:10.2105/AJPH.2006.100131)

The US Public Health Service Tuskegee Syphilis Study (1932–1972) is arguably the most infamous biomedical research study in US history.[1–5] This study enrolled 399 Black sharecroppers in Macon County, Ala, and studied the effects of not treating their syphilis.[6,7] There is widespread belief that the "legacy" of this unethical study is that the Black community has a greater reluctance to participate in clinical research studies because of the abuses foisted on the participants in that study. Although a considerable amount has been written about the long-lasting effects of the Tuskegee Syphilis Study on the Black community, most of this work has been from a legal, historical, ethical, or access to health care perspective.[8–20]

Surprisingly few research articles have directly examined whether any differential participation of Blacks or other minorities in biomedical studies compared with participation of Whites was because of the legacy of the Tuskegee Syphilis Study or because of other factors.[21–28] A recent literature review noted that only 5 of the published studies to date have presented quantified data that compared Black with White participation and the relation to the Tuskegee Syphilis Study,[29] and most of them only used a single question on willingness to participate as their measure of this complex decison.[30] A recent study used a series of questions to create 2 validated scales to measure willingness to participate and found that Blacks self-reported that despite having a higher fear of participation, they were just as likely as Whites to participate in biomedical research.[30]

For our study, we used data from a telephone survey of adults in 4 US cities that used the Tuskegee Legacy Project (TLP) Questionnaire.[30] We sought to compare racial/ethnic differences among Blacks, Whites, and Hispanics, in the level of awareness of the Tuskegee Syphilis Study and the US presidential apology made to the Black community, and to compare the self-reported influence among Blacks, Whites, and Hispanics of both the study and the presidential apology on the willingness to participate in biomedical studies.

METHODS

The TLP Questionnaire was administered via random-digit-dialed telephone interviews to 1133 Blacks, Hispanics, and Whites aged 18 years and older in 4 city and county areas: Birmingham and Jefferson County, and Tuskegee and Macon County, Ala; Hartford and Hartford County, Conn; and San Antonio and Bexar County, Tex. All interviews were conducted between March 1999 and November 2000.

The TLP Questionnaire, a 60-item instrument, addresses a range of issues related to the recruitment of minorities into biomedical studies. Details on the history and development of the TLP Questionnaire and justifications of the methodological decisions both for the selection of the 4 cities and for the analysis of the TLP Questionnaire have been described elsewhere.[3,30] All TLP Questionnaire interviews were conducted in English. Respondents answered questions but were provided no information about the Tuskegee Syphilis Study during the interview.

The interviews were administered by the Survey Research Unit of the University of Alabama at Birmingham. The target population consisted of noninstitutionalized adults who lived in households with working telephones in the 4 targeted cities and counties. The sample of households in each of the 4 locations was supplied by Survey Sampling Inc (Fairfield, Conn) and was based upon a simple random sampling of telephone numbers that used the 3-digit telephone exchanges for those local calling areas with partial screening

for nonworking or business numbers. Thirteen interviewers, trained for the survey, used the full computer-assisted telephone interviewing technology. Unresolved numbers were retired after 20 attempts. Interviewers were supervised at all times and randomly electronically monitored a minimum of 4 times per month.

We conducted unadjusted bivariate analyses, which were followed by multivariate logistic regression analyses, adjusted for age, gender, education, and income, as well as city. To acknowledge and account for cultural differences among the cities (i.e., above and beyond simple demographic differences), we included the variable *city* as a separate covariate in all multivariate analyses of the study sample as a whole. We conducted the bivariate and multivariate analyses using SPSS version 14.0 (SPSS Inc, Chicago, Ill) and SAS version 9.0 (SAS Institute Inc, Cary, NC). We calculated confidence intervals (CIs) for percentages using Stata version 9 (Stata Corp, College Station, Tex) with its module Confidence Interval for Proportions.

RESULTS

Response rates in Birmingham and Jefferson County, Tuskegee and Macon County, Hartford and Hartford County, and San Antonio and Bexar County were 70%, 65%, 49%, and 50%, respectively. The overall completion rate (number of completed interviews per number of initiated interviews) exceeded 90% in each city. For San Antonio, the major Spanish-speaking Hispanic population accessed in this survey, 10% of the contacted individuals indicated that they could not participate with the English-language-only instrument. Table 1 shows the age, gender, education, and income distribution of the 1133 respondents within the 3 racial/ethnic groups.

