Published in final edited form as:

J Health Care Poor Underserved. 2008 November ; 19(4): 1168–1180. doi:10.1353/hpu.0.0067.

The Legacy of the Tuskegee Syphilis Study: Assessing its Impact on Willingness to Participate in Biomedical Studies

Ralph V. Katz, DMD, MPH, PhD [Professor and Chair]

Department of Epidemiology & Health Promotion at the New York University College of Dentistry in New York

B. Lee Green, PhD [Executive Director]

Office of Institutional Diversity at the H. Lee Moffitt Cancer Center & Research Institute in Tampa, FL

Nancy R. Kressin, PhD [Associate Professor, senior researcher]

Department of General Internal Medicine at the Boston University Medical School and Center for Health Quality Outcomes & Economic Research Center in the Department of Veterans Affairs in Boston, MA

S. Stephen Kegeles, PhD [Professor]

Department of Behavioral Sciences and Community Health at the University of Connecticut School of Dental Medicine in Farmington CT

Min Qi Wang, PhD [Professor]

Department of Public and Community Health at the University of Maryland School of Public Health in College Park MD

Sherman A. James, PhD [Professor of Public Policy]

Terry Sanford Institute of Public Policy and the Department of Community Medicine and Family Medicine at Duke University in Durham North Carolina

Stefanie L. Russell, DDS, MPH, PhD [Assistant Professor]

Department of Epidemiology & Health Promotion at the New York University College of Dentistry in New York

Cristina Claudio, PhD [Professor]

Department of Health Behavior at the University of Puerto Rico School of Dentistry in San Juan Puerto Rico

Jan M. McCallum, MSPH [doctoral graduate student, Pre-doctoral Fellow]

Center for Health Promotion and Prevention Research at the University of Texas Health Science Center at Houston in Houston Texas

Abstract

The phrase, *legacy of the Tuskegee Syphilis Study*, is sometimes used to denote the belief that Blacks are more reluctant than Whites to participate in biomedical research studies because of the infamous study of syphilis in men run by the U.S. Public Health Service from 1932-72. This paper is the first to attempt to assess directly the accuracy of this belief within a multi-city, multi-racial, large-scale, detailed random survey. We administered the Tuskegee Legacy Project (TLP) Questionnaire to 826 Blacks and non-Hispanic White adults in three U.S. cities. While Blacks had higher levels of general

awareness of the Tuskegee Syphilis Study, there was no association between either awareness or detailed knowledge of the Tuskegee Syphilis Study and willingness to participate in biomedical research, either for Blacks or Whites observed in our survey. While this study refutes the notion that there is a direct connection between detailed knowledge of the Tuskegee Syphilis Study and willingness to participate in biomedical research, it does not assess the broader question of whether and how historical events influence people's willingness to participate in research. Future studies should explore this.

Keywords

Legacy of the Tuskegee Syphilis Study; minority participation in research; bioethics; health disparities

There is widespread belief that the U.S. Public Health Service (USPHS) Syphilis Study at Tuskegee (1932-72) has had a negative effect on African-Americans' willingness to participate as research subjects in biomedical studies.¹⁻⁵ That study, long-recognized as unethical, committed abuses against 399 African-American sharecroppers in Macon County, Alabama who were the subjects of a 40-year USPHS study of the effects of untreated syphilis in Black men.^{6,7} While a considerable amount has been written about the long-lasting effects of the USPHS Syphilis Study at Tuskegee on the Black community, most of this work has been from the perspective of history,⁸⁻¹⁵ ethics,⁸⁻¹⁷ access to health care,^{11,14-21} and law.^{15,20}

Given the federal government's 1994 directive for researchers to obtain study samples with diversity in race and gender,²² surprisingly little research has directly examined whether any differential participation of Blacks or other minorities in biomedical studies compared with Whites could be attributed to the USPHS Syphilis Study at Tuskegee,²³⁻³⁰ and only three of these studies used quantitative methods.²⁸⁻³⁰ A 2006 literature review pointed out the research design limitations of these three published quantitative studies on this specific topic³¹ (they had low response rates,³⁰ were limited in scope to a single city,²⁸⁻³⁰ or used study questionnaires containing only a limited set of variables²⁸⁻³⁰). Thus, while all three of these early exploratory studies concluded that awareness of the Tuskegee Syphilis Study did not affect willingness to participate in biomedical studies, they were limited in their scopes of inquiry as well as in their generalizability.

