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## Racial and ethnic differences in willingness to participate in psychiatric genetic research

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### Abstract

**Objective**—The National Institute of Mental Health’s effort to rectify the underrepresentation of American Blacks in the genetic studies of psychiatric disorders has met with mixed success. This study was designed to understand some of the barriers to recruitment.

**Methods**—Men and women, who were of Black, White or Hispanic race/ethnicity, aged 18–79 years ( $N\lambda=\lambda353$ ), were recruited from clinical and community settings in New York City Participants responded to a survey that was designed to measure willingness to participate and attitudes toward genetic research. Principal components analyses generated eight factors including perceived benefits, concerns about, and drawbacks of genetic research, and beliefs about genetic or environmental contributions to psychopathology. Analysis of variance assessed within-ethnic group differences on factor scores, as they related to willingness to participate in genetic research.

**Results**—Ethnic groups did not differ significantly in stated willingness to participate in genetic research; more than 70% in each group were willing to participate. Among Blacks and Hispanics, mistrust and wariness, and stigma were significantly increased in those unwilling to participate; for Whites, perceived benefit to society and perceived importance for knowledge/education were associated with willingness to participate. For Blacks and Hispanics, youth (aged 18–29 years) and college education reduced, but did not eliminate the association between wariness and mistrust and willingness to participate.

**Conclusion**—Findings suggest that recruitment efforts aimed at increasing the representation of Blacks should be aware of the barriers among those who are less educated, and involve interactive community collaborations, to fully address the mistrust in this population.

### Keywords

attitudes; Blacks; depression; genomic; recruitment; mental illness

### Introduction

Despite the increase in genetic research of psychiatric disorders in the last decade, (Rutter, 2000; Sullivan *et al.*, 2000; Levinson, 2003), and major efforts by the National Institute of Mental Health (NIMH) to ensure adequate representation of non-Hispanic American Blacks (NIMH, 2007), the success in increasing representation has been mixed. To reduce health

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Declaration of interest

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disparities, the NIMH has required inclusion of Blacks in these studies and has made efforts to increase recruitment. However, American Blacks remain underrepresented in family (Weissman *et al.*, 1984; Hettema *et al.*, 2001; Sullivan *et al.*, 2000), twin/adoption (Lyons *et al.*, 1998; Kendler and Prescott, 1999; Kendler, 1993, Kendler, 2001) and genetic studies (Badner and Gershon, 2002; Lohmueller *et al.*, 2003; Levinson *et al.*, 2007) of schizophrenia, mood and anxiety disorders. Non-Hispanic Blacks roughly comprise 12% of the US population over the last three decades (US Census Bureau, 1980, 1990, 2006), but typically account for less than 5% of the sample in these studies. Consequently, little is known about the hereditary component of depression or other psychiatric disorders among Blacks. The reasons for their underrepresentation in biomedical research, including genetic research is of scientific interest. (Buchwald *et al.*, 2006; Sterling *et al.* 2006).

The underrepresentation of Blacks in genetic studies of major depression is particularly important because differences in rates of disorders suggest possible genetic and/or social differences in causes. Compared with Whites, Blacks suffer higher rates of many serious physical illnesses such as hypertension and diabetes, (Williams, 1999), but paradoxically have lower rates of major depression (Breslau *et al.*, 2006; Williams & Earl, 2007). Several community-based epidemiological studies in the United States over the last 20 years show similar patterns of racial/ethnic differences, with Blacks reporting lower rates of major depression than Whites (Somerville *et al.*, 1989; Kessler *et al.*, 1994; Jackson *et al.*, 2004; Hasin *et al.*, 2005). Whether the difference is an artifact of sampling or reporting, is unclear. Assuming that the difference is nonartifactual, the mechanisms responsible for this persistent finding, genetic, environmental, or a combination of both, are poorly understood. Although preliminary research has suggested possible genetic differences between Blacks and Whites with regard to depression risk and the response to pharmacological treatments of depression (Lotrich *et al.*, 1997; Gelertner *et al.*, 1998; Gelertner *et al.*, 1999; Lotrich *et al.*, 2003; McMahon *et al.*, 2006), the findings are contradictory and difficult to interpret because these studies are few and the sample sizes are relatively small.

Efforts to include representative numbers of Blacks in biomedical research have been met with some difficulty, with successful recruitment usually entailing careful planning, extensive community engagement, time, and human resources (Shavers *et al.*, 2002; Clay *et al.*, 2005). The usual explanations for this difficulty typically involve mistrust, which is thought to be more prevalent among Blacks compared with Whites, because of the well-known historical legacy of the Tuskegee Syphilis Study, among others (Schulz *et al.*, 2003; Bates and Harris, 2004).

