

# The Association between Race and Attitudes about Predictive Genetic Testing

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## Abstract

**Objective:** To investigate differences in attitudes about predictive genetic testing for cancer risk between African-American and Caucasian residents of the city of Philadelphia. **Methods:** Cross-sectional survey of awareness of and attitudes about predictive genetic testing, using an instrument developed through focus groups with the general public, literature review, and expert opinion. **Setting:** Municipal County Courthouse of Philadelphia. **Respondents:** Male and female adults waiting to be assigned to jury duty. **Results:** Of the 430 respondents, 43% (170) were African-American and 45% (181) Caucasian. Awareness of predictive genetic testing was higher among Caucasians (72%) than African-Americans (49%). After adjustment for age, gender, and educational attainment, African-Americans were more likely to report that the government would

use genetic tests to label groups as inferior, and less likely to endorse the potential health benefits of testing, including "help my doctor manage my health care," "help me change my lifestyle," and "help scientists find cures for diseases." These associations remained if the sample was restricted to participants who had heard of genetic testing before the survey. **Conclusions:** In the city of Philadelphia, awareness of and attitudes about predictive genetic testing for cancer risk differ by race, with lower awareness, less belief in the potential benefits of testing, and more concern about racial discrimination from genetic testing among African-Americans than Caucasians. These differences may result in disparities in the uptake of predictive genetic testing in the future. (Cancer Epidemiol Biomarkers Prev 2004;13(3):361–365)

## Introduction

Genetic tests that identify individual susceptibility to several common adult-onset diseases are commercially available. Many professionals in the clinical and genetics communities believe that these tests have the potential to greatly improve patient care. However, the eventual benefit of predictive genetic testing will be determined, in part, by the willingness of patients to undergo testing. Attitudes about the risks and benefits of genetic tests are likely to be an important determinant of willingness to undergo testing.

Although there have been many studies of high-risk populations, relatively little is currently known about the attitudes of the general public (1–4). Most prior studies of the general public were conducted in the mid-1990s, focused on interest in undergoing testing and assessed relatively few attitudes about genetic testing (5–9). Furthermore, given current attention to racial disparities in health and health care and the racial focus of the eugenics movement in the past, empirical evidence about racial differences in attitudes about genetic testing in the general population is particularly important (10–15).

Thus, the purpose of this study was to compare awareness, knowledge, and attitudes about genetic testing for cancer risk between African-American and Caucasian individuals in the city of Philadelphia.

## Methods

**Study Design and Population.** We conducted a cross-sectional survey of residents of the city of Philadelphia who were called for jury duty at the Municipal County Courthouse. In the city of Philadelphia, prospective jurors are selected at random from a pool of registered voters and adult licensed drivers. We gave the questionnaire in the juror selection waiting room. Participants were offered a candy bar on completion of the questionnaire.

**Instrument Development.** Instrument development involved the following steps. First, we conducted four focus groups in the fall of 2001 with 38 members of the general public recruited through advertisement in free local newspapers (16, 17). Participants ranged in age from 20 to 60 years old; 26% were women; 37% Caucasian, 50% African Americans, and 13% from other racial groups. We asked open-ended questions to generate a discussion about people's understanding and attitudes of predictive genetic testing for cancer risk. Each session was audiotaped and transcribed. Transcripts were reviewed to identify major themes. Investigators then met to reconcile differences with the

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resultant identification of five major themes: (1) awareness of genetic tests; (2) ability to gain control from testing; (3) scientific advances from testing; (4) insurance and employment discrimination from testing; and (5) racial and ethnic discrimination from testing. Results from focus groups, literature review, and expert opinion were then used to develop a pilot instrument. The pilot questionnaire was given to 55 potential jurors in Philadelphia. This pilot sample had a mean age of 41 years; 69% were women; 54% were African-American, 42% Caucasian, and 4% from other racial groups. Pilot data and discussion with experts were used to revise the instrument.

The final questionnaire included two items to measure awareness of genetic testing for cancer risk: "Have you heard of genetic testing for cancer risk?" and "One of the genetic tests for cancer risk that is sometimes mentioned in the news is a test for breast cancer. It is called BRCA 1 and 2 testing, or BRACA testing. Have you heard of that test?" The response options were yes, no, and not sure. Nine items were created to measure attitudes about predictive genetic testing. These items reflected the themes that were identified in the focus groups and ranged in topics from the effects of genetic testing on health insurance to the benefits of genetic testing for scientific research. Response options were based on a four-point Likert scale: *not at all likely*, *slightly likely*, *somewhat likely*, and *very likely*. A short explanation of genetic testing was presented in the questionnaire before asking about attitudes.

**Data Collection.** Survey data were collected during December 2001 and January 2002, with a total of 430 completed questionnaires. Although courthouse procedures prevent the determination of a precise response rate, we estimate that over 75% of prospective jurors volunteer to participate and over 90% of individuals who volunteer complete the questionnaires. Approval from the University of Pennsylvania IRB was granted for focus groups and questionnaires.