In our first paper from the Tuskegee Legacy Project data, we reported that, despite having greater fear of participation in research studies, Blacks were just as likely as Whites to self-report willingness to participate in biomedical research.³² These initial findings were fully confirmed in our second major study on this same topic using the TLP Questionnaire in three different cities.³³ A third recent paper expanded our inquiry to address the impact of both the general awareness of the Tuskegee Syphilis Study and the 1997 Presidential Apology about the Tuskegee Syphilis Study on willingness to participate in biomedical studies; it reported that Blacks were 2-3 times *more* likely than Whites to be willing to participate in biomedical studies despite having heard of the Tuskegee Syphilis Study or the Presidential Apology.³⁴

This paper seeks to answer a related but different question: "Does awareness and/or detailed knowledge of the Tuskegee Syphilis Study influence one's willingness to participate in biomedical studies in 1999-2000?" Specifically, we examined whether either general awareness or detailed knowledge of the Tuskegee Syphilis Study influences willingness to participate in biomedical studies for Blacks and for Whites in different geographic areas.

Methods

The Tuskegee Legacy Project (TLP) Study administered the TLP Questionnaire via random-digit dial (RDD) telephone interviews to respondents aged 18 years and older in four U.S. cities: Tuskegee, Alabama; Birmingham, Alabama; Hartford, Connecticut; and San Antonio, Texas in 1999-2000. This report presents the findings for the Black and White respondents from the three cities that had a sufficient number of Black and White respondents to permit meaningful analysis for both racial groups (i.e., Tuskegee, Birmingham, and Hartford).

As this paper is a follow-up analysis to our first paper from our Tuskegee Legacy Project, we refer readers to the earlier work for a full description of the methods used in conducting the 1999-2000 4-City Tuskegee Legacy Project.³² This study was approved by the IRBs of the University of Connecticut Health Center and New York University.

The TLP Questionnaire contains two validated scales, the Likelihood of Participation (LOP) Scale (which measured the willingness to participate) and the Guinea Pig Fear Factor (GPFF) Scale (which measured the fear or wariness about participation), both of which are described in detail in the earlier publication.³² Scores for each scale ranged from 0-100, with the LOP Scale using 17 questions from the TLP Questionnaire to provide a nuanced measure of willingness to participate in biomedical studies, while the GPFF Scale uses 5 questions to determine the level of fear an individual has about participating in a biomedical study. Awareness of the Tuskegee Syphilis Study (TSS) was measured dichotomously (i.e., yes/no) according to participants' responses to two separate questions, spaced 7 questions apart, asking if they had "ever heard of the Tuskegee Syphilis Study."

Additionally, the TLP Questionnaire contains a set of seven questions on detailed knowledge of the Tuskegee Syphilis Study (TSS) that were utilized to create the TSS Facts & Myths Quiz score, a Tuskegee Syphilis Study (TSS) knowledge quiz score (lowest = 0, highest = 7). For the calculation of the TSS Facts & Myths Quiz score, *don't know/not sure* responses were treated as missing values. The selection of the seven items emerged from discussions among the research team members based upon their familiarity with the Tuskegee Syphilis Study history and literature, with a guiding criterion that only well-established facts associated with the Tuskegee Syphilis Study were to be used, i.e., questions that had face validity. The items on the TSS Facts & Myths Quiz were reviewed by an NIH Study Section (as part of an overall grant protocol review process) which had no negative comments about either the inclusion of any one of the 7 items, or the claim that they constituted a reasonable measure of detailed knowledge about the Tuskegee Syphilis Study. Similarly, the entire TLP Questionnaire was pretested in face-to-face interviews in 3 small pilot studies, as well as in a final RDD pilot study of 200 subjects. It was never challenged by any of the over 300 subjects in these pre-test pilot studies.

