Public Willingness to Participate in and Public Opinions About Genetic Variation Research: A Review of the Literature

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Scientists are turning to genetic variation research in hopes of addressing persistent racial/ethnic disparities in health. Despite ongoing controversy, the advancement of genetic variation research is likely to produce new knowledge and technologies that will substantially change the ways in which we understand and value health. They also may affect the ways in which individuals and groups organize socially, politically, and economically.

Addressing concerns that may exist in different communities is vital to the scientific and ethical advancement of genetic variation research. We review empirical studies of public willingness to participate in and opinions about genetic research with particular attention to differences in consent and opinion by racial/ethnic group membership. (*Am J Public Health.* 2006;96:1971–1978. doi:10.2105/AJPH.2005.069286)

POLICYMAKERS HAVE described the integration of new genetic knowledge and technologies into the practice of public health and medicine as unavoidable.[1] Newborn screening programs, prenatal testing, and genealogy documentation provide long-standing precedent for this integration. Scientists now are turning to research that seeks to understand genetic differences by racial/ethnic group membership (referred to as *genetic variation research*), in hopes of addressing persistent racial/ethnic disparities in health.

Researchers have criticized the lack of definitional clarity and inconsistent use of racial/ethnic group membership in US health research,[2] while at the same time depending on these categories to define and explain disparities in health and health care.[3] These categories generally include 1 or more of the categories used by the federal government, namely an ethnic group category—Hispanic/Latino—and several racial group categories—White American/White, African American/Black, Asian American, Native Hawaiian/Other Pacific Islander, and American Indian/Alaska Native—in addition to Other and more recently Mixed Race.

The proposed use of racial/ethnic group membership in genetic variation research has been widely debated. Advocates argue that significant genetic differences do exist by racial/ethnic group membership and that such information is critical to ensuring representative sampling.[4,5] Advocates also propose that genetic variation research may lead to health benefits, such as improved understanding of disease susceptibility and targeted pharmacogenomic innovations.[6,7] Critics raise methodological concerns about the validity of racial/ethnic group membership for studying genetic variation.[8–10] Furthermore, critics assert that such research may encourage genetic determinism and scientific racism, divert attention from the powerful social and environmental determinants of health, and reinforce stereotypes about minority groups.[10–12]

Despite ongoing controversy, the trajectories of genetic variation research are likely to produce new knowledge and technologies that will substantially change the ways in which we understand and value health. They also may affect the ways in which individuals and groups are organized socially, politically, and economically in society.[13] Given this potential, strong arguments have been made in the literature for public consultation regarding the advancement of genetic science.[13–15] Consultation with racial/ethnic minority groups is particularly important given these groups' past experience with the misuse of science. Addressing concerns that may exist in different communities is fundamental to the ethical advancement of genetic variation research and may facilitate the recruitment of diverse samples that are vital to answering the underlying scientific questions posed by genetic variation research.

What is known about the willingness of the public to participate in genetic variation research? Does willingness to participate in genetic variation research vary by racial/ethnic group membership? What concerns and other opinions do people have about genetic variation research? We present findings from a systematic review of empirical studies regarding US public willingness to participate in and opinions about genetic variation research and other genetic research and offer suggestions for future studies.

METHODS

We conducted preliminary searches for empirical studies of public willingness to participate in and opinions about genetic variation research in the National Library of Medicine Medline database and all databases under the Institute of Scientific Information Web of Science. Given limited results, we established broader parameters for a larger search using general search terms and including studies involving genetic research regardless of an explicit focus on variation by racial/ethnic group (Table 1). We excluded genetic research studies that referenced genetic testing (i.e., detection of specific genes or gene variants in individuals rather than in populations) but did not reference the donation or storage of genetic specimens for research (example[16]). Unlike the purpose and results of research involving

TABLE 1—Search Strategy for Empirical Papers Regarding Public Opinions About and Willingness to Participate in Genetic Research: July–August 2005

