

Racial Differences in Factors that Influence the Willingness to Participate in Medical Research Studies

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PURPOSE: The relative absence of racial/ethnic minorities among medical research subjects is receiving considerable attention because of recent government mandates for their inclusion in all human subject research. We examined racial differences in the prevalence of sociocultural barriers as a possible explanation for the underrepresentation of African Americans in medical research studies.

METHODS: During 1998–1999, a total of 198 residents of the Detroit Primary Metropolitan Statistical Area (PMSA) participated in a survey that examined impediments to participation in medical research studies. Chi square tests and logistic regression analyses were used to examine the association between race, issues related to trust of medical researchers, and the willingness to participate in medical research studies.

RESULTS: Study results indicate that African Americans and whites differ in their willingness to participate in medical research. Racial differences in the willingness to participate in a medical research are primarily due to the lower level of trust of medical research among African Americans. African American respondents were also somewhat less willing to participate if they attribute high importance to the race of the doctor when seeking routine medical care, believed that minorities bear most of the risks of medical research, and if their knowledge of the Tuskegee Study resulted in less trust in medical researchers.

CONCLUSION: These data reiterate the need for medical researchers to build trusting relationships with minority communities. Researchers can begin by acknowledging the previous medical abuse of minority research participants, discussing their specific plans to assure the protection of study participants, and explaining the need for the participation of racial/ethnic minorities including studies that specifically target or that are likely to result in disproportionate representation of racial/ethnic minorities among study participants.

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INTRODUCTION

Current public health focus on risk reduction and disease prevention has generated a number of health initiatives that target African Americans and other underserved populations. The disproportionately high rate of premature death from preventable or controllable diseases (1–3) suggests that disease prevention programs are needed. Nonetheless, African American participation in these programs and disease prevention research is low (4–6).

Despite the disproportionately higher representation of African Americans and Latinos among those infected with HIV (7), white men constitute the majority of research participants in HIV treatment trials (7–10). African Americans are also underrepresented in occupational cancer (11) and cancer prevention studies (12). Conversely, African American representation in cancer treatment trials has been found to be proportional to their representation among cancer patients (4, 13–14).

A number of authors have implicated several sociocultural barriers as factors that underlie the underrepresentation of African Americans in medical research (15, 16–23); however, few of these reports are based on empirical research. Suggested barriers include the Tuskegee Study (15, 18–19, 24–28) distrust (21, 23, 29–30), lack of awareness about research studies (21), fear of being used as guinea pigs (31–32), economic barriers (21, 33–34), communication issues (21, 35), disproportionate study exclusion (36–37), beliefs regarding researchers willingness to conduct ethical studies (38–39), the failure to actively recruit African Americans for studies (23, 31), fatalistic attitudes towards diseases such as cancer (40), negative attitudes towards study staff

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Selected Abbreviations and Acronyms

PMSA = Primary Metropolitan Statistical Area

SUDAAN = The Survey Data Analysis Program, Version 7.5

(41), the racial composition of study staff (18), and racism (42). An extensive review of this literature is provided elsewhere (23).

Previous studies of African American medical research participation focused on barriers to African American women's participation in cancer clinical trials (38), African American and Hispanic attitudes toward medical research participation (31); and factors that underlie African American participation and attrition in a stroke prevention study (43). These studies while providing valuable information on barriers to medical research among African Americans do not provide data on racial differences in the prevalence of research barriers.

To examine whether there are racial differences in barriers to medical research we conducted a cross-sectional survey of the Detroit Primary Metropolitan Statistical Area (Detroit PMSA) during 1998-1999. Our purpose was to determine if racial differences in the prevalence of sociocultural barriers might explain racial variation in rates of medical research participation.

METHODS

Eligible households were located in selected occupied housing units in the Detroit PMSA. Eligible respondents were 18 years of age or older and were current residents of a selected household. The head of the household or their spouse, at their discretion, completed the questionnaire/interview. Housing units were excluded if there were no eligible respondents (i.e., no respondent at least 18 years old, vacant housing units, respondent was too sick to participate or the respondent didn't speak English).

