

African American Women's Perceptions and Attitudes Regarding Participation in Medical Research: The Mayo Clinic/The Links, Incorporated Partnership

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Abstract

Objective: To examine perceptions and attitudes toward health-related research participation among professional African American women.

Methods: Participants were members of an African American women's service organization, The Links, Incorporated. Data were collected via self-administered questionnaires at The Links, Incorporated 2012 National Assembly. Sociodemographics, prior research experience, intention to participate (ITP), willingness to participate (WTP) in a variety of research studies and attitudes about research participation were measured.

Results: A total of 381 surveys were analyzed. A majority of respondents were married (66%), employed (69%), and college educated (96%). Median age was 59; 38% reported prior research participation. Overall, 78% agreed with the statement, "Participation in research will mean better care," 24% agreed "Participation in research is risky" and 3% agreed "Scientists cannot be trusted." Fifty-two percent agreed with the statement, "Research conducted in the U.S. is ethical." Mean ITP in research was 4.9 ± 1.7 on a rating scale of 1 ("definitely no") to 7 ("definitely yes"). WTP was highest for an interview study and providing a blood sample, and lowest for clinical trial and medical record review.

Conclusion: Attitudes toward research participation were generally favorable among professional African American women; many expressed WTP in a variety of research study types.

Introduction

HISTORICAL IMPROPRIETIES EXPERIENCED by African Americans as participants in medical research are still reflected as negative attitudes toward research and mistrust of scientists in some contemporary African American communities.¹ In particular, the legacy of the U.S. Public Health Syphilis Study at Tuskegee (Tuskegee Syphilis Study) among African Americans resulted in profound apprehension toward participation in health-related research and skepticism toward the benefits and implications of research.¹⁻⁷ However, recent evidence is equivocal about the lasting influence of the study on the willingness of African Americans to engage in medical research.^{8,9} Thus, increased attention has focused on understanding and overcoming barriers to research participation in minority groups. Passage of the

National Institutes of Health (NIH) Revitalization Act in 1993 required that scientists receiving NIH funding for their research articulate plans to enroll minorities and women into clinical research studies.¹⁰⁻¹³

While minority enrollment in clinical trials has generally improved, enrollment of African Americans in clinical trials remains suboptimal, particularly in trials related to cardiovascular¹⁴ and cancer outcomes.¹⁵ Underrepresentation of minority groups in research limits the validity and generalizability of study results, affects access to cutting-edge therapies for these groups, and propagates health disparities.^{10,16} Despite underrepresentation in clinical trials, recent studies suggest that African Americans, more than any other racial and ethnic group, have interest in participating in medical research.¹⁷⁻²²

Particularly challenging is the recruitment of African American women into clinical research.^{23,24} This has been

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attributed to factors including negative attitudes toward research participation,^{16,25} lack of knowledge or perceived relevance regarding clinical research, and concern that research participation would conflict with other responsibilities.^{26,27} An earlier study by Mouton et al. examined attitudes regarding research participation among 29 African American and 51 white women who did not respond to the initial recruitment mailing for the Women's Health Initiative (WHI).²⁵ The major barrier to participation for African American women was a lack of trust. Subsequent analysis of the clinical trial arm of the WHI study revealed that successful recruitment of minority women required increased effort, community outreach, culturally tailored materials, and resources to overcome distrust.²⁸

Little is known about the experiences and attitudes towards participation in medical research among professional African American women. They may have a unique set of barriers to recruitment in clinical research beyond those traditionally documented among low-income minorities^{27,29} (i.e., economic constraints, transportation, lack of knowledge about the benefits of medical research). The Links, Incorporated is an international, not-for-profit, African American service organization whose membership includes educated, professional women in 276 chapters located in 41 states, the District of Columbia, and the Commonwealth of the Bahamas. The organization has an established Health and Human Services (HHS) facet whose mission includes a sound commitment to health promotion through the expansion of health initiatives and partnerships with health agencies. Understanding attitudes and beliefs about research participation among a service-oriented, community population of African American women fills an important gap in the literature. The social influence of organizations such as The Links, Incorporated could potentially serve as a credible source of information about research participation to the African American communities reached through their national programming and volunteer efforts.

We examined attitudes and perceptions regarding participation in health-related research among members of The Links, Incorporated. Additionally, as the literature to date has focused on minority participation in clinical trials, the present study expands this focus by examining willingness to participate (WTP) in a variety of types of research such as genetic studies, interview studies, and studies involving medical record review.