To determine if a respondent was aware of the Tuskegee Syphilis Study, the TLP Questionnaire had 2 separate recognition probes. The first recognition probe consisted of the respondents being asked directly whether they had ever heard about the Tuskegee Syphilis Study. The 3 racial/ethnic groups differed markedly on responses to this first recognition probe for the Tuskegee Syphilis Study with 72.6% of Blacks, 55.2% of Whites, and 23.6% of Hispanics answering yes ($P<.001$, by the χ^2 test). Each contrast between any 2 of the racial/ethnic groups was also statistically significant at $P<.001$. The second probe, which occurred 6 questions later in the interview, was only asked of individuals who either said no to having heard of the Tuskegee Syphilis Study in the first probe or who answered yes to that first probe but could provide no details about that study.

Of the original 1133 respondents who were interviewed, 57.2% (95% CI=54.3%, 60.1%) indicated that they had heard of the Tuskegee Syphilis Study when the data from both probes were combined. For the 1128 respondents who filtered through the 2 probes with valid responses (i.e., a yes or no response), there were marked differences among the racial/ethnic groups on their final yes or no answer to the inquiry on whether they had ever heard of the Tuskegee Syphilis Study.

Results of an unadjusted bivariate analysis based upon the 2-probe combination showed that 76.4% of the 353 Blacks in the study (95% CI=71.7%, 80.8%), 56.8% of the 623 Whites in the study (95% CI=52.8%, 60.8%), and 25.3% of the 157 Hispanics in the study (95% CI=18.9%, 33.0%) had indicated that they had heard of the Tuskegee Syphilis Study (Figure 1). This difference was statistically significant across the 3 racial/ethnic groups ($P<.001$, by the χ^2 test), with each 2-way contrast also statistically significant ($P<.001$, by the χ^2 test). Across racial/ethnic groups, a comparison of yes responses to the first probe only versus the yes responses to the 2-probe combination revealed that only a very slight upward correction factor resulted from the use of the second probe for each of the 3 racial/ethnic groups (i.e., an increase of 3.8 percentage points in Blacks, 1.6 percentage points in Whites, and 1.7 percentage points in Hispanics).

Figure 1 also shows the percentage of correct responses to: "Has any US President ever apologized for the Tuskegee Syphilis Study?" and "Which US president?" Of the Blacks in the study, 42.5% had heard of the presidential apology (95% CI=27.3%, 47.8%) and 34.8% knew that President Clinton had given the apology (95% CI=29.9%, 40.0%). Of the Whites in the study, 28.1% had heard of the presidential apology (95% CI=24.6%, 31.8%) and 24.1% knew that President Clinton had given the apology (95% CI=20.8%, 27.6%). Of the Hispanics in the study, 8.3% had heard of the presidential apology (95% CI=4.5%, 13.7%) and 3.2% knew that President Clinton had given the apology (95% CI=1.0%, 7.3%).

Table 2 shows the multivariate logistic regression analyses of the responses to the

TABLE 1—Age, Gender, Education, and Income Distribution of Respondents (N = 1113), by Racial/Ethnic Group: Tuskegee Legacy Project Study, 1999–2000

	Blacks[a,b]	Whites[a,c]	Hispanics[b,c]
Total, No.	353	623	157
Age, mean (SD)	49.1 (16.5)	53.8 (17.0)	41.5 (16.1)
Male, % (95% CI)	52.1 (46.8, 57.4)	48.3 (44.3, 52.3)	39.5 (31.8, 47.6)
Education level, % (95% CI)			
Less than high school graduate	21.6 (17.4, 26.4)	11.8 (9.4, 14.7)	14.0 (9.0, 20.4)
High school graduate or some college	60.5 (55.3, 65.8)	51.3 (47.4, 55.4)	61.0 (53.5, 68.8)
College graduate or higher	17.9 (14.0, 22.2)	36.9 (33.1, 40.8)	25.0 (16.3, 32.4)
Income level, % (95% CI)			
< $20 000	42.8 (37.6, 48.1)	21.3 (18.2, 24.8)	41.7 (33.6, 49.5)
$20 000–$74 999	52.1 (46.8, 57.4)	58.4 (54.4, 62.3)	52.5 (44.1, 60.3)
≥ $75 000	5.1 (3.1, 7.9)	20.3 (17.1, 23.6)	5.8 (2.7, 10.6)

Note. CI = confidence interval.
[a]Statistically significant contrasts for Blacks versus Whites: differed on age, education, and income ($P \leq .05$).
[b]Statistically significant contrasts for Blacks versus Hispanics: differed on age and gender ($P \leq .05$).
[c]Statistically significant contrasts for Hispanics versus Whites: differed on age, gender, education, and income ($P \leq .05$).