A stratified multi-stage area probability sampling design was employed to select households (Figure 1). The race of the householder used for sampling was obtained from the 1990 U.S. Population Census. The 1990 U.S. Bureau computer file summary tape STF-1A (44) of population and housing data was used to identify census tracts and summary tape STF-3A (45) was used to identify census blocks. Street names and address ranges for the selected blocks were obtained from the Census of the Population Metropolitan Map Series and Enumeration District Maps (46) and from the Rand-McNally Street Index for the Detroit PMSA (47). Bresser's Cross Index Directory (48) was used to determine the addresses of occupied households in the Detroit PMSA and the names and telephone numbers of residents.

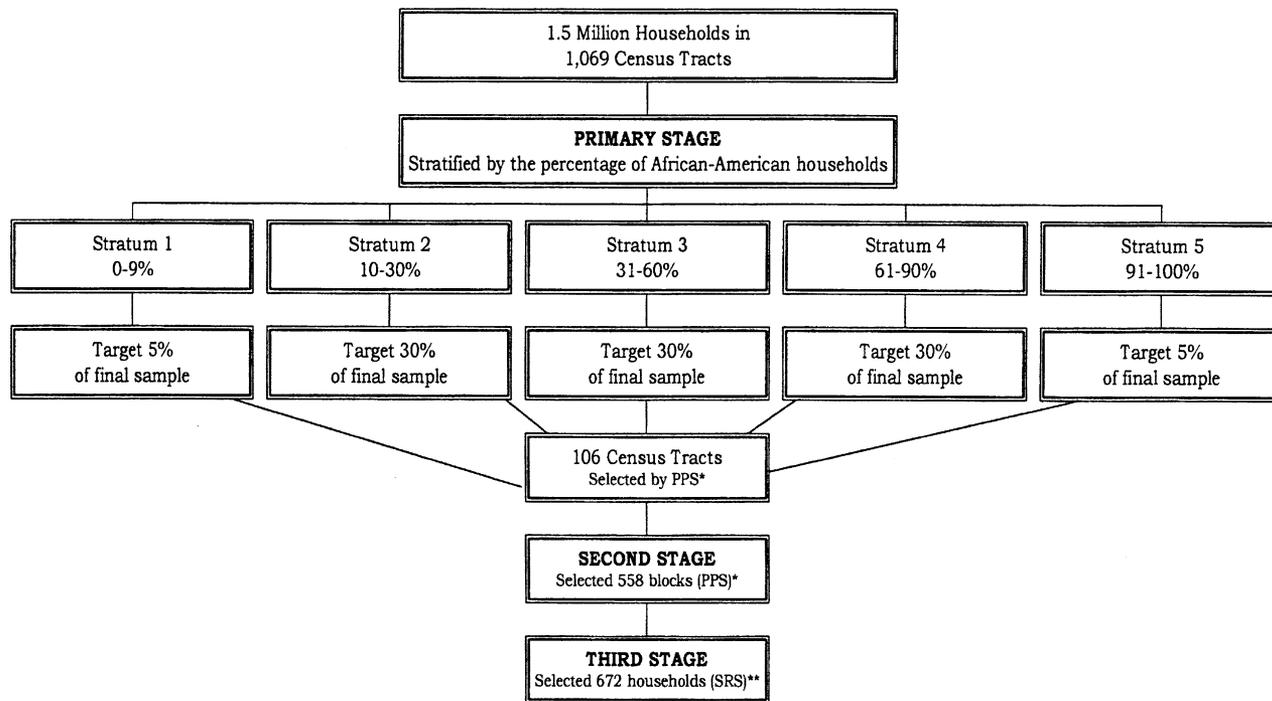
The main study instrument was a mail survey containing 24 questions (long version). There was also a short version of the mail survey, which contained seven questions that addressed the main study objectives and collected demographic data (i.e., age and race). The short questionnaire was sent to households that were non-respondents to two separate mailings of the long questionnaire. The third instrument was a telephone survey that contained all of the questions from the short mail survey and collected additional demographic data (i.e., education, income, and name). We attempted to interview non-responders to all of the mailed questionnaires by telephone. Non-respondent households that did not have listed telephone numbers or telephones were not further contacted. A professional interviewer conducted all telephone interviews. Four attempts were made to contact each eligible household. These consisted of at least one phone call during business hours of a weekday, an evening phone call, and a weekend call. The telephone interviewer was provided with a prepared script to assure that all participants were interviewed in the same manner.