Materials and Methods

Study design and participants

This cross-sectional study was conducted as part of a larger investigation aimed at understanding barriers and addressing ways to increase participation in health-related research among African American women. The study was conducted in collaboration with The Links, Incorporated at their 38th National Assembly held in Orlando, Florida, in July 2012. Approximately 2,000 members were registered to attend the Assembly and were therefore eligible to participate in the on-site research study.

Procedures

Study packets containing an introductory letter, oral consent script, and a self-administered, anonymous question-

naire were distributed at the registration desk and in the exhibition hall by study staff and designated members of The Links, Incorporated. Those returning a completed survey received a hardcover book on heart health and a National Medical Association Project I.M.P.A.C.T. (Increase Minority Participation and Awareness of Clinical Trials) brochure, *You've Got the Power*. Instructions for voluntary consent to participate in research were provided to all participants; completion and return of the study questionnaire conveyed consent to participate and to use survey responses in the research. This minimal risk study was reviewed and approved by the Mayo Clinic Institutional Review Board.

Survey design and content. Survey questions were designed to assess women's attitudes, knowledge, and WTP in research studies including a clinical trial, interview study, biobank, providing biological samples, medical record review, and a genetic research study. The survey also measured sociodemographic characteristics such as age, marital status, educational attainment, current employment, and insurance status. A single-item general self-rated health measure from the 36-item Medical Outcomes Study Short Form was included to characterize respondent health status.³⁰ Being invited to participate, seeking out a research opportunity, past participation in health-related research, and intention to participate (ITP) in the future were recorded. As part of a broader research question not addressed here, surveys also included an embedded experiment in which a written passage about research participation was presented that emphasized either the benefits associated with participation ("gain-framed" message) or the losses associated with not participating in research ("loss-framed" message). Survey items were pilot-tested at a Links chapter meeting in Chicago, Illinois, in April 2012. Preliminary data collected on 18 women ensured the understanding and readability of the final questionnaire.

Measures. Fourteen attitude statements^{25,31} were presented with a five-point, "strongly disagree" to "strongly agree" rating scale. As in Mouton et al., the responses "strongly agree" and "agree" were combined to reflect agreement.²⁵ Example items include "Participation in research is risky," "Participation in research will mean better care," and "Scientists cannot be trusted." In our sample, Cronbach α was 0.65 for the 14 items. Additional statements on the survey were the following: "Participation in health-related research by African American women can help reduce health disparities" (assessed using the same five-point rating scale). A "true" or "false" response was prompted for the following items: "The risks of participating in research are equally shared by all racial and ethnic groups" and "The risks of participating in research are equally shared by the rich and the poor."³²

Further survey items queried how willing respondents were to do the following: enroll in an appropriate clinical trial, give a blood sample for research, participate in an interview for research, participate in a genetic research study, allow their blood to be stored in a biobank for future research studies, and allow their medical records to be used for research. Response options ranged from 0 ("not at all willing") to 10 ("extremely willing"). An additional item assessed overall ITP in a health-related study in the future using a seven-point, "definitely yes" to "definitely no"

rating scale, with responses coded so that higher scores indicated greater ITP.

Statistical analysis. Descriptive statistics include mean \pm standard deviation, frequency, percentage, and median. To examine which, if any attitude statements were associated with overall ITP in research we performed both simple and multiple linear regression. Spearman rank order correlations are calculated to examine associations between attitude scores and overall ITP in a health-related research study, as well as WTP in each specific type of research study. Missing data were minimal (<8% of the data for each measure) and occurring at random. Statistical significance was set at $p < 0.05$. All statistical analyses were performed using SPSS, version 21 (IBM; Chicago, Illinois).