With regard to genetic research, much of Blacks' mistrust is thought to stem not only from fear of harm while participating in the study, but also from misgivings about the ultimate uses of the information garnered from the studies (Schulz *et al.*, 2003), because genetics have been misapplied in explaining racial differences on a number of indices including intelligence test scores (Hernstein and Murray, 1994), and pain perception (Hama, 2000). Like Blacks, Hispanics have also been shown to share similar concerns about misuses of genetic information (Schulz *et al.*, 2003).

Another element related to mistrust, and also relevant to genetics in psychiatry, is the stigma associated with having a mental illness, or carrying a genetic risk for one's family. Compared with Whites, Blacks have been shown to have more stigmatizing attitudes toward psychiatric disorders, perceiving individuals who suffer from these disorders as being violent or dangerous (Whaley, 1997; Anglin *et al.*, 2006; Rao *et al.*, 2007), and endorsing social distance from them or their relatives (Whaley, 1997; Rao *et al.*, 2007). Some research has suggested that Blacks are less likely than Whites to use genetic explanations as causes of psychiatric disorders, because they associate the term 'genetics' with dysfunctional families and upbringing, a

stigmatizing phenomenon stereotypically associated with Black communities (Schnittker *et al.*, 2000). Although studies have linked beliefs about causes of mental illness to Blacks' willingness to seek professional treatment for psychiatric disorders (Schnittker *et al.*, 2000), few other studies have also linked their beliefs about genetic causes of nonpsychiatric illness to their willingness to participate in genetic research, it is currently unknown whether this association is true when it comes to participating in genetic research for psychiatric illness.

Research has shown that age and educational levels, regardless of race/ethnicity background, determine participation, with older or less educated individuals less willing to participate in genetic research, (Wang *et al.*, 2001; Audrain *et al.*, 2002; Moorman *et al.*, 2004; Bogner *et al.*, 2004). Still, other studies have shown that the shared experiences of historical and institutional racism among Blacks contribute to stigma and mistrust independent of education or socioeconomic status (Furr, 2002; Laskey *et al.*, 2003; McQuillan *et al.*, 2003).

In summary, commonly occurring beliefs that may be associated with genetic research participation among Blacks include mistrust, stigma, perceived benefits or harm, and perceived causes of psychiatric illness. Although these themes have been identified, few, if any, studies have directly linked them to willingness to participate in psychiatric genetic research. Using an educationally and ethnically diverse sample of Blacks, Hispanics, and Whites, the purpose of this study is to first determine differences among the groups in willingness to participate in genetic studies of psychiatric disorders, and how these differences relate to attitudes, beliefs, age, and education.

## Materials and methods

### Sample

The study used a convenience sample, in which participants of any racial or ethnic background, aged 18 years or older (all based on self-report), and who were English-speaking, were included. To obtain a range of education levels, we recruited volunteers from local hospitals, community settings including local businesses, and college campuses in the New York City area. The study was advertised through word-of-mouth referrals, and through flyers posted on bulletin boards in college and community service lobbies, and in clinical waiting room areas. The study was approved by the Institutional Review Board at the New York State Psychiatric Institute, and by the Institutional Review Boards from two local hospitals, which granted permission to recruit individuals receiving treatment at their outpatient mental health clinics.

### Procedure

Individuals who indicated an interest in participating were asked to read and sign written consent that explained the purpose of the study, procedures involved, risks and benefits, compensation, limits of confidentiality and participant rights. Participants were then provided with a confidential self-report questionnaire, containing a cover note with a brief introduction and basic description of genetic research on psychiatric disorders and some of the procedures associated with that kind of genetic research. Staff members were always present and available to respondents who needed further explanation of the consent form and the study procedures, or for a few who needed assistance in completing the questionnaire. Respondents were compensated \$10 in cash for participating.

### Research instrument

The questionnaire consisted of demographics (Table 1), 38 items consisting of statements reflecting attitudes, beliefs, and concerns about genetic research, two items assessing willingness to participate in genetic research, and four items assessing mental illness (clinical) and research participation history (available upon request). The 38 attitudinal statements were

developed for this study and were based on themes described in the literature on attitudes toward research, and themes obtained from a series of focus groups, consisting of mostly Black participants (Murphy and Thompson, in press). Generally, most respondents in the focus groups felt that genetic research would be helpful for the prevention and/or cure of certain diseases, and beneficial for educating society in general. The primary negative themes that emerged from the groups were fear of harmful or unpleasant procedures (e.g. having blood drawn, having to ingest substances, etc.), fear of loss of confidentiality, stigma associated with mental illness and family involvement, and lack of knowledge or education about genetics and genetic research. An example of one of the attitudinal statements in the questionnaire is 'genetic research is important for educating patients and health professionals'. Items were scored on a 4-point Likert scale ranging from 1 to 4 (1=strongly disagree, 2=somewhat disagree, 3=somewhat agree, 4=strongly agree). Higher scores on a given item indicated greater agreement with that item.