Study envelopes were stamped "do not forward" so that letters would be returned when sent to the address of a vacant lot, unoccupied housing unit, incorrect street address, or when the resident was incorrectly identified. Letters returned from the post office had addresses corrected when possible and were sent out again. Individuals who completed and returned a survey received a new two dollar bill. The incentive was mailed after receipt of the completed mail survey or telephone interview.

Statistical Methods

The sample was weighted to estimate population parameters for the entire Detroit Metropolitan Statistical Area. The adjusted sampling weight was calculated as the product of the selection probability and an adjustment for unit non-response.

The Survey Data Analysis Program Version 7.5 (SUDAAN) (49) was used to analyze weighted data. SUDAAN produced statistics adjusted for the effect of clustering. Analyses of unweighted data were limited to sample demographics and response rates, and were performed with SAS (50) and SPSS (51). Chi-square tests were performed to assess differences in the distribution of proportions between study groups. Univariate analyses were run to determine factors that may be associated with the willingness to participate in a medical research studies. Factors with a significance level of 0.20 or less were entered into a multivariate logistic regression model. Separate logistic regression models were run for African Americans and whites. A significance level of 0.05 (two-tailed) was used for all analyses.



*PPS=Probabilities proportionate to size

**SRS=Simple random sampling

FIGURE 1. Summary of the sampling design.

Completing either a mail questionnaire or a telephone interview was deemed consent to participation in this study. The institutional review board of the University of Iowa (Committee A) approved the study protocol.

RESULTS

Six hundred seventy-two households were eventually selected from the 1069 occupied census tracts in the Detroit PMSA (Figure 1). Response rates and eligibility are provided in Figure 2. A total of 42 households were coded as ineligible for the mail survey portion of the study. The proportion of households coded as ineligible for the mail survey within the City of Detroit and suburban areas was about 6% for each.

Among the 284 households initially identified for the telephone survey, nine percent had telephone numbers that were not for the selected household, 12% were disconnected numbers, 2% had respondents that did not speak English, in 1% the respondent was too sick to participate, and in 1% the respondent did not meet eligibility criteria. Eligible households that were not reached after four telephone attempts were coded as refusals.

One hundred ninety-eight individuals participated in this study for a total response rate of 36%. Of these, 91 were African American, 88 whites, and 19 were from other racial/ethnic groups. Overall, the most frequent mode of response was the long version of the mail questionnaire followed by the telephone interview and the short version of the mail questionnaire (Figure 2). Data on response rates are provided for all participants, however only African Americans and Whites are included in the analyses.

The demographic characteristics of study respondents are listed in Table 1. African American respondents were on the average, younger than whites and more frequently female. The two race groups had similar education and income distributions.

Willingness to Participate

Overall, respondents more often indicated a willingness to participate in a medical research study if they were white, female, under age 65, and if they had a high school education or more. With the exception of educational level, these differences were not statistically significant (data not presented). The demographic characteristics of respondents