Results

A total of 391 women returned completed questionnaires. Ten surveys from The Links, Incorporated members who previously participated in questionnaire pilot testing were excluded from analysis, leaving a final sample size of 381. Sociodemographic characteristics of survey respondents are shown in Table 1. On average, participants were 58 ± 10 years

TABLE 1. CHARACTERISTICS OF THE LINKS, INCORPORATED SURVEY RESPONDENTS (N=381)

Characteristic	n (%)
Age, years	
<50	62 (16.3)
50–59	127 (33.3)
60–69	146 (38.3)
≥ 70	31 (8.1)
Missing	15 (3.9)
Marital status	
Married/committed relationship	249 (65.3)
Divorced/separated	57 (15)
Single	38 (10)
Widowed	32 (8.4)
Missing	5 (1.3)
Education	
Some college	8 (2.1)
Bachelor's degree	44 (11.5)
Master's degree	175 (45.9)
Doctoral degree	66 (17.3)
Professional degree	68 (17.8)
Other	15 (4)
Missing	5 (1.3)
Employment status	
Employed full-time	226 (59.3)
Employed part-time	28 (7.3)
Retired	97 (25.5)
Other (volunteer, unemployed, homemaker, on disability)	19 (4.4)
Missing	11 (2.9)
Annual income, USD ^a	
<50,000	20 (5.5)
50,000–74,999	43 (11.3)
75,000–99,999	61 (16)
100,000–149,999	78 (20.5)
$\geq 150,000$	163 (42.8)
Missing	16 (4.2)

^aUSD=United States dollars.

of age (median = 59, range 20–87 years), with nearly one-half (49%) describing their health status as excellent or very good and 97% reporting that they have health insurance. Forty-six percent of women indicated that they had been invited to participate in a health-related research study in the past and 22% had sought out a research opportunity on their own. Overall, 38% of respondents had previously participated in a health-related research study. Only about half of respondents answered “true” for the items relating to equal distribution of research risks between racial/ethnic groups and income (50% and 49%, respectively, of those answering the question, with approximately 8% of women not answering these items). Ninety-three percent agreed (combining responses of “agree” and “strongly agree”) with the statement, “Participation in health-related research by African American women can help reduce disparities.”

Attitudes toward research participation

Overall, the respondents had favorable attitudes about research participation (Table 2). The vast majority believed that participation in research benefits society (95%) and that participation in research will mean better care (78%). Responses regarding their attitudes towards researchers were positive as only 3% and 11% of respondents expressed agreement with the statements, “Scientists cannot be trusted” and “Researchers do not care about me” respectively.

TABLE 2. PERCENTAGE OF LINKS SURVEY RESPONDENTS (N=381) REPORTING AGREEMENT WITH EACH STATEMENT REGARDING RESEARCH PARTICIPATION

Statement	Percent agreement ^a
Participation in research benefits society	95%
Participation in research will mean better care	78%
Participation in research is risky	24%
Researchers do not care about me	11%
Participation in research is enjoyable	21%
Participation in research allows me to socialize	17%
Participation in research is against my religion	0.8%
Participation in research is morally wrong	1%
Transportation is a problem for people who participate in research	24%
Scientists cannot be trusted	3%
It is better to be treated by doctors who are researchers	28%
I prefer a study that is headed by an African American scientist	34%
I prefer a study that is headed by a Latino scientist	7%
Research conducted in the United States is ethical	52%

^aPercent agreement combines the responses: “agree” and “strongly agree.”

Twenty-eight percent (28%) agreed with the statement, "It is better to be treated by doctors who are researchers." Approximately one-quarter (24%) said that participation in research is risky. Finally, slightly over one-half (52%) of respondents agreed with the statement, "Research conducted in the U.S. is ethical."

ITP in health-related research

Overall mean ITP in health-related research was 4.9 ± 1.7 (median = 5, range 1–7 years). In a series of simple linear regression analyses, eight attitude statements were associated with intention scores (scientists cannot be trusted, research benefits society, participation is risky, participation will mean better care, researchers do not care about me, participation is enjoyable, participation is against my religion, participation is morally wrong), all $p < 0.05$. Six statements were not significantly associated with intention scores, including: research allows me to socialize, transportation is a problem, better to be treated by a doctor who is a researcher, prefer an African American scientist, prefer a Latino scientist, and research conducted in the U.S. is ethical. A multiple linear regression including the eight attitude statements that were independently associated with ITP in research resulted in significance being maintained only for "Participation in research is enjoyable," ($p = 0.011$), with the statements "Participation in research benefits society," and "Participation in research is risky" showing marginal significance ($p = 0.054$ and $p = 0.080$, respectively).

WTP in specific study types

Agreement with the statement, "Scientists cannot be trusted" was negatively associated with WTP in all types of studies (Table 3; all $p < 0.01$). The statement "Participation

in research is risky" was negatively associated with WTP in a clinical trial, genetic study, and a medical record review (all $p < 0.05$); this statement was unassociated with WTP in an interview study, a biobank, and research involving a blood sample. Statements reflecting positive beliefs about research (i.e., "Participation in research will mean better care" and "Research conducted in the U.S. is ethical") were positively associated with WTP in each of the study types (all $p < 0.01$). Preference for a study headed by an African American or Latino scientist was not associated with WTP in any of the study types (all $p > 0.05$) and are not shown in Table 3.