Keywords and Boolean terms	Medline[a]		ISI Web of Science[b]	
	Search Results	Relevant Papers[c]	Search Results	Relevant Papers
Geneti* AND [Racial OR Race OR Ethnicity] AND Attitud*	279	7	50	3
Geneti* AND [Racial OR Race OR Ethnicity] AND Awar*	132	0	41	0
Geneti* AND [Racial OR Race OR Ethnicity] AND Consent	120	5	22	5
Geneti* AND [Racial OR Race OR Ethnicity] AND Inten*	290	1	90	1
Geneti* AND [Racial OR Race OR Ethnicity] AND Knowledge	472	2	130	0
Geneti* AND [Racial OR Race OR Ethnicity] AND Opinio*	50	4	13	1
Geneti* AND [Racial OR Race OR Ethnicity] AND Participat*	433	13	77	8
Geneti* AND [Racial OR Race OR Ethnicity] AND Perspectiv*	146	2	73	2
Geneti* AND [Racial OR Race OR Ethnicity] AND Willin*	30	3	10	1
Genom* AND [Racial OR Race OR Ethnicity] AND Attitud*	14	2	5	1
Genom* AND [Racial OR Race OR Ethnicity] AND Awar*	4	0	2	0
Genom* AND [Racial OR Race OR Ethnicity] AND Consent	23	0	4	0
Genom* AND [Racial OR Race OR Ethnicity] AND Inten*	27	0	22	0
Genom* AND [Racial OR Race OR Ethnicity] AND Knowledge	56	1	31	0
Genom* AND [Racial OR Race OR Ethnicity] AND Opinio*	2	1	1	0
Genom* AND [Racial OR Race OR Ethnicity] AND Participat*	28	3	17	0
Genom* AND [Racial OR Race OR Ethnicity] AND Perspectiv*	19	1	12	1
Genom* AND [Racial OR Race OR Ethnicity] AND Willin*	1	1	0	0
Total[d]	2126	46	600	23

Note. ISI = Institute of Scientific Information.
[a]Search for keywords in all fields of document with human subjects, in English language, and not a letter, comment, editorial, or news (i.e., NOT letter[pt] NOT comment[pt] NOT and so on, where [pt] stands for publication type), published 1985 to 2005.
[b]Search for keywords as topic (TS field tag) in all document types, English language, published 1985 to 2005, in all 3 Web of Science databases.
[c]Relevant papers selected after 2 stages of review: (1) title and abstract review and (2) full paper review of those selected in first stage.
[d]Duplicate papers included in totals. Nonduplicate totals in both Medline and ISI search results = 1793 papers, 13 relevant papers.

genetic testing, the purpose and results of research involving specimen donation may not be shared with human subjects, particularly in the case of long-term storage. Furthermore, research involving specimen donation is less likely to offer human subjects the direct and immediate benefits associated with research involving genetic testing, such as test results, medical treatment, or other interventions. Therefore, findings from these 2 types of studies are not comparable.

We conducted systematic searches of the Medline and Institute of Scientific Information Web of Science databases during July and August 2005 using the parameters specified in Table 1. Search results, citations, and available abstracts for 2126 papers were downloaded into a citation database for review and tracking. Two authors reviewed titles and available abstracts. The vast majority of papers presented findings from gene prevalence studies in various populations. Thirty-three papers were selected as potentially relevant by at least 1 of the 2 authors during this initial review. Twenty papers were excluded because they were not empirical studies on willingness to participate in or opinions about genetic research (13 studies), they involved international populations (5 studies), or they were published only as abstracts (2 studies). Thirteen papers were determined to be relevant after full-text review.

Reference lists from the 13 relevant papers were reviewed for additional papers that may not have been captured by the database searches. Twenty-eight papers were identified in reference lists as potentially relevant, 1 of which was determined to be relevant after abstract or full-text review.[17]

Among the 14 relevant studies, 1 did involve genetic testing[18] and was included because participants were informed that they would not receive test results and also were asked for consent to store DNA—2 features more typical of research involving genetic specimen donation. Finally, 1 relevant article identified in the preliminary search did not appear in the systematic search and therefore was not included in this review.[19] This article did not use the terms *race, ethnicity,* or any variation (excluding 1 appearance of *race* in a table), nor did it have these terms assigned as keywords.

Findings from the reviewed studies are presented in 3 tables: Table 2, studies reporting willingness to participate only; Table 3, studies reporting willingness to participate and reasons for declining; and Table 4, studies reporting opinions only. Study reference numbers appear in the tables and are used to discuss review findings.