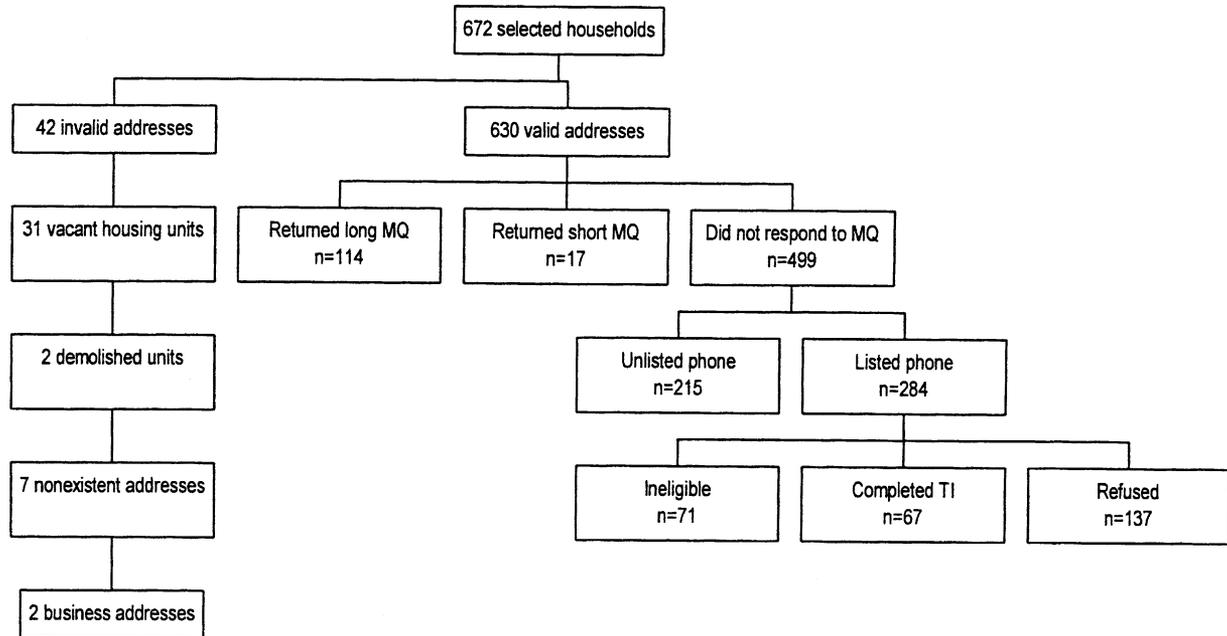


FIGURE 2. Overall survey response*.

who were willing to participate in medical research stratified by race are provided in Table 2.

Race of the Doctor when Seeking Medical Care

Nearly 22% of African Americans reported that when seeking routine medical care, the race of the doctor was very

important, 30% as somewhat important, and 48% as not important compared to 9%, 20%, and 71% of white respondents, respectively. Among African Americans, 34% of those who felt that the race of the doctor when seeking routine medical care was very important, 67% of those who felt it was somewhat important, and 72% who felt it was not

TABLE 1. Characteristics of respondents

Variable	African Americans N = 91	Whites N = 88	Other ^a N = 19
Gender			
Male (%)	39	55	53
Female (%)	62	45	47
Age			
Mean age (years)	41.9	50.2	48.1
Median age (years)	42.0	47.0	40.5
Educational level			
Less than 8th grade (%)	1	2	0
Between 8th and 11th (%)	8	13	19
H.S. grad or GED (%)	19	24	25
Some college/or college grad (%)	73	60	56
Total household income			
Less than \$10,000 (%)	6	9	21
\$10,000 to \$19,999 (%)	17	12	29
\$20,000 to \$29,000 (%)	15	17	7
\$30,000 to \$49,999 (%)	18	25	7
\$50,000 or more (%)	44	38	36

^aIncludes respondents who did not answer the race/ethnicity question.

TABLE 2. Demographic characteristics of respondents willing to participate in a medical research study in the future by race

Demographic characteristic	Willing to participate in a medical research study		
	African American (%)	White (%)	P-value
Gender			
Male	53	62	0.09
Female	58	88	
Age			
Under age 65	54	85	0.06
Over age 65	76	49	
Education			
Less than high school	33	23	0.05
High school grad. or GED	71	92	
College	56	73	
Income			
Less than \$10,000	38	44	0.62
\$10,000 to \$19,999	85	53	
\$20,000 to \$29,999	39	79	
\$30,000 to \$49,999	61	65	
Over \$50,000	53	76	

important were also willing to participate in a medical research study in the future. In contrast, 90% of white respondents who reported the race of the medical doctor was very important, 71% somewhat important, and 74% not important were willing to participate in a medical research study group in the future ($p = 0.20$).