The two items specifically assessing willingness to participate were also scored on the same 4-point Likert scale as the attitudinal items. One was positively worded ('I would be willing to participate in genetic research') and the other was negatively worded ('I would not be willing to participate in genetic research'). We selected the negatively worded item as our outcome variable of interest because it correlated more strongly with the other items, and yielded a higher response variance (0.91 vs. 0.86), than its positively worded counterpart, which enabled superior differentiation among respondents. We reverse-scored this item for further analyses.

Four dichotomously scored items (1=yes; 0=no), assessed whether respondents had suffered from an emotional problem or mental illness such as depression, whether they had ever sought professional treatment for an emotional problem, whether they knew a friend or family member who had suffered from an emotional problem, and whether they had ever participated in a health research study.

### Statistical analyses

All analyses were performed using the Statistical Package for Social Sciences (SPSS) version 14.0 (2005). The three ethnic groups were compared on demographic indicators and clinical characteristics and research participation history, using  $\chi^2$  goodness-of-fit tests. The item that assessed willingness to participate in genetic research of mental illness was dichotomously recoded (collapsing 'somewhat' and 'strongly' agree into 1=yes, and collapsing 'somewhat' and 'strongly' disagree into 2=no). With this recoded item, we used a  $\chi^2$  test to compare the ethnic groups on willingness to participate, and then within these ethnic groups we examined the demographic and clinical or research factors associated with the willingness to participate.

Of the 38 attitudinal items, we excluded nine items because they were significantly modified because of lack of clarity (based on participant responses), after roughly half of the sample had participated in the study. Therefore, 29 items were used for further statistical analyses. Using an exploratory principal components analysis (PCA) (Jolliffe, 2002) based on varimax rotation with Kaiser Guttman normalization, we obtained factors for which we computed the mean scores for each ethnic group. The initial solution yielded nine factors with eigenvalues of more than 1.00, accounting for 61% of the cumulative variance in the group of questions. We excluded additional five items, which loaded on factors that were uninterpretable, or had factor loadings of less than 30. We reperformed the PCA on the remaining 24 items, which yielded a solution of eight components accounting for 64% of the cumulative variance.

Our decision to retain an item as part of a given factor was based on two criteria: the factor loading for that item had to be  $\geq 0.4$  (i.e. account for approximately 16% or more of the explained variance in that factor), and the item could not load on another factor within  $\pm 0.1$ . According to Ho, *et al.* (2001), the minimally acceptable coefficient is 0.33 because the squared

proportion accounts for at least 10% of the variance in a given factor. We dropped one item from factor 4 (item 37) because it loaded within 0.1 on factor 5. We retained the remaining 23 items for further analysis.

Once we determined the items comprising each factor, we obtained composite scores for each factor by summing its respective item scores. With the understanding that these summary scores may obscure the variation of individual items in a given factor, we were interested in the general trends for the purposes of this study. We conducted univariate analyses of variance, using the general linear model, to assess within each group, whether average scores on the factors obtained from the exploratory PCA differentiated willingness to participate in genetic research. Using analyses of covariance, we obtained adjusted mean factor scores after controlling for demographic or other relevant factors, where necessary.

## Results

### Demographic, clinical, and research characteristics

Table 1 shows the details of the Black, Hispanic and White samples ( $N\lambda=353$ ). An additional 52 Asians participated, but because of a small and skewed sample with 78% below the age of 23 years, we excluded them from further analyses. Eighty-three individuals (31%) were recruited from outpatient mental health clinics. Compared with the nonpatient sample, these individuals were more likely to be Black [ $\chi^2(4)\lambda=29.95, P<0.0001$ ], female, [ $\chi^2(2)\lambda=7.26, P<0.05$ ], separated/divorced or widowed [ $\chi^2(4)\lambda=76.91$ ], older [ $\chi^2(4)\lambda=194.44$ ], and less educated [ $\chi^2(4)\lambda=68.21$ ]. Blacks ( $n\lambda=174$ ), Hispanics ( $n\lambda=103$ ), and Whites ( $n\lambda=76$ ) did not differ significantly on sex (57% female), education level (61% college or higher), history of emotional problems/mental illness (42%), sought/received mental illness treatment (72%; of those who reported a history of emotional problems), or knowing friend/family member who suffered from mental illness (43%). Blacks were significantly older than Whites or Hispanics; they were also more likely to be divorced, separated, or widowed than Whites or Hispanics. Whites had more participants who had an annual household income of more than \$60,000 than Hispanics or Blacks, but Blacks had more participants earning \$20,000-\$59,000 than Whites or Hispanics. More Hispanics than Blacks or Whites had volunteered to participate in health research in the past.