RESULTS

Our literature search produced 14 empirical studies on willingness to participate in and opinions about genetic research. Only 1 of these 14 studies made clear references to genetic variation research exploring relations among race, genes, and health.[29] The purpose of most studies (10 studies) was to measure consent rates in response to requests for participation in genetic research (Tables 2 and 3). Three of these 10 studies asked participants why they declined consent (Table 3), with 2 providing frequencies for reported reasons.[18,26] Additional detail regarding participants' concerns was described in 4 qualitative studies (Table 4). Finally, 8 of the 14 studies asked participants to consider specific information regarding the use of

TABLE 2—Descriptive Summary of Studies Regarding US Lay Public Willingness to Participate in Genetic Research (n = 7)

Author Year	Purpose	Sample	Methods	Consent to Participation in Research	Less Likely to Consent
Cozier et al. 2004[20]	Compare consent to genetic research and DNA yield for different specimen collection methods	National (n = 644) Former Black female health research participants with personal history of cancer Some college/higher 80%	2, 3, 7, 11	37% of total sample	Not reported
Le Marchand et al. 2001[17]	Assess feasibility of obtaining DNA by mail for analysis and storage	Hawaii (n = 355) Current cohort study participants Whites 34%, Japanese 33%, Hawaiian 33%	1, 3, 7, 10, 11	67% of total sample	Hawaiians
McQuillan et al. 2003[21]	Identify factors associated with consent to donate and store specimens	National (2-y mean n = 3201) NHANES study participants White 47%, Mexican American 23%, Black 20%, Other 10%	1, 3, 5, 7, 9	85% of total sample (2-y mean, 100% responding)	Blacks,[b] females, older age
Moorman et al. 2004[22]	Identify factors associated with consent to enroll in cancer genetics registry	North Carolina (n = 872) Former female genetic research participants Personal or familial history of various cancers White 59%, Black 41% College grad 30%	2, 3, 7, 10, 11	28% of total sample, 47% of responders (n = 469)	Blacks,[a b] older age,[a b] lower income,[a] less education,[a] higher occupation category,[a] later- stage first cancer diagnosis (among Blacks only),[b] higher body mass index,[a] higher waist-to-hip ratio[a]
Ottoman et al. 2005[23]	Identify factors associated with consent to enroll in epilepsy genetic research	New York (n = 320 families) White 51%, Other 28%, Unknown 21%	2, 3, 7, 8, 10, 11, 12	21% of total sample, 26% of responders (n = 232), 54% of eligible families (n = 126), 79% of individuals within eligible families (n = not reported)	Recruited in specialty clinic,[a] initial contact by letter,[a] males, racial/ethnic minority,[a] relatives of affected participant
Schwartz et al. 2001[24]	Measure willingness to donate and store blood specimens and the need for informed consent	Maryland, District of Columbia (n = 273) Jewish College or higher 87%	2, 3, 6	Physical/mental health genetic research: 85%–90% of total sample Creativity/intelligence genetic research: 70%–85% of total sample Stigmatizing trait genetic research: 60%–75% of total sample	Weaker Jewish cultural identity,[a] when DNA is collected in research settings (vs clinical settings), in studies identifying stigmatizing traits (including frugality, homosexuality)[a]
Wang et al. 2001[25]	Measure opinions and willingness to donate and store blood specimens	National (n = 2621) Whites 83%, Black or Hispanic 17% College or higher 60% Family history genetic condition 12%	1, 4, 6	Donate: 53% of total sample Donate and store: 43% of total sample Will not donate or store: 21% of total sample	Racial/ethnic minority,[a] older age,[a] less education,[a] no family history,[a] low-risk lifestyle,[a b] low support of government research,[b] no belief in medical benefit of genetic research,[b] no belief in genetic determinism[b]

Note. Table presents 7 of 14 total studies identified in literature search. Methods: 1 = random sampling; 2 = nonrandom sampling; 3 = primary data collection; 4 = secondary data analysis; 5 = household specimen collection; 6 = individual phone/self-administered survey; 7 = actual request; 8 = health care setting/physician request; 9 = in-person request; 10 = telephone request/follow-up; 11 = mailed request; 12 = Web site request.
[a]Statistically significant in multivariate regression analysis ($\alpha = .05$).
[b]Statistically significant association found with willingness/consent in bivariate or stratified analysis ($\alpha = .05$).

their DNA,[18,22–24,26,27] or a specific relation among genes, racial/ethnic group membership, or health.[29,30]

Sample Characteristics

There was limited racial/ethnic group diversity across studies; however, all studies included 1 or more racial/ethnic minority groups. African Americans constituted the entire sample of 3 studies,[20,27,30] and Jews the entire sample of 1.[24] Asian Americans and Native Hawaiians/Other Pacific Islanders were least represented,[17,26,29]

TABLE 3—Descriptive Summary of Studies Regarding US Lay Public Willingness to Participate in Genetic Research and Reasons for Declining Consent (n = 3)