Beliefs about Equal Sharing of the Risks of Medical Research

Thirty-five percent of African American and 41% of white respondents indicated that all racial/ethnic groups equally share the risks of medical research ($p = 0.78$). Among respondents who did not believe that research risks were equally shared, African Americans more frequently than whites responded that most of the risks are borne by minorities (Table 3). Among respondents who believed that minorities bore the greatest burden of medical research risks, 55% of African American compared to 88% of white respondents indicated that they would be willing to participate in medical research ($p = 0.05$).

Sixty-six percent of African Americans and 42% of whites reported that the poor bear most of the risks of medical research ($p = 0.04$). African Americans who indicated that the poor bear most of the risks of medical research less frequently indicated willingness to participate in a medical research study than did African Americans who believed that risks were equally shared and those who believed that the rich bear most of the research risks. In contrast, among whites the willingness to participate in a medical research study varied little with regard to beliefs about whether the rich or poor bear most of the medical research risks ($p = 0.78$).

Tuskegee Study

Eighty-one percent of African Americans and 28% of whites were aware of the Tuskegee Study ($p \leq 0.01$). African Americans and whites differed with respect to the effect that their knowledge of the Tuskegee Study had on their trust of medical researchers ($p = 0.02$). About 51% of African Americans reported that their knowledge of the Tuskegee Study resulted in them having less trust in medical researchers, 48% reported that their trust had not changed, and 1% reported that they had more trust. In comparison, among white respondents who had knowledge of the Tuskegee Study, 17% responded that they now had less trust in medical researchers, 83% had no change in their level of trust, and none had more trust in medical researchers ($p = 0.02$).

Forty-nine percent of African Americans and 17% of whites that responded that their knowledge of the Tuskegee Study would affect their future participation indicated that they would not be willing to participate in a medical research study in the future ($p = 0.05$).

Because of the racial differences in the effects of the independent variables on the willingness to participate in

TABLE 3. Beliefs about which group bears the largest burden of medical research risks

Belief ^a	African Americans (%)	Whites (%)
Risks are equally shared by all racial/ethnic groups	34.6	40.5
Risks are not equally shared by all racial/ethnic groups		
Minorities bear most of the risk	25.2	5.2
Other racial/ethnic groups bear most of the risk	8.2	5.0
Group bearing most of the risk nor specified	32.0	49.3
Risks are equally shared by the rich and the poor	22.8	57.8
Risks are not equally shared by the rich and the poor		
The poor bear most of the risks	65.9	42.2
The rich bear most of the risks	11.3	0

^aWeighted proportion.

medical research studies, race stratified logistic regression analyses were preformed. Univariate logistic regression analyses identified the Tuskegee Study, changes in trust from knowledge of the Tuskegee, beliefs regarding the racial sharing of the risks of medical research, rich/poor sharing of the risks of research and income as factors that may be related to the willingness of African Americans to participate in medical research studies (Table 4).

When these four terms were entered into a race stratified multivariate logistic regression model, factors that predicted the willingness to participate in a medical research study included knowledge of the Tuskegee Study and changes in trust of medical researchers due to this knowledge. After adjusting for changes in trust resulting from knowledge of the Tuskegee Study, African Americans who knew about the Tuskegee Study were significantly more likely than those who didn't to be willing to participate in a medical research study in the future [odds ratio (OR): 464.4, confidence interval (CI): 44.4–4864.4]. The willingness to participate in a research study was lower if the effect of knowledge of the Tuskegee Study was a reduction in the level of trust of medical researchers (OR: 0.21, CI: 0.04–0.98) when compared to no change in trust and increased level of trust.

Univariate logistic regression analyses for whites identified beliefs regarding the racial sharing of medical research risks, age group, educational achievement (high school grad or not), and gender as factors related to the willingness to participate in a medical research study.