Initial unadjusted bivariate analyses that examined frequency distributions were followed by multivariate general linear model ANCOVA analyses, and multiple linear regression analyses, for dichotomous or continuous dependent variables, respectively. The multivariate analysis tested an overall model of each dependent variable (LOP and GPFF) for the primary independent variable of interest (either awareness or detailed knowledge) with ethnicity, age, gender, education, and income as covariates at four strata: total sample, by city, by race, and by race-within-city. When significant factors were detected, additional analyses were conducted to assess the direction and the magnitude of the difference. If the significant factor had more than two levels, a *post hoc* test of the adjusted means with Tukey criterion was conducted to control for Type I error. All analyses were conducted using either SPSS v14.0 software³⁵ or SAS v9.0 software.³⁶

Results

In this report, we present the TLP Questionnaire findings for the 826 adult Blacks and non-Hispanic Whites in three cities (Tuskegee, Alabama; Birmingham, Alabama; and Hartford, Connecticut) which had overall response rates of 65%, 70%, and 49%, respectively. The overall completion rate (number of completed interviews/number of initiated interviews) exceeded 90% in each city. Table 1 shows the age, sex, education, and income distribution of the 826 subjects by race for each of the three cities.

In addition, Table 1 shows the proportion of Blacks and Whites, by city, who had “ever heard of the Tuskegee Syphilis Study.” Awareness of the TSS ranged from a high of 93.3% for Blacks in Tuskegee to a low of 41.9% for Whites in Hartford. Across cities differences in the proportion of respondents who had ever heard of the TSS were statistically significant (89.9% vs. 70.9% vs. 49.0%, in Tuskegee, Birmingham, and Hartford, respectively; $p < .05$). Additionally, within city analyses by race revealed that a statistically significant ($p < .05$) higher percentage of Blacks than of Whites, had heard of the TSS in Birmingham (77.7% for Blacks vs. 64.0% for Whites) and Hartford (62.5% for Blacks vs. 41.6% for Whites), but not in Tuskegee (93.3% for Blacks vs. 87.8% for Whites).

The TSS Facts & Myth Quiz was administered to the 68.4% of subjects (n=565) who indicated that they had heard of the TSS. Figure 1 illustrates, by race within each city, the proportion of these 565 respondents who answered *true* to each of the 7 items on the Tuskegee Syphilis Study (TSS) Facts & Myth Quiz, having given a valid response (i.e., either *true* or *false*). All *don't know/not sure* responses for this analysis were treated as missing data; typically, across the 7 questions, the *don't know/not sure* responses constituted about 20% of the responses, with a low of 15% up to a high of 55%. In Figure 1, true statements are indicated in capital letters along the abscissa axis and any observed statistically significant differences by race within city are marked with asterisks. There was great variation across the 7 items by race within each city, with answers of *true* ranging from a high of 85% for the statement that subjects “were injected with syphilis” (a false statement) to a low of 2% for the statement that the study was “run by U.S. government doctors” (a true statement). For the former statement (i.e., subjects were injected with syphilis) the findings were that more Blacks than Whites thought it was true, and these differences were statistically significant ($p < .05$) for both Tuskegee and Hartford, and approached statistical significance ($p = .068$) in Birmingham.

Figure 2 reinforces the finding illustrated in Figure 1 concerning the relatively high frequency of incorrect answers on the details of the TSS for the TSS Facts & Myths Quiz. As Figure 2 shows, of a maximum 7 potential correct answers, neither Blacks nor Whites in any of the 3 cities achieved a mean TSS Facts & Myths score greater than 2, and no statistically significant racial differences were observed (mean scores $\pm$ standard deviations for Blacks = 1.6 ± 1.4 , and for Whites 1.7 ± 1.3). For the TSS Facts & Myth Quiz, 90% of the 565 respondents who had heard of the TSS had a detailed knowledge score of 3 or less, with the top scores achieved being 5 and 6 for Blacks and Whites, respectively.

Table 2 shows the findings from the multivariate analyses that were conducted to determine the impact of both awareness and detailed knowledge of the Tuskegee Syphilis Study on two dependent variables: 1) the willingness to participate (as measured by the LOP Scale), and 2) the degree of fear of participation (as measured by the GPFF Scale). Awareness of the Tuskegee Syphilis Study did not have a statistically significant relationship with either the willingness to participate (as measured by the LOP Scale, $p = 0.71$) or the fear of participation (as measured by the GPFF Scale, $p = 0.53$) when adjusted for race, age, sex, education, and income for the sample of 826 respondents taken as a whole, or for Whites when analyzed separately. However, an ANCOVA analysis by race of the relationship between awareness and GPFF in Blacks was

statistically significant ($p=0.02$), with Blacks who were aware of the TSS having a higher mean GPFF score than Blacks who were not aware of the TSS (65.1 vs 57.3, $p=.02$). For the other ANCOVA analyses related to awareness by city and by race-within-city, no consistent pattern of significant findings was observed.