Descriptive data depicting mean WTP scores for each of the study types as well as the zero-order correlation matrix are shown in Table 4. WTP was lowest for a clinical trial and highest for an interview study. The distribution of WTP scores was examined for each of the study types. Scores of nine or ten (reflecting the highest WTP), were indicated by approximately 58% of women for an interview study, 52% for a blood sample, 45% for a genetic study, 44% for a biobank, 35% for medical record review, and 25% of women for a clinical trial. Scores of zero indicating "not at all willing" were given by approximately 9% of women for a clinical trial and a medical record review, 8% for a biobank study, 6% for a genetic study, 4% for blood sample, and 3% for an interview study. The correlation coefficients between WTP scores for the various studies were positive in direction (WTP in one study type was associated with WTP in other study types) and moderate in magnitude.

Discussion

This cross-sectional survey study of African American women who are members of a volunteer service organization, The Links, Incorporated demonstrates generally favorable

TABLE 3. ZERO-ORDER CORRELATIONS BETWEEN ATTITUDE STATEMENTS AND WILLINGNESS TO PARTICIPATE IN EACH TYPE OF RESEARCH STUDY^a

	Clinical Trial	Interview	Genetic study	Biobank	Blood sample	Medical record review
Participation in research benefits society	0.293***	0.237***	0.285***	0.312***	0.251***	0.320***
Participation in research will mean better care	0.174**	0.199***	0.248***	0.231***	0.164**	0.246***
Participation in research is risky	-0.132*	-0.066	-0.128*	-0.077	-0.055	-0.107*
Researchers do not care about me	-0.154**	-0.101	-0.132*	-0.118*	-0.077	-0.142**
Participation in research is enjoyable	0.173**	0.063	0.153**	0.078	0.095	0.097
Participation in research allows me to socialize	-0.108	-0.077	-0.174**	-0.117*	-0.076	-0.149**
Participation in research is against my religion	-0.194***	-0.303***	-0.267***	-0.251***	-0.214***	-0.233***
Participation in research is morally wrong	-0.196***	-0.298***	-0.276***	-0.267***	-0.211***	-0.263***
Transportation is a problem for research participants	-0.068	0.003	-0.028	-0.040	-0.068	-0.168**
Scientists cannot be trusted	-0.208***	-0.193***	-0.238***	-0.158**	-0.171**	-0.206***
It is better to be treated by doctors who are researchers	-0.078	-0.059	-0.098	-0.149**	-0.045	-0.086
Research conducted in the US is ethical	0.180**	0.152**	0.210***	0.141**	0.117*	0.192***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.0001$.

^aAttitude statements are scored toward agreement; willingness to participate for each study type is scored such that higher scores indicate greater willingness to participate.

TABLE 4. DESCRIPTIVE STATISTICS FOR WILLINGNESS TO PARTICIPATE IN DIFFERENT TYPES OF HEALTH-RELATED RESEARCH AND ZERO-ORDER CORRELATIONS^a

	Willingness score ^b		1	2	3	4	5
	<i>M (SD)</i> ^c	Median					
1. Clinical trial	6.05 (3.1)	6	1.00				
2. Interview	8.18 (2.4)	9	0.509	1.00			
3. Genetic study	7.20 (3.0)	8	0.629	0.656	1.00		
4. Biobank	6.88 (3.3)	8	0.495	0.622	0.691	1.00	
5. Blood sample	7.72 (2.8)	9	0.432	0.693	0.633	0.743	1.00
6. Medical record review	6.25 (3.3)	7	0.606	0.538	0.622	0.684	0.501

^aFor all correlations, $p < 0.001$.

^bWillingness score scale: 0 = "not at all willing" to 10 = "extremely willing."