### Willingness to participate in genetic research

More than 70% of each ethnic group stated that they would be willing to participate in genetic research. There were no significant differences between groups [ $\chi^2(2)\lambda=1.66, P\lambda=0.437$ ]. Table 2 shows the within-group comparisons across demographic, clinical, and research characters by willingness to participate in genetic research. For all the three ethnic groups, willingness to participate was not significantly associated with age, marital status, history of mental illness or treatment seeking, knowing friend/family member who had mental illness, and volunteering for health research in the past. Among Whites, significantly more females (89%) than males (69%) stated that they would be willing to participate. The percentage of Blacks willing to participate increased with education, with 79% of college-educated or higher, 70% of high school graduates, and 53% of those less than high school educated being willing to participate.

### Attitudinal factors from the survey assessment

Table 3 lists the factors, items, and their loadings, as well as the reliability coefficient of internal consistency, as measured by Cronbach's  $\alpha$  for each factor. On the basis of the questionnaire items associated with the factors, they were named (1) beneficial to individual and society, (2) important to participate for education and knowledge, (3) mistrust and wariness, (4) desire to learn more about genetic research, (5) stigma, (6) participating only for incentives, (7) mental

illness is caused by both genes and the environment, and (8) mental illness is caused primarily by genes. Factors 7 and 8 showed poor internal consistency, but we decided to retain them to examine whether they had any impact on stated willingness to participate.

### Attitudes and willingness to participate within ethnic groups

Table 4 shows the within-group association with eight attitudinal factors by the participants' stated willingness to participate in genetic research. To ensure that we did not distort the structure of the original data through dichotomization of the item that assessed willingness to participate, we performed within-group linear regressions in which we regressed each factor on the original 4-point coded item. With the exception of a nonsignificant trend becoming significant for stigma among Whites, we obtained identical results; we therefore retained the dichotomized item for clarity and interpretability. As individual item scores could range from 1 (lowest) to 4 (highest), scores on a given factor could range from the number of items in that factor (lowest) to 4 times that number (highest). The scores shown in the table represent the average scores on each factor among those who stated that they would be willing to participate in genetic research (yes), and among those who stated that they would not be willing to participate (no). Factors on which the two groups' scores differed significantly from each other are noted with asterisks. Blacks who were unwilling to participate in genetic research were more likely to endorse mistrust and wariness, stigma, and participating only for incentives. Hispanics showed similar trends for mistrust and wariness, and stigma. Unlike Blacks and Hispanics, the only two factors that were significantly associated with the willingness to participate for Whites were, beneficial to individual and society, and important to participate for education and knowledge.

### Attitudes and willingness to participate in college-educated participants aged 18–29 years

Although we controlled for education and other demographics in these analyses, we were concerned that simply controlling for these variables was not sufficient to overcome the limitations of a skewed age and education distribution. Age and education are important because studies have suggested that younger, more educated persons have more positive views toward genetic research. To address this potential limitation, we selected a subsample consisting of college-educated, younger (aged 18–29 years) participants, in which the three ethnic groups were comparable on the key demographic variables such as age and education.

In the stratified sample ( $n=148$ ), the three groups did not differ significantly on demographics or clinical and research characteristics, recruitment venue, or stated willingness to participate in genetic research (data available upon request). We examined within ethnic group associations among sex, marital status, clinical/research characteristics, and willingness to participate, and found that among Whites, significantly more females (89%) agreed to participate than males (59%,  $\chi^2(2)=5.55, P<0.05$ ). Among Hispanics, all of those who had volunteered in the past for health research were willing to participate, compared with 71% of those who did not ( $\chi^2(2)=4.51, P<0.05$ ).

Table 5 shows identical analyses as in Table 4, but now restricted to college-educated, young participants aged 18–29 years. The results also show that youth and college education substantially reduced, but did not fully eliminate the relationship between negative attitudes and willingness to participate among Blacks and Hispanics. Among Blacks, the association between stigma, participating for incentives only, and willingness to participate disappeared, but the association between mistrust and wariness and willingness to participate remained. For Hispanics the associations between mistrust, stigma and willingness to participate remained, but were generally weaker than that of Hispanics in the full sample.

## Discussion

This study used an educationally and ethnically diverse sample to examine attitudes associated with the willingness to participate in genetic research of psychiatric disorders. Even after controlling for potential confounders, Blacks, Hispanics, and Whites did not differ significantly on willingness to participate in a study, if fully informed of the procedures, risks, and benefits involved. However, the demographic characteristics and attitudes that are associated with willingness to participate were different for each ethnic group. The results suggest that among Blacks and Hispanics, willingness to participate in genetic research is more strongly influenced by perceived concerns or deterrents, rather than perceived benefits. The trend seems to be in the opposite direction for Whites, with the exception of stigma, which follows a similar but weaker pattern as in Blacks and Hispanics. Finally, we find evidence to support the idea that among Blacks, education and youthful age reduces but does not eliminate the impact of mistrust on willingness to participate in psychiatric genetic research.