Table 2 also shows similarly adjusted ANCOVA analyses on the relationship between detailed knowledge of the TSS and the LOP and GPFF Scales. These analyses were conducted only for that subset of 565 respondents who indicated that they had heard of the TSS. The results were that detailed knowledge of the TSS, as measured by the mean Facts & Myth Quiz score, had no statistically significant relationship with either the LOP or GPFF Scale for Blacks or for Whites. However, a weak, albeit statistically significant inverse relationship was observed between the detailed knowledge and the GPFF Scale ($p=0.04$) for all subjects combined.

Discussion

The Tuskegee Legacy Project (TLP) had its origins in a 1994 bioethics conference held at the University of Virginia entitled *The Tuskegee Legacy: Doing Bad in the Name of Good*.³⁷ All the speakers at that conference discussed consequences of the Tuskegee Syphilis Study, especially the possibility that African Americans were more reluctant to participate in biomedical research because of the abuse they suffered in that infamous study. However, often speakers appeared to assume that the central hypothesis was true, i.e., that African Americans were, in fact, more reluctant to participate in biomedical studies and that the Tuskegee Syphilis Study was at the heart of this reluctance to become a research subject. To date, most notions regarding this purported consequence of the Tuskegee Syphilis Study have been based on anecdote and, speculation, rather than on systematic empirical research.^{5,9,11,20,23-26,29,30,37}

Our findings reveal a clear gradient across the three cities on the percentage of respondents who had ever heard of the Tuskegee Syphilis Study: nearly 90% having heard of the TSS in Tuskegee, the historical epicenter of the TSS; just over 70% in Birmingham, the nearest big city to Tuskegee with a university medical center that would conduct clinical studies; and just under 50% in Hartford, a distant city in a different region of the U.S. with a university medical center that would conduct clinical studies and with a demographic profile similar to Birmingham's. Our findings also showed that a lack of knowledge about the details of the TSS was fairly common among both Blacks and Whites (i.e., 90% of respondents gave factually correct answers on 3 or fewer of the 7 tested items).

The answer to our first central research question, "Did awareness of the Tuskegee Syphilis Study influence one's willingness to participate in biomedical studies in 1999-2000?" was a straightforward *No*, for both Blacks and for Whites. Our adjusted multivariate analyses revealed no statistically significant relationships between awareness of the TSS and either the LOP or the GPFF Scales.

However, the findings within the city of Tuskegee differed from the findings in the cities of Birmingham and Hartford. A significant relationship was observed among Blacks between awareness of the TSS and willingness to participate, but only in the small city of Tuskegee, the epicenter of this infamous event.

The answer to our second central research question in this report, namely, "Among those who had heard of the Tuskegee Syphilis Study, did detailed knowledge of the Tuskegee Syphilis Study influence one's willingness to participate in biomedical studies in 1999-2000?" is also a straightforward *No* for Blacks and for Whites, when analyzed either together as a whole sample or separately. However, the data on fear of participation, as measured by the GPFF Scale for the sample as a whole (i.e., Blacks and Whites together), revealed a statistically

significant but weak inverse relationship between GPFF and detailed knowledge for the study sample as a whole (but this finding did not hold for Blacks or for Whites when analyzed separately). This observation for the study sample as a whole regarding detailed knowledge may well be a spurious finding as the direction of the relationship is opposite to what one might anticipate, and thus may be an artifact simply of the large number (n=548) of statistical tests conducted for the analyses shown in Table 2.

Our findings of an overall lack of detailed knowledge about the Tuskegee Syphilis Study within both Blacks and Whites (as evidence by the low scores on the TSS Facts & Myth Quiz), echo the findings of two previous reports.^{18,30}

While this study refutes the notion that there is a direct connection between detailed knowledge of the Tuskegee Syphilis Study and willingness to participate in biomedical research, one limitation of this study was that it did not assess the broader question of whether and how historical events influence people's willingness to participate in research. It would be perfectly consistent with our results if the TSS had more diffuse effects on people's willingness to participate in biomedical research (e.g., a general distrust of biomedical research might be passed on after the TSS became known without any details about the particular study having been retained). Future studies should explore this possible diffusion effect to determine if it exists, and if so, how the diffusion occurs, both within individuals and within communities.