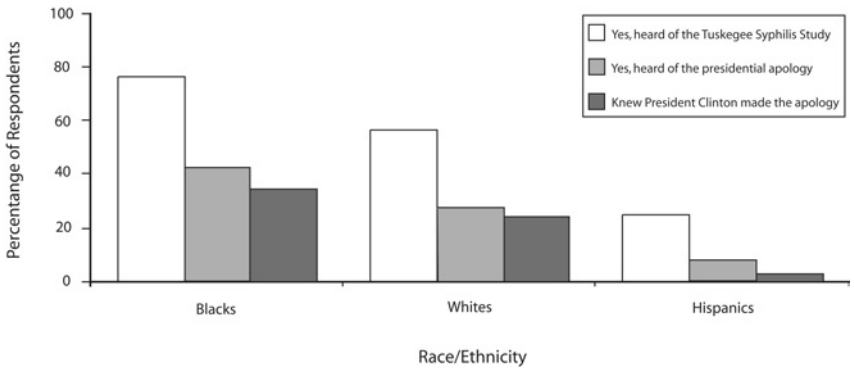

FIGURE 1—Responses to having heard of the Tuskegee Syphilis Study and the presidential apology, and knowing who made that apology, among Blacks, Whites, and Hispanics: Tuskegee Legacy Project Study, 1999–2000.

same 3 questions adjusted for age, gender, education, income, and city. The adjusted multivariate analysis shows that the odds of hearing of the Tuskegee Syphilis Study were nearly 4 times greater for Blacks than for Whites (odds ratio [OR]=3.9; 95% CI=2.6, 5.7). The difference in odds between Hispanics and Whites was not statistically significant (OR=1.6; 95% CI=0.93, 2.7). The adjusted multivariate analysis for having heard of the presidential apology showed that whereas the odds for Blacks did not significantly differ from the odds for Whites (OR=1.6; 95% CI=0.91, 2.7), the odds of correctly naming Clinton as the President who made the apology were 2 times greater for Blacks than for Whites (OR=2.3; 95% CI=1.6, 3.4). Too few Hispanics had heard of the apology to include Hispanics in these latter 2 analyses.

Given that the ORs for these 3 questions by city (Table 2) showed a strong effect of city of residence on awareness of the study and of the presidential apology, adjusted ORs were computed to assess the racial difference for each of the 3 questions within each city. Because of the limitations of sample size on the stability and interpretation of data, this further analysis was only conducted for Blacks and Whites in the 3 cities with substantial numbers of these 2 racial groups (i.e., Birmingham, Tuskegee, and Hartford). The results of this additional within-city analysis indicated that the odds of Blacks having ever heard of the Tuskegee Syphilis Study were 4 to 5 times higher than were the odds for Whites in the cities of Hartford and Birmingham (OR=4.37 [95% CI=2.40, 7.96] and OR=5.47 [95% CI=2.35, 12.71], respectively), but not significantly different from Whites in the city of Tuskegee (OR=2.37; 95% CI=0.89, 6.34).

Although there were no statistically significant differences in odds between Blacks and Whites for the question "Has any US President ever apologized for the Tuskegee Syphilis Study?" in any of the 3 cities, statistically significant differences were observed for the third question: "Which US President?" For each of the 3 cities, Blacks were 2.5 to 3 times more likely than were Whites to correctly name Clinton as the president who made the apology (Hartford: OR=2.81 [95% CI=1.31, 6.03]; Birmingham: OR=2.97 [95% CI=1.44, 6.11]; and Tuskegee: OR=2.50 [95% CI=1.33, 4.70]).