Among Blacks and Hispanics, mistrust, wariness, and stigma emerged as the strongest predictors of willingness to participate in genetic research. This pattern remained even after stratifying by age and education and is consistent with earlier research, which has emphasized this robust association found among Blacks at all socioeconomic levels (Furr, 2002; Laskey *et al.*, 2003; McQuillan *et al.*, 2003). The promise of genetics as a potential tool for more effective detection and prevention of serious disorders represents a double-edged sword, an idea that has not been lost on health research professionals and laypersons. The usual research practice of relying on self-reported racial categories, combined with differential patterns of disease etiologies and outcome reflected among these categories, has raised questions in the minds of some scientists, as to the ultimate purpose and consequence of genetic research. Similarly, for Blacks, and to a lesser extent Hispanics, many of these concerns evoke images of a kind of science that is rooted in eugenics, and hail back to historical research projects that used questionable methodologies – the result of which rationalized the division of society by race, and ethnicity, creating further health disparities (Jackson, 1999; Ossario and Duster, 2005; Shields *et al.*, 2005) and engendering a perception of genetic research as being harmful to society (Jackson, 1999; Furr, 2002). With psychiatric disorders, genetic findings still may be perceived as tentative at best (Biesecker and Peay, 2003; Appelbaum, 2004). Therefore, potential research participants may be wary of participating in an exploratory genetic study with questionable benefit and possibly undesirable outcomes. As other studies have shown, engaging black communities in a manner that is transparent, meaningful and collaborative, and including Black recruiters and investigators, could help to alleviate the pervasive mistrust that exists in this population (Shavers *et al.*, 2002; Clay *et al.*, 2003; Fuqua *et al.*, 2005).

Stigma, like mistrust, also seems to be an important determinant of willingness to participate among Hispanics and less educated Blacks. Mental illness, a constellation of emotions, cognitions and behaviors technically labeled as ‘deviant’, is associated with the concept of stigma, which includes negative labeling and characterization from dominant groups in the societal hierarchy, negative emotional reactions from others, social distancing, loss of societal esteem, and discrimination against the sufferer (Link and Phelan, 2001; Link *et al.*, 2004). According to the attribution theory of genetics, (Weiner *et al.*, 1988), the belief that a disorder or trait is etiologically genetic may lead to the destigmatization of that disorder/trait through reduction of personal blame or responsibility, and increased empathy and caring toward the sufferer and kin. The genetic essentialist theory in contrast (Alper and Beckwith, 1993), predicts that believing in genetic causes would indirectly lead to increased stigma through the perceptions of heightened familial risk, gravity and intractability of the disorder/trait, and genetic determinism.

Using the 1996 General Social Survey data, Schnittker *et al.* (2000) found that Blacks have been shown to be associated with genetics from a stigmatizing perspective (poor family upbringing), and also showed that the relationship between believing in a genetic cause and seeking professional help was stronger among Blacks than Whites. The overall implications of these findings are that, if Blacks endorse genetic causes, they are more likely to consider them from an essentialist perspective, and they are more likely to seek professional treatment. To the degree that they do not invoke genetic explanations, they are less likely to seek professional treatment for psychiatric disorders, believing that the cause is rooted in society. Similarly, studies investigating research participation showed that Blacks were less likely than Whites to consent for DNA donation storage for genetic research, but Blacks who endorsed genetic causes were more likely to consent for DNA storage than those who did not (Wang *et al.*, 2001).

Contrary to our expectations, beliefs about the relative contribution of genes and environment in psychiatric disorders did not seem to play a significant role, if any, in Blacks' willingness to participate in genetic research. This may have been because of our particular study items, which were not high in internal consistency (see factors 7 and 8), and, therefore, did not yield particularly meaningful information. In contrast, there have been mixed findings with regard to ethnic group differences in beliefs about genetic contributions to mental disorders (Schnittker *et al.*, 2000; Singer *et al.*, 2007) showing that Blacks may be more or less likely than Whites to endorse genetic causes, depending on the specific disorders or traits, and the way in which the questions are asked. This suggests that the Blacks may be using attribution or essentialist notions of genetics, depending on the situation, thereby canceling out specific effects and leading to different outcomes. However, the scope of this study did not allow for the examination of hypothetical influences of particular theories in determining the relative contribution of genes or the environment, and their effects on willingness to participate in genetic research. This is an important area that calls for further research.