A further limitation of this study was the post-data collection realization that the wording of one of the seven facts in the TSS Facts & Myths Quiz was not historically precise. Specifically, the fact would be more precisely worded as "The study ended once penicillin became widely available as a treatment for syphilis."

The reality that this was the first use of the TSS Facts & Myths Quiz as a measure of detailed knowledge of the TSS is yet another inherent limitation of this study. Future studies should investigate the reliability, as well as the validity, of our 7 items as a consistent and accurate measure of detailed knowledge of the TSS. Finally, space limitations prevent us from giving detailed presentation of these findings for males and for females separately, given that a previous investigation reported gender differences in awareness about the Tuskegee Syphilis Study for Whites (more males aware than females, 54% vs 38% respectively), but not for Blacks (males at 53%, female at 54%).²⁹

Conclusion

The data from this follow-up analysis based upon the 1999-2000 4-City Tuskegee Legacy Project Study fail to show that being aware of the Tuskegee Syphilis Study directly affects one's willingness to participate in biomedical studies for either Blacks or for Whites, across the three cities, nearly three decades after the ending of the Tuskegee Syphilis Study. The only statistically significant finding was that in the city of Tuskegee, the historical epicenter of the index event, Blacks who had heard of the Tuskegee Syphilis Study indicated that they were willing to participate less often than Blacks who had not heard of the Tuskegee Syphilis Study. Additionally, while our previous publications revealed that Blacks were significantly more likely than Whites to have greater fear of participating (as measured by the GPFF Scale),^{32, 33} the data from the current report based on the same study population showed no relationship between detailed knowledge of the Tuskegee Syphilis Study and the fear of participation for either Blacks or Whites.

While there have been many discussions in the published literature, popular media, and in the community regarding the impact of the USPHS Syphilis Study at Tuskegee on the African American community,^{8-21,23-34,37} it is critically important that we have a true scientific understanding of its impact on minority participation in biomedical research studies. If the

Tuskegee Syphilis Study is, indeed, the reason for poor participation by minorities in biomedical studies,^{23-27,30} then researchers ought to develop subject recruitment strategies for future studies that would target this issue. On the other hand, if the Tuskegee Syphilis Study it is neither the sole nor primary reason—nor after three decades even a distinctly identifiable reason—for poor levels of participation, then other strategies for are called for to ensure minority enrollment in biomedical studies.

Box 1. THE 7 ITEMS ON DETAILED KNOWLEDGE OF THE TUSKEGEE SYPHILIS STUDY (TSS) THAT CONSTITUTED THE QUESTIONS TALLIED TO CREATE THE TSS FACTS & MYTH QUIZ SCORE

The following was asked of subjects who had already indicated that they had heard of the Tuskegee Syphilis Study.

Introduction

I would like to know what specific facts you remember about the Tuskegee Syphilis Study. Would you tell me whether the following statements are True or False. If you don't know, please tell me that.

7 items on the TSS Facts & Myth Quiz:

Factually Correct Answers
for the TSS Facts & Myth
Quiz Score^a

1) Black men and women were subjects in the study	False
2) The subjects were injected with syphilis	False
3) The nurse who recruited them was Black	TRUE
4) The study lasted 40 years	TRUE
5) The subjects were told they had syphilis	False
6) The study was run by U.S. government doctors	TRUE
7) The study ended when penicillin was discovered as a cure for syphilis	False

^aTotal score could range from 0-7, with one point for each factually correct answer given.