**Data Analysis.** All analyses were conducted using STATA 7.0 software. Of the 430 questionnaires returned, 79 were excluded because the participant was neither African-American nor Caucasian. To facilitate the presentation of inferential analyses, awareness of genetic testing was dichotomized by grouping participants who answered not sure with participants who answered no. Similarly, responses to attitudinal items were dichotomized into *not at all likely* and *slightly likely* defined as "no" and *somewhat likely* and *very likely* defined as "yes." Alternative categorizations were tested and did not change the main results.

Bivariate associations were examined using ordinary  $\chi^2$  tests for categorical variables and ordinary independent sample *t* tests for continuous variables. Multivariate analyses were conducted using logistic regression. Because we had not planned to create attitudinal summary scores and preliminary analyses did not support the reliability of such scores, we conducted separate analyses for each attitude. Variables were entered into the model if they were associated with the outcome or the primary exposure of interest (*i.e.*, race) in bivariate analyses ( $P < 0.10$ ) or had been specified *a priori* (*i.e.*, age, gender). Variables were

retained in the model if they were associated with the outcome with a  $P$  value  $< 0.05$  or altered the coefficient for another variable by 15% (18). Because prior awareness of genetic testing could be considered a prerequisite for having a meaningful attitude about genetic testing, we assessed the association between race and attitudes in the overall sample and within the subgroup of participants who were aware of genetic testing.

## Results

Participant demographics are reported in Table 1. Of the 351 participants, 170 (48%) were African-American and 181 (52%) were Caucasian. African-American participants were more likely to report that their highest level of education was a high school diploma or less and were less likely to have graduate school education.

Two hundred and fourteen participants (61%) had heard of genetic testing for cancer risk. Awareness was lower among African-American than Caucasian participants (Table 2). Awareness was also lower among less educated participants with 53% of participants with a high school education or less reporting that they had heard of genetic testing for cancer risk compared to 66% ( $P = 0.005$ ) of respondents who had completed at least some college. Awareness of genetic testing was not associated with gender or age ( $P$  values  $> 0.5$ ). Overall fewer respondents had heard of BRCA tests (31%); however, the racial difference in awareness persisted, with 36% of Caucasians reporting having heard of BRCA testing, compared to 25% of African American ( $P = 0.03$ ).

Responses to attitudinal items are reported in Table 2. Overall, positive attitudes about the benefits of genetic testing were prevalent with over 80% of respondents reporting that genetic tests were likely to be used to help doctors manage health care, patients change their lifestyle, and scientists find cures for diseases. Fewer respondents reported that genetic tests would be used

**Table 1. Participant characteristics**

	Overall (N = 351)	African- American (N = 170)	Caucasian (N = 181)	P value
Female (%)	63	63	61	0.56
Education (%)				
≤High school diploma	28	37	20	0.01
Some college	32	33	31	
College degree	19	15	23	
≥Some graduate school	21	15	25	
Age (%) (mean = 41)				
19–30	24	20	29	0.43
31–40	24	29	20	
41–50	26	27	25	
51–60	15	14	15	
61–73	11	10	11	
Heard of genetic testing (%)	61	49	72	<0.005
Heard of BRCA tests (%)	31	25	35	0.03

**Table 2. Attitudes about predictive genetic testing according to race**

	Overall sample * (N = 351)		Subgroup aware of genetic testing (N = 214)		
	% somewhat or very likely	African-American <i>vs.</i> Caucasian		African-American <i>vs.</i> Caucasian	
		OR	95% CI	OR	95% CI
To help my doctor manage my health care.	88.0	0.28	0.53–2.40	0.34	0.14–0.84
To help me change my lifestyle.	81.7	0.50	0.28–0.89	0.50	0.23–1.11
To help prevent cancer.	82.6	0.56	0.31–1.02	0.48	0.22–1.02
To help scientists find cures for disease.	91.5	0.45	0.20–1.03	0.45	0.17–1.22
To limit my health insurance coverage.	47.1	0.84	0.54–1.32	1.02	0.58–1.77
To prevent my family from getting health insurance.	18.1	0.57	0.31–1.03	0.48	0.22–1.02
To prevent me from getting life insurance.	44.9	0.73	0.47–1.14	0.99	0.57–1.72
To prevent me from getting a new job or promoted.	16.6	0.93	0.50–1.71	0.93	0.44–1.96
To allow the government to label groups inferior.	16.1	2.15	1.15–4.03	4.00	1.82–8.77

for insurance or job discrimination, ranging between 17% who believed genetic tests were likely to be used for job discrimination and 47% who thought genetic tests were likely to be used to limit health insurance coverage. Sixteen percent of respondents thought genetic tests were likely to be used to allow the government to label certain groups as inferior.

After adjustment for age, gender, and educational level, African-Americans remained more likely to report that the government would use genetic tests to label groups as inferior, and less likely to endorse the potential health benefits of testing (Table 2). These associations remained if the sample was restricted to participants who had heard of genetic testing before the survey. There were no racial differences in attitudes about insurance or job discrimination from genetic testing.