Results from race-stratified multivariate logistic regression analyses for whites indicated that educational level and beliefs regarding the racial sharing of medical research risks predicted their willingness to participate in medical

TABLE 4. Race-stratified univariate logistic regression models of the willingness to participate in a medical research study

Variable	Odds ratio	95% CI	Adjusted P-value
African Americans			
Gender			
Male	0.8	0.26–2.64	0.75
Female	1.0	Ref ^a	
Educational attainment			
Less than high school	0.35	0.06–2.0	0.23
High school/GED or more ^a	1.0	Ref ^a	
Age group			
Less than 50	1.6	0.50–5.11	0.42
50–64	1.0	Ref ^a	
65 and older ^a	^b	NA	
Income			
Less than \$10,000	0.5	0.07–3.90	0.16
\$10,000–\$19,999	5.1	1.1–24.3	
\$20,000–\$29,999	0.6	0.1–2.4	
\$30,000–\$49,999	1.3	0.3–5.6	
\$50,000 or more	1.0	Ref ^a	
Knowledge of the Tuskegee Study			
Knew about the study	2.7	0.99–7.40	0.05
Did not know about the study	1.0	Ref ^a	
Effect of knowledge on trust of medical researchers			
Less trust in researchers	0.2	0.04–0.8	0.01
Same or more trust in researcher ^a	1.0	Ref ^a	
Which group bear more risks			
Minorities bear more risks	0.4	0.1–1.3	0.15
Other groups bear more risks ^a	1.0	Ref ^a	
Which group bear more risks			
Poor bear more risks	0.3	0.06–1.2	0.09
Rich bear more risks	1.0	Ref ^a	
Importance of the race of doctor			
Very important	0.2	0.03–1.5	0.28
Somewhat important	0.8	0.1–4.4	
Not important	1.0	Ref ^a	
Whites			
Gender			
Male	0.20	0.03–1.3	0.09
Female	1.0	Ref ^a	
Educational attainment			
Less than high school	0.06	0.01–0.31	0.001
High school/GED or more ^a	1.0	Ref ^a	
Age group			
Less than 50	3.4	0.8–13.9	0.03
50–64	17.3	2.1–140.0	
65 and older ^a	1.0	Ref ^a	
Income			
Less than \$10,000	0.3	0.04–2.4	0.80
\$10,000–\$19,999	0.4	0.07–2.8	
\$20,000–\$29,999	1.4	0.2–8.9	
\$30,000–\$49,999	0.7	0.2–3.1	
\$50,000 or more	1.0	Ref ^a	
Knowledge of the Tuskegee Study			
Knew about the study	1.6	0.2–11.4	0.63
Did not know about the study	1.0	Ref ^a	
Effect of knowledge on trust of medical researchers			
Less trust in researchers	NA ^b		0.32
Same or more trust in researcher ^a	1.0	Ref ^a	
Which race/ethnic group bears more risks			
Risks equally shared	1.0	Ref ^a	0.17
Minorities take more risks	4.1	0.38–45.5	
Other groups take more risks ^a	1.7	0.31–9.2	
Risks unequally shared (group not specified)	9.9	1.03–94.7	
Which group bears more risks			
Poor bear more risks	0.81	0.18–3.6	0.77
Rich bear more risks	1.0	Ref ^a	
Importance of the race of doctor			
Very important	3.3	0.2–50.8	0.64
Somewhat important	0.9	0.1–6.0	
Not important	1.0	Ref ^a	

^aReference group.

^bSample size too small to calculate odds ratio.

research studies. Whites with less than a high school education were significantly less likely than those with more education to be willing to participate in a medical research study (OR: 0.04, CI: 0.01–0.43). In addition among whites the belief that racial groups did not equally share risks of medical research was associated with a higher willingness to participate in medical research (OR: 12.4, CI: 1.9–82.0).

DISCUSSION

Study results indicate that association between race and the willingness to participate in a medical research study is a result of racial differences in issues related to trust of medical research. African American respondents more frequently attributed race/ethnicity as a factor in the distribution of the burden of medical research risks than did whites. A large proportion of whites indicated that more of the risks of medical research are borne by the poor. This was considerably less than the proportion that indicated that blacks and other minorities bear more of medical research risks. This suggests a failure to reconcile the belief that the poor bear a greater burden of medical research risks with the fact that racial/ethnic minorities are disproportionately represented among the poor.

A reduction in trust as a result of knowledge of the Tuskegee Study more frequently had a negative impact on the future willingness of African Americans to participate in a medical research study. Similar to findings of Fouad and coworkers (52), we found that having knowledge of the Tuskegee alone did not seem to impact the willingness to participate in medical research. The role of Tuskegee appears to lie with its contribution to the overall distrust of medical research among African Americans, Racial differences in how knowledge of affected trust and future research participation decisions may lie with the fact that the study only involved African American men. It can be reasonably assumed African Americans could more readily identify with Tuskegee ‘participants’ than whites.