The education hypothesis predicts that Blacks with higher education may be more willing to participate in biomedical research or related activities. We found that education level not only influenced the relationship between attitudes and willingness to participate, but was also directly related with willingness to participate, among Blacks. Lower education may also imply poorer communities, which typically are associated with physical distance from research sites, lack of medical insurance required for participation in some studies, working shifts that are at odds with researchers' schedules, difficulty in taking time off from work to participate, other time pressures, and inability or unwillingness on the part of researchers to adequately engage these communities (Wendler *et al.*, 2006). Researchers' inability to recruit Blacks compared with Whites may be further exacerbated by the structural realities of differential educational attainment among Blacks and Whites along with racial and ethnic clustering in residential settings. In the general US population, Blacks, on average, have lower education levels than Whites, with 14.3% of Blacks reporting a bachelor's degree, compared with 26% among Whites (US Census Bureau, Census 2000 Brief, 2003). In less affluent urban areas, populated predominantly by Blacks and other ethnic minorities, residents tend to have lower levels of education, compared with those who live in more ethnically integrated neighborhoods, where their concentrations are lower. If more educated Blacks are the ones who are more inclined to participate in genetic research, then it is probable that recruitment would be more difficult as the more educated residents are more sparsely distributed in a given location.

Although our findings suggest that recruitment efforts might be directed toward Blacks who have had at least a high school education, and preferably some college-level education, caution needs to be exercised in light of some of the study limitations, including relatively small samples, which were conveniently recruited. Moreover, we only examined the stated willingness and not actual enrollment to genetic studies. Although our reports about the



respondents' past participation in health research showed consistent patterns with their reports on willingness to participate in genetic research, there can be discrepancies between people's responses on a survey and their actual behavior. Finally, the exploratory nature of this study leaves room for further refinement of measures that assess perceived barriers and attitudes toward research of psychiatric disorders.

Along with the need for continued research in this area, our findings have provided additional hints that are consistent with earlier studies. Despite the consensus that education may reduce the effect of stigma and mistrust on willingness to participate in genetic research, less educated or poorer Blacks should not be summarily excluded. However, the additional time, financial, and human resources required to adequately engage such communities, need to be factored into the planning and design of studies in which they are to be recruited. Although this may improve response rates for genetic studies, there remains significant work to be done in terms of addressing the significant reasons for mistrust associated with genetic research. The expected increase in molecular genetic research of psychiatric disorders over the next decade duly calls for continued attention to the perceived barriers and potential concerns expressed by populations that are underrepresented in such research.

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**Table 1**  
Demographic, clinical, and research experience characteristics by ethnic group

Characteristic	Blacks, <i>n</i> (%)	Hispanics, <i>n</i> (%)	Whites, <i>n</i> (%)	$\chi^2$
Sex				3.60
vMale	67 (39)	45 (44)	39 (51)	
vFemale	107 (62)	58 (56)	37 (49)	
Age (years)				25.53 <sup>≅</sup>
v18–29	86 (52)	69 (70)	61 (84)	
v30–49	53 (32)	24 (24)	6 (8)	
v50 and above	25 (15)	6 (6)	6 (8)	
Marital status				16.20 <sup>***</sup>
vSingle	122 (70)	83 (81)	64 (85)	
vMarried	22 (13)	15 (15)	7 (9)	
vDivorced/separated/widowed/	30 (17)	4 (4)	4 (5)	
Education level completed				7.34
vLess than high school	19 (11%)	8 (8)	4 (5)	
vHigh school/GED	59 (34)	28 (28)	17 (23)	
vCollege or higher	95 (55)	66 (65)	54 (72)	
Annual income (household)				19.27 <sup>***</sup>
vLess than \$20,000	65 (39)	50 (51)	32 (44)	
v\$20,000–\$59,000	80 (48)	28 (28)	19 (26)	
v\$60,000 or higher	21 (13)	21 (21)	21 (29)	
Has suffered mental illness				3.22
vYes	39%	49%	43%	
vNo	61%	51%	57%	
Has sought or received treatment <sup>a</sup>				5.72
vYes	69%	72%	84%	
vNo	31%	28%	15%	
Knows friend/family with mental illness				7.40 <sup>*</sup>
vYes	51%	37%	38%	
vNo	49%	63%	62%	
Has volunteered for health research				7.92 <sup>**</sup>
vYes	21%	65%	29%	
vNo	79%	35%	71%	

<sup>a</sup>These percentages are based on the numbers reported for history of mental illness – *n* (Blacks) $\lambda$ = $\lambda$ 66; *n* (Whites) $\lambda$ = $\lambda$ 33; *n* (Hispanics) $\lambda$ = $\lambda$ 50.

The  $\chi^2$  test two-tailed significance:

\*  $P < 0.10$ .