Respondents who replied yes to the 2-probe series on ever having heard of the Tuskegee Syphilis Study were then asked the follow-up question: "As a result of what you have heard about the Tuskegee Syphilis Study, how likely are you to participate in a medical research study?" with responses on a 5-point Likert scale ranging from *much more likely* to *much less likely.* Because very few Hispanic respondents had responded yes to this 2-probe series (n=39), this analysis was performed only for Black and White respondents.

Figure 2 shows an unadjusted bivariate analysis that revealed that among those who had heard of the Tuskegee Syphilis Study, the negative influence on the likelihood of participation in future studies was less among Blacks than among Whites; i.e., 50.0% of Blacks and 70.3% of Whites reported that they were less likely to participate as a result of what they had heard about the Tuskegee Syphilis Study ($P<.001$; Kendall's tau-B).

Multivariate logistic regression analysis of this question (adjusted for age, gender, education, income, and city) revealed that despite what they had heard about the Tuskegee Syphilis Study, the odds of Blacks indicating a willingness to participate in biomedical studies were nearly 3 times greater than the odds of Whites (OR=2.9; 95% CI=1.4, 6.2).

After the respondent was asked "Has any US President ever apologized for the Tuskegee Syphilis Study?" a follow-up question was asked: "Based upon what you heard about the apology, would it influence your decision to join a biomedical research study today? Did that apology make you more or less likely to join a study?" This question also had a 5-point Likert scale of responses ranging from *much more likely* to *much less likely.*

The results from an unadjusted bivariate analysis of this follow-up question are shown in Figure 2 and again revealed a much less negative influence on Blacks, with 41.3% (vs 61.8% of Whites) self-reporting that they were less likely to join a biomedical study as a result of the presidential apology ($P=.008$, by the χ^2 test). Multivariate logistic regression analysis of this question (adjusted for age, gender, education, income, and city) revealed that the odds of indicating that they were more likely to participate in biomedical studies as a result of having heard of the presidential apology were more than 2 times greater for Blacks than for Whites (OR=2.3; 95% CI=1.4, 3.9).

DISCUSSION

Aspects of Current Study

This study clearly shows marked and statistically significant differences among Blacks, Whites, and Hispanics with regard to their awareness of the Tuskegee Syphilis Study and the presidential apology for that study. The 3 key questions analyzed in this report (Have you ever heard of the Tuskegee Syphilis

TABLE 2—Logistic Regression Multivariate Analyses for Key Questions on Questionnaire: Tuskegee Legacy Project Study, 1999–2000

	"Have You Ever Heard of the Tuskegee Syphilis Study?" OR (95% CI)	"Has Any US President Ever Apologized for the Tuskegee Syphilis Study?" OR (95% CI)	"Which US President?" OR (95% CI)
Race/ethnicity[a]			
Blacks	3.87 (2.63, 5.70)	1.58 (0.91, 2.72)	2.33 (1.63, 3.80)
Hispanics	1.59 (0.93, 2.73)	. . .[b]	. . .[b]
Education levels[c]			
High school graduate	1.36 (0.84, 2.20)	1.30 (0.58, 2.94)	1.36 (0.79, 2.34)
Some college	2.20 (1.28, 3.78)	1.70 (0.71, 4.11)	2.05 (1.14, 3.68)
College graduate	3.14 (1.73, 5.69)	2.19 (0.83, 5.79)	3.62 (1.91, 6.85)
Higher than college graduate	5.89 (2.90, 11.99)	2.16 (0.72, 6.52)	3.49 (1.70, 7.17)
Income levels,[d] $			
20 000–34 999	1.29 (0.85, 1.96)	0.74 (0.37, 1.47)	1.60 (1.00, 2.55)
35 000–49 999	1.53 (0.93, 2.52)	1.18 (0.51, 2.71)	2.60 (1.50, 4.52)
50 000–74 999	2.20 (1.28, 3.77)	1.66 (0.66, 4.14)	2.97 (1.65, 5.36)
≥ 75 000	1.66 (0.94, 2.92)	1.10 (0.42, 2.88)	1.89 (0.97, 3.58)
Gender[e]			
Female	0.66 (0.48, 0.90)	0.99 (0.00, 1.63)	0.61 (0.43, 0.87)
City[f]			
Birmingham, Ala	3.34 (2.17, 5.12)	1.93 (0.97, 3.84)	3.32 (2.07, 5.32)
Tuskegee, Ala	16.76 (10.02, 28.02)	3.24 (1.66, 6.30)	7.81 (4.97, 12.29)
San Antonio, Tex	0.71 (0.45, 1.10)	0.62 (0.22, 1.74)	0.44 (0.20, 0.99)
Age, y	1.02 (1.01, 1.03)	1.01 (1.00, 1.03)	1.02 (1.01, 1.03)