^cWillingness score values presented as mean (standard deviation) [M(SD)].

attitudes toward research and high WTP in a variety of types of research studies. Our data suggest that attitudes regarding research participation are positive in regard to societal benefit, the belief that research leads to better medical care, and that research conducted in the US is ethical. Moreover, there was less agreement with negative perceptions regarding research risk, depersonalization of research subjects, and scientists' lack of trustworthiness. By using attitude statements previously studied among a demographically similar group of African American women (service-oriented, higher socioeconomic status, married), we were able to probe multiple domains and factors influencing research participation (i.e., societal benefits, ethics, researcher characteristics and personal values).²⁵ Although our sample and Mouton's sample both appreciated the benefits of research to society, our study participants showed more trustworthiness of researchers and a perception of less risk associated with research participation relative to the earlier study by Mouton. These findings while noteworthy and quite promising also highlight potential areas where further education and research is warranted. For instance, it still remains that almost half disagreed that research conducted in the US is ethical. This could potentially be a reflection of their perceived vulnerability in biomedical research in the context of past historical exploitation and abuse of African Americans in research.^{33,34}

Our findings are consistent with other studies examining the perceptions towards medical research participation of African American women of professional organizations. A recent survey of members of the National Black Nurses Association (NBNA) toward genetic research revealed that the vast majority would themselves participate in genetic research and would support research awareness initiatives sponsored by a local NBNA chapter.²¹ In general, our study participants expressed a strong WTP in a variety of research studies. WTP was comparatively highest for an interview study, and lowest for a clinical trial. A perhaps unexpected finding was that the mean willingness score for enrolling in an appropriate clinical trial was similar to that for allowing medical records to be used for research. This is a novel finding in the literature and invites further research. One explanation for these results involves a concern over privacy protections, although this is speculative.

Nearly all (93%) of the respondents agreed that participation in research by African American women can help reduce disparities, yet only 38% of women had actually done so at the time of the survey, perhaps in part because only 46%

reported ever being invited to participate in a health-related research study. Literature on clinical trial recruitment has suggested that minorities are less likely to be offered a clinical trial, in part owing to perceptions that they will be less adherent to trial demands and less likely to be retained over time.^{29,35,36} African American women who are not offered a research opportunity are not likely to become research participants.²³ Less than one-quarter of study respondents had sought out an opportunity to participate in health-related research. This may be consistent with the observation that African American women are more likely to participate in research addressing a personal medical problem,²³ and the fact that many of the participants reported excellent overall health status. Altogether, these findings suggest that African American women in particular may be less likely to seek opportunities to participate in research as healthy volunteers. Therefore, more active efforts to reach this group may be needed, particularly in older African American women.^{37,38} As a first step, education regarding the scientific importance of having a pool of healthy volunteers for research could be achieved through HHS programming within The Links, Incorporated.

Clearly, opportunities to engage and enroll African American women in research are being missed. National attention has shifted toward increasing participation of women and minorities in research through the mission of the NIH Office of Research on Women's Health, and more recent community engagement initiatives of the NIH Clinical and Translational Science Awards (CTSA) with the overarching goal of eliminating healthcare and health disparities.^{13,39,40} The community engagement efforts initiated in 2007 by the NIH CTSA encourage research investigators to move from an "us and them" to a "we" orientation when defining research goals and priorities.⁴¹ Since its inception by the passage of the Minority Health and Health Disparities Research and Education Act of 2000, the National Center on Minority Health and Health Disparities has continued to foster an increase in minority research recruitment efforts through transdisciplinary coalitions between academic institutions and community partners.⁴² Furthermore, there has been a call for restructuring of the current institutional review board (IRB) system to increase African American research participation by including racial minorities as vulnerable groups, increasing minority representation on IRBs, and most paramount, requiring community consultation in minority research.³³ Recently, Mayo Clinic and The Links, Incorporated

have entered into a formal academic-community partnership with an ultimate goal of developing long-term collaborative efforts to close health disparities gaps within the African American community. Partnerships with organizations such as The Links, Incorporated who have a strong allegiance towards health promotion, offer tremendous opportunities to educate, mobilize, and empower minority communities in ways that can have a positive impact on health and health outcomes.

In light of this study's many strengths, several weaknesses are acknowledged. A cross-sectional study design and convenience sampling of The Links, Incorporated membership at a single event introduce sampling (self-selection) bias and limit the conclusions that can be drawn. It is possible that women holding negative attitudes toward research participation were less likely to complete a survey and are therefore underrepresented in our sample. Moreover, the precise response rate was unable to be calculated due to the various methods of survey distribution at the Assembly. Our use of a self-report survey can lend itself to response bias including socially desirable responding. However, our careful survey design, pilot testing, use of published items, and standard response formats with good psychometric properties and minimal missing data provide confidence in the integrity of the data. As we describe intentions and willingness regarding participation in health-related research, the reader is cautioned about drawing conclusions related to actual participation. We also recognize that our sample of professional women of high socioeconomic status may lack generalizability to all African American women. Furthermore, they may have a different level of exposure to health messaging and education on research participation than other minority groups. Nevertheless, this is an understudied group within the medical literature. While our findings are by no means comprehensive and reflective of the entire African American community, it is a starting point that incorporates the introspection of academic researchers and community partners across the nation.