\*\*  $P < 0.05$ .

\*\*\*  $P < 0.01$ .

<sup>≅</sup>  $P < 0.0001$ .

**Table 2** Willingness to participate in genetic research by demographics and clinical/research characteristics within ethnic groups

Demographic	Blacks (n=1,174)		Hispanics (n=1,103)		Whites (n=1,716)	
	Agree to participate (%)	$\chi^2$	Agree to participate (%)	$\chi^2$	Agree to participate (%)	$\chi^2$
$\lambda$ Sex						
vMale	72		80		69	
vFemale	73	0.02	75	0.30	89	4.55*
Age (years)						
v18-29	75		78		75	
v30-49	69		75		83	
$\geq 50$	61	2.27	60	0.90	100	2.04
Education						
v $\leq$ High school	53		75		75	
vHigh school	70		78		77	
v $\geq$ College	79	5.88*	77	0.03	80	0.11
Marital Status						
vSingle	74		77		77	
vMarried	59		87		86	
vWidowed/divorced	73	2.19	50	2.45	100	1.46
Has suffered mental illness						
vYes	72		78		79	
vNo	71	0.03	77	0.02	79	0.001
Has sought/received mental illness treatment <sup>d</sup>						
Yes	67		80		79	
No	84	2.03	71	0.42	80	0.01
Knows friend/family with mental illness						
vYes	71		83		86	
vNo	72	0.02	75	1.01	75	1.49
Has volunteered for health research						
vYes	74		86		75	
vNo	71	0.12	72	2.31	79	0.04

Demographic	Blacks (nλ=λ174)	Hispanics (nλ=λ103)	Whites (nλ=λ76)
	Agree to participate (%)	Agree to participate (%)	Agree to participate (%)
	$\chi^2$	$\chi^2$	$\chi^2$

<sup>a</sup> Percentages for this item are based on the numbers reported for history of mental illness – n (Blacks)λ=λ66; n (Whites)λ=λ33; n(Hispanics)λ=λ50.

\* P<0.05,  $\chi^2$  test two-tailed significance.

**Table 3**  
Attitudinal factors and item loadings

Factors and items <sup>a</sup>	Factor loadings
$\lambda$ Factor 1: Beneficial to individual and society ( $\alpha\lambda=\lambda 0.82$ )	
v21. I would participate to help future generations	0.48
v23. Genetic research is beneficial to Society	0.60
v24. Genetic research will benefit me	0.73
v25. Genetic research will benefit people of my race	0.86
v26. Genetic research will benefit people of other races	0.83
Factor 2: Important to participate for education and knowledge ( $\alpha\lambda=\lambda 0.83$ )	
v11. Genetic research is important for education of patients and health professionals	0.86
v13. It is important for people to know about genetic causes of mental illness	0.86
v14. It is important to participate in genetic research when given opportunity to do so	0.69
Factor 3: Mistrust and wariness ( $\alpha\lambda=\lambda 0.57$ )	
v27. Do not trust researchers conducting the genetic studies	0.59
v30. Worry about private information not being kept private	0.59
v32. Do not like some procedures associated w/genetic research (e.g. blood draws)	0.55
v34. Participating in genetic research is a hassle	0.69
Factor 4: Desire to learn more about genetic research ( $\alpha\lambda=\lambda 0.83$ )	
v39. I would like to learn more about genetic research	0.82
v40. Would like to learn more about the genetic causes of mental illness	0.84
Factor 5: Stigma ( $\alpha\lambda=\lambda 0.85$ )	
v28. Ashamed to participate in research that asks questions about my mental health	0.77
v29. Ashamed to participate in research that asks questions about my family's mental health	0.76
Factor 6: Participating only for incentives ( $\alpha\lambda=\lambda 0.65$ )	
v22. Would participate only if getting free meds/treatment	0.80
v35. Would participate only if getting paid (e.g. cash, gift certificates, etc.)	0.75
Factor 7: Mental illness caused by both genes and environment ( $\alpha\lambda=\lambda 0.48$ )	
v7. Mental health problems are caused by the environment	0.76
v8. Mental health problems are caused by both genes and environment	0.67
v10. Certain environments will cause depression regardless of genes	0.52
Factor 8: Mental illness caused primarily by genes ( $\alpha\lambda=\lambda 0.29$ )	
v6. Mental health problems are caused mostly by genes	0.60
v9. If one has genes for depression, they will become depressed, regardless of environment	0.77

<sup>a</sup>The six survey items not listed here, but used in the analysis will be furnished upon request from corresponding author.