Note

1. Jones, JH. Bad blood: the Tuskegee Syphilis Experiment. Free Press; New York: 1993. 1981
2. Gamble, VN.; Fletcher, JC.; Chapter, X. Tuskegee Syphilis Study Legacy Committee Report of 1996. In: Reverby, SM., editor. Tuskegee's truths: rethinking the Tuskegee Syphilis Study. University of North Carolina Press; Chapel Hill and London: 2000.
3. Katz RV, Kegeles SS, Green BL, et al. The Tuskegee Legacy Project: history, preliminary scientific findings, and unanticipated societal benefits. *Dent Clin North Am* Jan;2003 47(1):1–19. [PubMed: 12519002]
4. Hunninghake DB, Darby CA, Probstfield JL. Recruitment experience in clinical trials: literature summary and annotated bibliography. *Control Clin Trials* Dec;1987 8(4 Suppl):6S–30S. [PubMed: 3326716]
5. Swanson MS, Ward AJ. Recruiting minorities into clinical trials: toward a participantfriendly system. *J Natl Cancer Inst* Dec 6;1995 87(23):1747–59. [PubMed: 7473831]
6. Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *Am J Public Health* Nov;1991 81(11): 1498–505. [PubMed: 1951814]

7. Kressin NR, Meterko M, Wilson NJ. Racial disparities in participation in biomedical research. *J Natl Med Assoc* Feb;2000 92(2):62–9. [PubMed: 10800293]
8. Shavers-Hornaday VL, Lynch CF, Burmeister LF, et al. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health* Mar-Jun;1997 2(12):31–45. [PubMed: 9395587]
9. Gamble VN. A legacy of distrust: African Americans and medical research. *Am J Prev Med* Nov-Dec; 1993 9(6 Suppl):35–8. [PubMed: 8123285]
10. Benedek TG. The 'Tuskegee Study' of syphilis: analysis of moral versus methodologic aspects. *J Chronic Dis* Jan;1978 31(1):35–50. [PubMed: 346597]
11. Corbie-Smith GM. Minority recruitment and participation in health research. *N C Med J* Nov-Dec; 2004 65(6):385–7. [PubMed: 15714732]
12. Gamble VN. The Tuskegee Syphilis Study and women's health. *J Am Med Womens Assoc* 1997;52 (4):195–6. [PubMed: 9354052]Fall
13. Pressel DM. Nuremberg and Tuskegee: lessons for contemporary American medicine. *J Natl Med Assoc* Dec;2003 95(12):1216–25. [PubMed: 14717481]
14. Fairchild AL, Bayer R. Uses and abuses of Tuskegee. *Science* May 7;1999 284(5416):919–21. [PubMed: 10357678]
15. Washington, HA. Medical apartheid: the dark history of medical experimentation on Black American from colonial times to the present. Doubleday Press; New York: 2006.
16. Caplan, AC. Twenty years after The Legacy of the Tuskegee Syphilis Study: when evil intrudes: the Hastings Center Reports. Hastings Center; Garrison: 1992.
17. White RM. Misinformation and misbeliefs in the Tuskegee Study of Untreated Syphilis fuel mistrust in the healthcare system. *Natl Med Assoc* Nov;2005 97(11):1566–73.
18. Matthews AK, Sellergren SA, Manfredi C, et al. Factors influencing medical information seeking among African American Cancer patients. *J. Healthcommun* May-June;2002 7(3):205–19.
19. Bouleware LE, Cooper LA, Ratner LE, et al. Race and trust in the Elath care system. *Public Health Rep* Jul-Aug;2003 118(4):358–65. [PubMed: 12815085]
20. Rathore SS, Krumholtz HM. Race, ethnic group, and clinical research. *BMJ* Oct 4;2003 327(7418): 763–4. [PubMed: 14525851]
21. Brandon DT, Issac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust of medical care? *J Natl Med Assoc* Jul;2005 97(7):951–6. [PubMed: 16080664]
22. U.S. Department of Health and Human Services, National Institutes of Health. National Institutes of Health Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research. Vol. 23. National Institutes of Health/Office of Extramural Research; Bethesda, MD: Mar 18. 1994 Available at http://grants.nih.gov/grants/funding/women_min/guidelines_update.htm
23. Corbie-Smith GM, Thomas SB, Williams MV, et al. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med* Sep;1999 14(9):537–46. [PubMed: 10491242]
24. Green BL, Partridge EE, Fouad MN, et al. African-Americans attitudes regarding cancer clinical trials and research studies: results from focus group methodology. *Ethn Disease* 2000;10(1):76–86.
25. Freimuth VS, Quinn SC, Thomas SB, et al. African Americans' views on research and the Tuskegee Syphilis Study. *Soc Sci Med* Mar;2001 52(5):797–808. [PubMed: 11218181]
26. Bates BR, Harris TM. The Tuskegee Study of Untreated Syphilis and public perceptions of biomedical research: a focus group study. *J Natl Med Assoc* Aug;2004 96(8):1051–64. [PubMed: 15303410]
27. Sengupta S, Strauss RP, DeVellis R, et al. Factors affecting African-American participation in AIDS research. *J Acquir Immune Defic Syndr* Jul 1;2000 24(3):275–84. [PubMed: 10969353]
28. Brown DR, Topcu M. Willingness to participate in clinical treatment research among older African Americans and Whites. *Gerontologist* Feb;2003 43(1):62–72. [PubMed: 12604747]
29. Green BL, Maisiak R, Wang MQ, et al. The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research. *J Health Care Poor Underserved* Nov;2006 17(4):698–715. [PubMed: 17242525]