Notes. OR = odds ratio; CI = confidence intervals. Analyses of a "yes" answer to the first 2 questions and a correct answer to the third, open-ended question. Analyses adjusted for race, age, gender, education, income, and city.
[a]Reference group was Whites.
[b]Hispanics excluded from analysis because of too few respondents to this question.
[c]Reference group was less than high school graduate.
[d]Reference group was less than $20 000.
[e]Reference group was male.
[f]Reference group was Hartford, Conn.

Study? Has any US President ever apologized for the Tuskegee Syphilis Study? Which US President made the apology?) led to the conclusions that Blacks were much more aware of the Tuskegee Syphilis Study than either Whites or Hispanics, and that the odds of knowing that President Clinton had made the apology were much higher for Blacks than for Whites. But Blacks and Whites did not differ significantly on knowing that a presidential apology had been made.

The responses to these 3 questions showed a much stronger impact of the Tuskegee study in the 2 southern cities of Birmingham and Tuskegee than in the northern city of Hartford, as shown in Table 2. The odds ranged up to nearly 17-times greater for Tuskegee than for Hartford. Interestingly, although the intracity adjusted analyses for each of these 3 cities by race revealed that Blacks were more likely than were Whites to know that President Clinton had made the apology for that study, a racial difference was only observed in the 2 cities of Birmingham and Hartford (not in Tuskegee) for the question "Have you ever heard of the Tuskegee Syphilis Study?" Because the city of Tuskegee is the historical epicenter of this issue and its legacy, this seemingly unexpected result is likely because of an exceptionally high rate of having heard of the Tuskegee Syphilis Study among both Whites and Blacks in the city of Tuskegee (i.e., about 90% for both Blacks and Whites in Tuskegee).

Overall, because nearly 60% of the Black respondents had heard of the Tuskegee Syphilis Study (ranging from 89.8% to 71.1% to 46.5% to 29.6% in Tuskegee, Birmingham, Hartford, and San Antonio, respectively) health disparities researchers working in the Black communities in the future must acknowledge this level of awareness. Specifically, for researchers to create a respectful, comfortable, and inviting atmosphere for all potential participants when planning and recruiting participants into studies, the researchers must take this overall high level of awareness into account.

Because Blacks overall were much more aware of the Tuskegee Syphilis Study and generally knew more details about the apology than did Whites and Hispanics, the impact of this increased awareness of the study in Blacks is most interesting. Overall, the plurality of both Blacks and Whites who had heard of the Tuskegee Syphilis Study indicated that they were less likely to participate in biomedical studies, but this negative impact was far more pronounced among Whites (71%) than among Blacks (50%). Hence, Blacks who had heard of the Tuskegee Syphilis Study were much less negatively affected by that awareness than were Whites. This was true regardless of whether it was the impact of having heard about the Tuskegee Syphilis Study or of having heard of the presidential apology for the study.

Conversely, Whites' willingness to participate in biomedical research studies was much more negatively affected by awareness of each of these events. This marked difference in the observed impact may reflect the daily cultural reality in the Black community, which has for a long time been accustomed to increased risks for Blacks in many activities. For Whites, this type of information (or news) may have been more shocking and at odds with their daily expectations and, thus, led to a stronger negative impact on their future decisionmaking.

The major methodological finding of this study, which resulted from the use of 2 recognition probes to determine whether a respondent was aware (i.e., recognized the name) of the Tuskegee Syphilis Study, provides clear evidence that a single probe suffices when one is asking about awareness of the