**Table 4**  
Differences in attitudes according to willingness to participate in genetic research by ethnic group

Genetic research attitudes	Mean scores (standard deviation) <sup>a</sup>					
	Blacks Willing to participate		Hispanics Willing to participate		Whites Willing to participate	
	Yes ( <i>n</i> λ=λ125)	No ( <i>n</i> λ=λ48)	Yes ( <i>n</i> λ=λ79)	No ( <i>n</i> λ=λ23)	Yes ( <i>n</i> λ=λ60)	No ( <i>n</i> λ=λ16)
λBeneficial to individual and society	15.12 (4.76)	15.98 (3.63)	16.47 (3.56)	16.26 (3.52)	17.03 (2.58)	14.88 (2.96) <sup>b, **</sup>
Important to participate for education and knowledge	9.94 (3.20)	10.17 (2.45)	10.59 (2.13)	10.17 (2.03)	11.18 (1.29)	9.63 (1.48)***
Mistrust and Wariness	8.36 (3.58)	10.78 (2.75)***	8.44 (2.65)	10.09 (2.65)**	8.76 (2.44)	8.33 (2.80)
Desire to learn more about genetic research	6.71 (2.25)	6.70 (1.67)	6.65 (1.49)	6.61 (1.73)	6.93 (1.44)	6.75 (1.66)
Stigma	3.24 (2.35)	4.07 (1.82)*	3.13 (1.51)	3.87 (1.84)*	3.68 (1.64)	4.25 (1.88)
Participate only for incentives	4.09 (2.53)	5.28 (1.96)***	5.02 (1.76)	5.13 (2.01)	5.55 (1.43)	5.42 (1.64)
Mental illness caused by both genes and environment	8.01 (2.75)	8.46 (2.12)	8.39 (2.11)	8.83 (1.77)	8.77 (1.54)	8.79 (1.77)
Mental illness caused primarily by genes	4.79 (1.93)	5.10 (1.49)	5.34 (1.47)	5.78 (1.24)	5.15 (1.28)	4.75 (1.46)

<sup>a</sup> Higher mean scores indicate greater endorsement of a given factor

<sup>b</sup> Analysis of variance based on the general linear model, F-ratio two-tailed significance:

\*  $P \leq 0.05$ .

\*\*  $P \leq 0.01$ .

\*\*\*  $P \leq 0.001$ .

**Table 5**  
Differences in attitudes according to willingness to participate in genetic research by ethnic group (among college-educated who are 18–29 years old)

Genetic research attitudes	Mean scores (standard deviation) <sup>a</sup>					
	Blacks Willing to participate		Hispanics Willing to participate		Whites Willing to participate	
	Yes (n <sub>λ</sub> =λ45)	No (n <sub>λ</sub> =λ12)	Yes (n <sub>λ</sub> =λ36)	No (n <sub>λ</sub> =λ10)	Yes (n <sub>λ</sub> =λ34)	No (n <sub>λ</sub> =λ11)
Beneficial to individual and society	15.16 (3.64)	15.33 (2.90)	17.17 (2.73)	15.80 (3.90)	17.41 (2.41)	16.40 (2.53) <sup>b, **</sup>
Important to participate for education and knowledge	10.36 (2.24)	10.67 (1.72)	10.92 (1.77)	9.90 (1.45)	11.38 (1.13)	10.45 (1.19)
Mistrust and wariness	8.96 (2.31)	11.08 (2.47) <sup>***</sup>	8.04 (2.84)	10.50 (2.68) <sup>*</sup>	8.49 (2.37)	8.48 (2.49)
Desire to learn more about genetic research	6.53 (1.56)	6.08 (1.88)	6.83 (1.25)	6.90 (0.99)	6.84 (1.56)	6.73 (1.64)
Stigma	3.71 (1.73)	3.50 (1.68)	3.00 (1.59)	4.30 (1.50) <sup>*</sup>	3.83 (1.75)	4.58 (1.84)
Participate only for incentives	5.00 (1.89)	5.83 (1.75)	5.22 (1.74)	4.60 (2.22)	5.74 (1.38)	5.46 (1.45)
Mental illness caused by both genes and environment	8.07 (1.90)	8.33 (2.06)	8.67 (1.69)	7.70 (1.59) <sup>**</sup>	8.66 (1.60)	9.13 (1.68)
Mental illness caused primarily by genes	4.86 (1.14)	4.66 (1.23)	5.61 (1.08)	5.50 (1.51)	5.20 (1.27)	4.67 (1.34)

For Whites, scores shown are adjusted after controlling for sex. For Hispanics, scores shown are adjusted after controlling for research participation history.

<sup>a</sup> Higher mean scores indicate greater endorsement of a given factor

<sup>b</sup> Analysis of covariance based on general linear model, F-ratio two-tailed significance:

\*  $P < 0.10$ .

\*\*  $P < 0.05$ .

\*\*\*  $P < 0.01$ .