30. Shavers VL, Lynch CF, Burmeister LF. Knowledge of the Tuskegee study and its impact on the willingness to participate in medical research studies. *J Natl Med Assoc* Dec;2000 92(12):563–72. [PubMed: 11202759]
31. McCallum JM, Arekere DM, Green BL, et al. Awareness and knowledge of the U.S. Public Health Service syphilis study at Tuskegee: implications for biomedical research. *J Health Care Poor Underserved* Nov;2006 17(4):716–33. [PubMed: 17242526]
32. Katz RV, Kegeles SS, Kressin NR, et al. The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research. *J Health Care Poor Underserved* Nov;2006 17(4):698–715. [PubMed: 17242525]
33. Katz RV, Green BL, Kressin NR, et al. Willingness of minorities to participate in biomedical studies: confirmatory findings from a follow-up study using the Tuskegee Legacy Project Questionnaire. *J Natl Med Assoc* Sep;2007 99(9):1052–60. [PubMed: 17913117]Erratum in: *J Natl Med Assoc*. 2007 Nov;99(11):1216
34. Katz RV, Kegeles SS, Kressin NR, et al. Awareness of the Tuskegee Syphilis Study and the U.S. Presidential Apology and their influence on minority participation in biomedical research. *Am J Public Health* June;2008 98:1137–42. [PubMed: 17901437]
35. SPSS Inc. SPSS for Windows 14.0. SPSS Inc.; Chicago, IL: 2006. Available at [http:// www.spss.com/](http://www.spss.com/)
36. SAS Institute Inc. SAS 9.1. Help and documentation. SAS Institute Inc.; Cary, NC: p. 200-2004.
37. Echtenkamp-Klein, J.; Fletcher, JC. Doing bad in the name of good: the legacy of the Tuskegee Syphilis Study; Presented at: University of Virginia Bioethics Conference; Charlottesville (VA). Apr 1994; organizers Available at http://www.hsl.virginia.edu/historical/medical_history/bad_blood/symposium.cfm

Figure 1.

The percentage of respondents who answered 'true' to the 7 items on the Tuskegee Syphilis Study (TSS) Facts & Myth Quiz by race within city among those who had heard of the TSS (n=565).

Note: Capital letters indicate a TRUE statement.

*Statistically significant between Blacks vs. Whites within city at $p < .05$.

Figure 2.

Mean scores* on TSS Facts & Myths Quiz by race within city for the 565 respondents who had heard of the Tuskegee Syphilis Study.

Note: none of the Black vs. Whites contrasts for either quiz score within city are statistically significant.

*(Mean # of correct answers).

Table 1

DEMOGRAPHIC CHARACTERISTICS BY RACE AND AWARENESS OF THE TUSKEGEE SYPHILIS STUDY (TSS) FOR TUSKEGEE, AL, BIRMINGHAM, AL AND HARTFORD, CT (N=826)

Characteristic	Tuskegee, AL		Birmingham, AL		Hartford, CT	
	Black (n=104)	White (n=180)	Black (n=103)	White (n=100)	Black (n=120)	White (n=219)
Age ^a , years (± s.d.)	49.8 (±16.7)	56.1 (±17.0)	49.2 (±15.8)	51.7 (±16.8)	48.2 (±16.8)	52.7 (±16.0)
% male ^b	50.9	53.3	39.4	31.4	63.0	58.1
Education level ^c , %						
< H.S.	26.7	24.0	19.2	8.6	19.7	6.3
H.S. graduate	53.3	54.6	61.5	60.0	65.4	45.7
College graduate +	20.0	21.3	19.2	31.4	15.0	48.0
Income level ^d						
<\$20,000	46.9	29.4	52.0	30.2	31.4	11.2
\$20,000-74,999	51.0	63.8	44.0	55.2	60.2	51.6
>\$74,999	2.0	6.7	4.0	14.6	8.5	37.2
Awareness of TSS ^e (% of respondents)	93.3%	87.8%	77.7%	60.0%	62.5%	41.9%