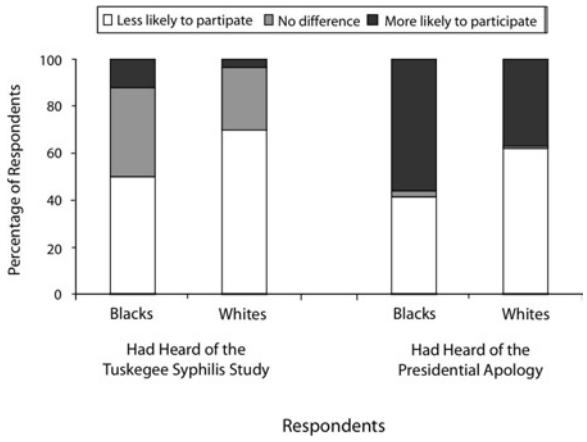

FIGURE 2—Percentage of respondents having heard about the Tuskegee Syphilis Study and about the presidential apology for the study and the influence of both on the likelihood to participate in biomedical studies, by race/ethnicity: Tuskegee Legacy Project Study, 1999–2000.

Tuskegee Syphilis Study. The second probe did slightly increase the number of respondents in each of the racial/ethnic groups that indicated awareness of the study—by only 3.8, 1.7, and 1.6 percentage points for Blacks, Hispanics, and Whites, respectively. These findings suggest that use of a single recognition probe, as was done in all the prior studies that investigated the Tuskegee Syphilis Study, is quite accurate and would be sufficient for future studies.

Comparison With Prior Literature

Five published studies have reported both on having heard of the Tuskegee Syphilis Study and on willingness to participate in biomedical research by race.[18,25–28] Across these 5 studies, the percentage of Blacks who had heard of the Tuskegee Syphilis Study ranged from 42% to 81%; for Whites the range was between 18% and 46%. Our findings are at the high end of the percentages reported to date, both for Blacks (73% on our first probe, 76% after the second probe) and for Whites (55% on our first probe, 57% after the second probe). No ready explanation for this observation is provided by demographic differences (such as age, gender, education, or income) between our study population and those previous studies.

Although the professional literature related to health care in the United States is replete with articles that refer to the impact and assumed legacy of the Tuskegee Syphilis Study,[1–3,6,13–24,28–30] perhaps the most unusual measure of the depth of cultural influence of this legacy is documented by its recent appearance as the core theme of a Marvel comic book 7-issue series: "Truth: Red, White and Black," written in 2003 as a presequel to the Captain America series. In this fictional presequel series, research abuses abound in experiments done on a Black military unit. An injected compound is used to biomedically develop a "supersoldier," one that once perfected on this "research abused" Black military unit is then used safely to create Captain America, a White supersoldier of comic book fame.[31]

Conclusions

Our study of the reputed legacy of the Tuskegee Syphilis Study reports on the largest and most geographically diverse study sample to date. This study is also the first to quantitatively report on the community impact—among Blacks, Whites, and Hispanics—of President Clinton's 1997 apology for the Tuskegee Syphilis Study. This apology was made to the Black community at large, as well as directly to surviving study participants and the families of the nonsurvivors.

Our findings provide clear evidence that Blacks were both much more likely than Whites or Hispanics to have heard of the Tuskegee Syphilis Study and to know that President Clinton had made the apology. Most interestingly, despite Blacks being more aware of both the Tuskegee Syphilis Study and who made the presidential apology, Whites who had heard either of the study or of the presidential apology were more negatively influenced toward participation in biomedical research than were Blacks who had heard of either event.

These findings, plus the regional differences observed between the northern city of Hartford and the southern cities of Birmingham and Tuskegee, strongly suggest that if future studies are to attain their goal of having a diverse set of study participants as mandated by federal research guidelines, investigators who conduct clinical and community-based studies in the future need to recognize and incorporate these racial/ethnic, geographical, and cultural differences into their recruitment and retention plans. ■

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Contributors

R.V. Katz originated and directed the study, led the development of the Tuskegee Legacy Project Questionnaire and the data analysis, wrote the initial draft of the article, and led the team's crafting of the final article. S.S. Kegeles, N.R. Kressin, S.A. James, and B.L. Green

developed the Tuskegee Legacy Project Questionnaire, assisted with the writing of the grants that supported this research, helped plan the data analysis and data interpretation, and contributed to the writing of the final article. M.Q. Wang and S.L. Russell conducted the statistical analyses, helped to plan and finalize the data interpretation and contributed to the writing of the final article. C. Claudio helped plan the data analysis and data interpretation, and contributed to the writing of the final article.

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Human Participant Protection

This study was approved by the institutional review boards of the University of Connecticut Health Center and of New York University.

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