Conclusions

There are generally favorable attitudes toward medical research participation among professional African American women, with many expressing high WTP in a variety of research studies. Leveraging the influence of The Links, Incorporated and similar groups within African American communities may improve trust and increase research participation, thereby improving health and reducing disparities.

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Author Disclosure Statement

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References

1. Fouad MN, Partridge E, Green BL, et al. Minority recruitment in clinical trials: A conference at Tuskegee, researchers and the community. *Ann Epidemiol* 2000;10: S35–S40.
2. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med* 1999; 14:537–546.
3. Freimuth VS, Quinn SC, Thomas SB, Cole G, Zook E, Duncan T. African Americans' views on research and the Tuskegee Syphilis Study. *Soc Sci Med* 2001;52:797–808.
4. Hamilton LA, Aliyu MH, Lyons PD, et al. African-American community attitudes and perceptions toward schizophrenia and medical research: An exploratory study. *J Natl Med Assoc* 2006;98:18–27.
5. Moore S, Collins W. African-American and clinical trials research: Recommendations for client engagement. *Adv Soc Work* 2002;3:46–59.
6. Green B, Maisiak R, Wang M, Britt M, Ebeling N. Participation in health education, health promotion, and health research by African Americans: Effects of the Tuskegee syphilis experiment. *J Health Educ*. 1997;28:196–201.
7. Pinn V. From exclusion to inclusion—Participation in biomedical research and the legacy of the Public Health Syphilis Study at Tuskegee. In: Katz, et al. *Essay 1. The Search for the 'legacy' of the U.S. Public Health Syphilis Study at Tuskegee*. Lanham: Lexington Books 2011; 1–18.
8. Brown DR, Topcu M. Willingness to participate in clinical treatment research among older African Americans and whites. *Gerontologist* 2003;43:62–72.
9. Katz RV, Kegeles SS, Kressin NR, et al. Awareness of the Tuskegee Syphilis Study and the US presidential apology and their influence on minority participation in biomedical research. *Am J Public Health* 2008;98:1137–1142.
10. Ford ME, Siminoff LA, Pickelsimer E, et al. Unequal burden of disease, unequal participation in clinical trials: solutions from African American and Latino community members. *Health Soc Work* 2013;38:29–38.
11. Melloni C, Berger JS, Wang TY, et al. Representation of women in randomized clinical trials of cardiovascular disease prevention. *Circ Cardiovasc Qual Outcomes* 2010;3: 135–142.
12. Fisher JA, Kalbaugh CA. Challenging assumptions about minority participation in US clinical research. *Am J Public Health* 2011;101:2217–2222.
13. Quinn SC, Kass NE, Thomas SB. Building trust for engagement of minorities in human subjects research: Is the glass half full, half empty, or the wrong size? *Am J Public Health* 2013;103:2119–2121.
14. Zhang T, Tsang W, Wijeyesundera HC, Ko DT. Reporting and representation of ethnic minorities in cardiovascular trials: A systematic review. *Am Heart J* 2013;166:52–57.
15. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: Race-, sex-, and age-based disparities. *JAMA* 2004;291:2720–2726.
16. BeLue R, Taylor-Richardson KD, Lin J, Rivera AT, Grandison D. African Americans and participation in clinical trials: Differences in beliefs and attitudes by gender. *Contemp Clin Trials* 2006;27:498–505.