Note: Statistically significant findings (p<.05) across cities, and for Blacks vs. Whites within each city:

^a **Age:** within city finding: Whites were older than Blacks in each city.

^b **% male:** across city finding: Hartford had higher % male respondents than Tuskegee, which had higher % male respondents than Birmingham.

^c **Education Level:** across city finding: Hartford had higher education levels than Birmingham, which had a higher education level than Tuskegee. within city finding: Whites had higher educational levels in Hartford and in Birmingham than Blacks.

^d **Income Level:** across city finding: Hartford had higher incomes than Birmingham and Tuskegee. within city finding: Whites had higher incomes than Blacks in each city.

^e **Awareness (%) of TSS:** across city finding: Respondents in Tuskegee had a higher awareness of the TSS than in Birmingham which had a higher awareness among respondents than in Hartford. within city finding: A higher percentage of Blacks were aware of the TSS in Hartford and in Birmingham.

Table 2

SUMMARY OF ADJUSTED MULTIVARIATE ANALYSES^a FINDINGS ON RELATIONSHIP BETWEEN AWARENESS AND DETAILED KNOWLEDGE OF THE TUSKEGEE SYPHILIS STUDY ON LIKELIHOOD OF PARTICIPATION (LOP) SCALE AND GUINEA PIG FEAR FACTOR (GPFF) SCALE FOR ALL SUBJECTS, WITHIN EACH CITY, AND WITHIN EACH CITY BY RACE

	Awareness ^b and		Detailed knowledge ^c and	
	LOP	GPFF	LOP	GPFF ^{>}
All subjects	ns	ns	ns	p=.04 ⁱ
By race:				
Blacks	ns	p=.02 ^g	ns	ns
Whites	ns	ns	ns	ns
By city:				
Tuskegee	ns	ns	ns	ns
Birmingham	ns	ns	ns	ns
Hartford	p=.02 ^d	ns	ns	p=.02 ^j
By race within city:				
Tuskegee:				
Blacks	p=.02 ^f	ns	ns	ns
Whites	ns	ns	ns	ns
Birmingham:				
Blacks	ns	ns	ns	ns
Whites	ns	ns	ns	ns
Hartford:				
Blacks	ns	ns	ns	p=.01 ^k
Whites	p=.03 ^e	ns	p=.02 ^h	ns

^a Adjusted for race, age, sex, education level, and income level with p=.05.

^b Conducted for all 826 subjects in ANCOVA models.

^c Conducted only for the 565 respondents who had heard of the TSS, using the TSS Facts & Myth Quiz as the independent variable in multiple linear regression models.

^d In Hartford, those who were aware of the TSS had higher mean LOP scores compared with those who were not aware of the TSS (47.3 vs 41.9).

^e Whites in Hartford who were aware of the TSS had higher mean LOP scores compared with Whites who were not aware of the TSS (49.7 vs 42.7).

^f Blacks in Tuskegee who were aware of the TSS had lower mean LOP scores compared with Blacks who were not aware of the TSS (34.7 vs 55.9).

^g Blacks, as a total group, who were aware of the TSS had higher mean GPFF scores compared with Blacks who were not aware of the TSS (65.1 vs 57.3).

^h Whites in Hartford who were aware of the TSS had an inverse relationship between their Detailed Knowledge score and LOP score (regression coefficient = -23.77).

ⁱ For all who were aware of the TSS, there was an inverse relationship between their Detailed Knowledge score and GPFF score (regression coefficient = -1.72).

^j In Hartford, those who were aware of the TSS had an inverse relationship between their Detailed Knowledge score and GPFF score (regression coefficient = -3.35).

^kBlacks in Hartford who were aware of the TSS had an inverse relationship between their Detailed Knowledge score and GPFF score (regression coefficient = -5.40).