Study Strengths and Limitations

The sampling design was a major strength of this study for two reasons. First, this design yielded greater precision than what would have been obtained with the sample size using simple random sampling. The design effects for this study were all less than one and ranged from 0.65 to 0.80. Unlike many studies that make racial comparisons, there was a deliberate attempt to recruit African Americans from both inner city and suburban areas. This strategy also provided control of the overall socioeconomic make-up of the sample.

A possible source of bias for this study is the age of the census data used for sampling. The most recent census data available are nearly 10 years old. Non-coverage errors may have occurred due to an increase in new housing construc-

tion that may have resulted in the creation of new census tracts or blocks that were not included as sampling units for this study. There has been a net decrease in the number of housing units and an exodus of individuals from the city of Detroit, whereas the opposite is true for suburban areas (53). The population of the City of Detroit decreased by 5.7% between 1995 and 1998, whereas the population of some suburban areas increased as much as 20% (54).

These data suggest that non-coverage is more likely to have occurred in suburban areas. In spite of the age of the census data, the sampling objective of nearly equal numbers of African American and white participants was achieved. Census data were also used for weighting purposes. This could have resulted in the over weighting of responses from the city of Detroit and the under weighting of responses from suburban areas.

Non-response was another possible source of bias. Non-response jeopardizes the ability to generalize results to the target population when non-responders differ from responders among important study characteristics. Although only 36% of eligible households participated in the study, the low response rates are not believed to be a substantial impediment to generalizing study results to the Detroit PMSA. A comparison of early and late responders, used as a proxy for assessing differences between participants and non-participants, did not show differences that were likely to have changed the direction of the main study findings. Nevertheless, because non-responders were not actually compared to participants, selection bias cannot be ruled out.

CONCLUSION

Human behavior and motivation are products of the complex interrelationship of social conditions, environmental exposures, and historical experiences. Race and ethnicity have been major influences on individual and group experiences of minorities in the U.S. (29, 55–57). This is the basis for the distrust that impedes African American participation in medical research studies. Trust building with African Americans, therefore, will be dependent upon reducing the occurrence of experiences and conditions that cause distrust. Racial/ethnic differences in access to care, quality of medical care received, and other appearances of racism and discrimination in the health care setting must be eliminated.

Individual researchers can begin to establish trust with minority communities by conducting research projects in an open and honest manner. It is also important to accurately describe known or potential differences in the level of risk or benefit for specific population subgroups. (i.e., racial/ethnic minorities, women, or children, etc.). This will allow participants to better assess the impact of any potential risks and benefit to themselves and allow them to

weight these appropriately when making their research participation decisions.

Researchers should encourage open discourse on the past misuse of minority participants that generated the overall distrust of researchers and describe provisions that they have made to protect participants in their particular studies. The presence of institutional review boards has done little to alleviate fear and suspicion of research among racial/ethnic minorities (38-39); therefore acknowledging institutional review board approval for a project is not sufficient. Researchers should also provide frank explanations for studies and initiatives that specifically target racial/ethnic minorities or that are likely to result in the disproportionate representation of racial/ethnic minorities among study participants.

Researchers should establish partnerships with the community to give the community ownership of the research project. This will help to generate interest and encourage community involvement. Helping communities establish infrastructure to facilitate the continuance of health promotion activities after the research study has been completed will also help establish trust and goodwill between the community and researchers.

At a 1996 conference on minority recruitment to clinical trials, African-American community leaders complained that universities frequently begin research programs without input from residents of the study community (52). Community involvement should be encouraged in all phases of a research project (58). First, community residents can be invaluable in helping to design appropriate studies. Second, when the community is involved they are likely to have a better understanding of the research project, which, will be conducive to eliciting research participation.

Most importantly, researchers must adhere to ethical rules for research conduct. This includes maximizing benefits, reducing risks, and assuring distributive justice to *all* medical research study participants.

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