## Discussion

This study demonstrated significant differences in awareness and attitudes about predictive genetic testing between African-Americans and Caucasians in the city of Philadelphia. African-Americans were less likely to be aware of the existence of genetic testing, and, even after adjusting for awareness, were less likely to endorse the potential benefits of genetic testing than were Caucasians. Furthermore, although the overall prevalence of concern about the use of genetic tests for racial discrimination was relatively low, African-American participants were much more likely to believe that this would happen than were Caucasian participants.

The finding of greater concern about racial discrimination on the basis of genetic information among African-Americans is not surprising. The advent of genetic testing for cancer risk has occurred within a social and historical context. This historical context includes the policy failures of genetic testing for sickle

cell screening in the 1970s, the racial motivation of the eugenics movement in the first half of the 20th century, and abuse of African-Americans in scientific research, including the infamous Tuskegee Syphilis study (13, 19–23). The current social context includes widespread discussion of racial disparities in health and health care, persistent evidence of racial discrimination in many areas of society, and generalized distrust of social institutions including the health care system (10, 24, 25). Multiple studies have documented greater concerns about and reports of racial discrimination among minority groups (26–28). To our knowledge, this study provides the first empirical evidence that this pattern extends to the area of genetic testing.

The racial differences in attitudes about the potential health benefits of genetic testing are less easily explained, particularly as these persisted after adjustment for awareness of testing and education. Cultural differences in temporal orientation, religious beliefs, or models of health maintenance may make the predictive ability of genetic testing less salient for African-Americans than Caucasians (29–31). Distrust of the health care system and health care interventions in general may be greater among African-Americans and Caucasians (32, 33). Alternatively, racial differences in perceptions of the potential benefit of genetic testing may represent residual differences in knowledge about genetic testing that were not accounted for by the relatively coarse measures of education and awareness included in our survey. Prior studies have documented lower levels of awareness of genetic testing among African-American women but have generally shown similar levels of interest in undergoing testing (34–36). Interestingly, one prior randomized trial documented that African-American women were more likely to undergo genetic testing after participating in an education and counseling intervention compared to an educational intervention alone, raising the

possibility that African-American women may have had less positive attitudes about genetic testing (37).

These findings have several implications for improving the delivery of predictive genetic testing in the future. Racial disparities in the uptake of *BRCA1/2* testing have been documented (14). If racial differences in attitudes about the benefits and risks of genetic testing exist, it becomes important to understand why these attitudes differ and to determine to what extent these differences should be addressed. Clearly, the potential for racial discrimination on the basis of genetic information exists. As the number of genetic tests with direct implications for health and health care grows, the development of policy or legislative initiatives to allay this concern becomes increasingly important. To the extent that differences in attitudes represent inadequate or uneven diffusion of information about predictive genetic testing, careful and culturally sensitive public health educational efforts may be instrumental in mitigating potential disparities in who benefits from genetic technology. However, it is important to recognize that racial differences in attitudes may also represent enduring cultural differences in values and preferences that should be respected rather than fixed. Although debate continues about the extent to which predictive genetic testing will improve health and health care, we believe the opportunity to reduce the risk of future racial disparities in the use of genetic tests should not be overlooked because of uncertainty about the exact clinical circumstances where these tests will provide the most benefit (38).

This study has several limitations. Although considerable judicial effort is directed to ensuring the representativeness of juror pools, prospective jurors may not be an unbiased sample of Philadelphia residents (1, 5). Concerns have been raised that jurors may differ from the source population in race, age, and gender (3). In addition, jury pools are likely to underrepresent individuals who move frequently, have prior criminal records, or are in active military service. Despite these concerns, the demographics of our sample before excluding other racial groups are very similar to those of the city of Philadelphia according to the 2000 Census, a standard method of assessing the representativeness of the jury pool (4). (Table 3) Thus, based on jury pool standards, our sample would be considered highly representative of the source population. Because we are unable to determine a precise response rate and nonresponders may differ from responders, it is difficult to exclude the possibility of a response bias. However, we believe it is unlikely that the primary factors affecting participation in the survey (*e.g.*, being called for a jury panel) would have biased our analyses of the association between race and attitudes about genetic testing. We chose to focus on differences between African-Americans and Caucasians and are unable to provide information about attitudes among other racial groups. Measuring awareness of genetic testing is challenging. Individuals who have some level of awareness of genetic tests may not be captured by our measures of awareness because of the need to use specific words to describe genetic tests, for example, "genetic testing for cancer risk," the potential for narrow interpretation of phrases such as "heard of," and reluctance to admit awareness because of concerns about being expected to

**Table 3. Comparison to demographics of Philadelphia City**

	Study sample	Philadelphia City 2000 census
Age (mean)	41.3	41.3
Race (%):		
African-American	42.6	43.2
Caucasian	45.4	45.0
Other	12.0	11.8
Male (%)	36.0	33.6
Education (%):		
Some college or less	70.8	77.7
College or higher	29.2	22.3

answer topical questions or demonstrate knowledge. The similarity of attitudes between participants reported being aware of genetic testing and those who did not highlights the limitation of the measure included in this survey. Thus, we chose to present analyses of the association between race and attitudes in the overall sample and in the subgroup who reported having heard of genetic tests for cancer risk.

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