17. Cottler LB, McCloskey DJ, Aguilar-Gaxiola S, et al. Community needs, concerns, and perceptions about health research: Findings from the clinical and translational science award sentinel network. *Am J Public Health* 2013; 103:1685–1692.
18. Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med* 2006;3:201–210.
19. Byrd GS, Edwards CL, Kelkar VA, et al. Recruiting intergenerational African American males for biomedical research studies: a major research challenge. *J Natl Med Assoc* 2011;103:480–487.
20. Durant RW, Davis RB, Marcantonio E, Freeman MB, Landon BE. Willingness to participate in clinical trials among elderly whites and African Americans. *J Gen Intern Med* 2005;20:131–131.
21. Powell-Young YM, Spruill IJ. Views of Black nurses toward genetic research and testing. *J Nurs Scholarship* 2013; 45:151–159.
22. Research!America. New poll shows minority populations support clinical trials to improve health of others but participation remains low among African-Americans, Hispanics and Asians. Available at www.researchamerica.org/release_31july13_clinicaltrials.html Accessed January 15, 2014.
23. Smith YR, Johnson AM, Newman LA, Greene A, Johnson TRB, Rogers JL. Perceptions of clinical research participation among African American women. *J Womens Health* 2007;16:423–428.
24. Killien M, Bigby JA, Champion V, et al. Involving minority and underrepresented women in clinical trials: The National Centers of Excellence in Women's Health. *J Womens Health Gend Based Med* 2000;9:1061–1070.
25. Mouton CP, Harris S, Rovi S, Solorzano P, Johnson MS. Barriers to black women's participation in cancer clinical trials. *J Natl Med Assoc* 1997;89:721–727.
26. Brown DR, Fouad MN, Basen-Engquist K, Tortolero-Luna G. Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. *Ann Epidemiol* 2000;10:S13–21.
27. Martin A, Negron R, Balbierz A, Bickell N, Howell EA. Recruitment of black and Latina women to a randomized controlled trial. *J Health Care Poor Underserved* 2013;24: 1102–1114.
28. Fouad MN, Corbie-Smith G, Curb D, et al. Special populations recruitment for the Women's Health Initiative: Successes and limitations. *Control Clin Trials* 2004;25: 335–352.
29. Ejiogu N, Norbeck JH, Mason MA, Cromwell BC, Zonderman AB, Evans MK. Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the Healthy Aging in Neighborhoods of Diversity across the Life Span study. *Gerontologist* 2011;51 Suppl 1:S33–45.
30. DeSalvo KB, Fan VS, McDonnell MB, Fihn SD. Predicting mortality and healthcare utilization with a single question. *Health Serv Res* 2005;40:1234–1246.
31. Millon-Underwood S, Sanders E, Davis M. Determinants of participation in state-of-the-art cancer prevention, early detection screening, and treatment trials among African-Americans. *Cancer Nurs* 1993;16:25–33.
32. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol* 2002;12:248–256.
33. Rencher WC, Wolf LE. Redressing past wrongs: Changing the common rule to increase minority voices in research. *Am J Public Health* 2013;103:2136–2140.
34. Chiu CT, Katz RV. Identifying the “vulnerables” in biomedical research: The vox populis from the Tuskegee Legacy Project. *J Public Health Dent* 2011;71:220–228.
35. Lindenstruth KA, Curtis CB, Allen JK. Recruitment of African American and white postmenopausal women into clinical trials: The beneficial effects of soy trial experience. *Ethnic Dis* 2006;16:938–942.
36. Chandra A, Paul DP, 3rd. African American participation in clinical trials: Recruitment difficulties and potential remedies. *Hosp Top* 2003;81:33–38.
37. Moorman PG, Newman B, Millikan RC, Tse CKJ, Sandler DP. Participation rates in a case control study: The impact of age, race, and race of interviewer. *Ann Epidemiol* 1999; 9:188–195.
38. Trauth J, Musa D, Siminoff L, Jewell I, Ricci E. Public attitudes regarding willingness to participate in medical research studies. *J Health Soc Policy* 2000;12:23–43.
39. Kelly M, Bates A, Pinn V. National Institutes of Health Policy on the inclusion of women and minorities as subjects in clinical research. In: Gallin JI, Ognibene FP. *Principles and practice of clinical research*, 3rd ed. Amsterdam: Academic Press, 2012:147–159.
40. Ahmed SM, Palermo AGS. Community engagement in research: Frameworks for education and peer review. *Am J Public Health* 2010;100:1380–1387.
41. The Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee. *Researchers and their communities: The challenge of meaningful community engagement*. Available at www.ctsacentral.org/documents/BestPractices_inCommunityEngagement_Summary_2007_08.pdf Accessed April 19, 2014.
42. National Institutes of Health (NIH). The NIH almanac. Available at www.nih.gov/about/almanac/organization/NIMHD.htm Accessed April 19, 2014.

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