Author Year	Purpose	Sample	Methods	Consent to Participation In Research	Less Likely to Consent	Reasons for Decline[a]
Audrain et al. 2002[26]	Establish longitudinal cohort for study of genetic and other factors associated with teen smoking	Virginia (n = 2120) Parents of eligible teens Responders only[b]: White 64%, Asian 13%, Hispanic 12%, Black 7%, Other 4%, College grad 59%	1, 2, 4, 7, 8	54% of parents in total sample, 75% of parent responders (n = 1533), 99% of teens with parental consent (n = 1151)	Nonsmokers,[c] less education,[c] racial/ethnic minority,[c] Whites with less education[d]	No interest 47%, confidentiality 16%, no time 10%, teen doesn't smoke 10%, no benefit 5%
Bogner et al. 2004[18]	Identify factors associated with willingness to participate in genotyping and DNA storage for mental health and aging research	Maryland (n = 3459) Current mental health research participants Primary care patients Aged ≥ 65 y Screened for eligibility only[b]: Black 30%, ≥ 80 y 33%	1, 2, 3, 4, 5	Genotyping: 9% of total sample, 88% of eligible responders (n = 342) Storage given genotyping: 7% of total sample, 68% of eligible responders (n = 342)	Genotyping and storage given genotyping: older age,[c d] Black[c d e]	Genotyping: confidentiality 22%, no benefit 26%, don't feel well 15%, not comfortable/fear 15%, don't know 11%, Storage given genotyping: confidentiality 65%, concern over unknown 27%, don't know 9%, no good reason for storage 7%
Royal et al. 2000[27]	Establish longitudinal cohort for prostate cancer genetic research	Multistate (n = 8249 families) Black	1, 2, 4, 5, 6, 7, 8, 9, 10	0.5% of families in total sample, 1% of families expressing initial interest (n = 3400), 75% of interested and eligible families (n = 43 reflecting 25% attrition rate)	Less education (anecdotal observation)	Did not want family to know they had cancer, lack of trust of government, researchers, etc., fear of being used as guinea pigs, researchers do not give back to community, fear misuse of genetic information (charged higher insurance premiums), lack of immediate or direct benefit

Note. Table presents 3 of 14 total studies identified in literature search. Methods: 1 = nonrandom sampling; 2 = primary data collection; 3 = household specimen collection; 4 = actual request; 5 = health care setting/physician request; 6 = other in-person request; 7 = mailed request; 8 = telephone request/follow-up; 9 = Web site request; 10 = other mass media request.
[a]Proportions given when provided by study.
[b]Statistically significant association found with willingness/consent in bivariate or stratified analysis ($\alpha = .05$).
[c]Statistically significant in multivariate regression analysis ($\alpha = .05$)
[d]Larger sample demographics not provided.
[e]Other covariates used in multivariate regression analysis included measures of mental and physical health, and cognitive functioning.

whereas American Indians/Alaska Natives were not represented in any of the studies. Six quantitative studies allowed comparisons in consent by racial/ethnic group membership,[17,18,21,22,25,26] and only 1 study specified frequencies in different opinions by racial/ethnic group membership.[28] Finally, 4 studies included former participants in health[17,18,20] or genetic[22] research, and 4 studies included participants personally affected by a genetic condition.[20,22,25,30]

TABLE 4—Descriptive Summary of Studies Regarding US Lay Public Opinions About Genetic Research (n = 4)

Author Year	Purpose	Sample[a]	Benefits of Genetic Research and Facilitators to Participation[b]	Concerns and Barriers[b]
Bates et al. 2005[28]	Identify concerns regarding genetic research	Georgia (n = 91, 9 focus groups) Black, 63%, White 28%, Hispanics 9% Some college/higher 59%	Benefits: Prevention/treatment of genetic disease: 82% Whites, 75% Hispanics, 67% Blacks Inclusive research protocols: 28% Blacks	Concerns: Familial expectations/designer babies: 27% Hispanics, 26% Whites, 9% Blacks Racial discrimination: 23% Blacks, 23% Hispanics, 10% Whites Offense to religion: 19% Hispanics, < 7% Whites/Blacks Employment discrimination: 12% Blacks, 12% Hispanics, 10% Whites Government/corporate exploitation: 13.6% Whites, < 9% Blacks/Hispanics Unequal economic access to benefits: 12% Blacks, < 9% Whites/Hispanics
Fisher et al. 2000[29]	Identify opinions about ethical issues in research on genetic basis of adolescent risk behaviors and other research	New York (n = 101, 13 focus groups) 9th–11th graders 54% Parents 46% Majority Black, Hispanic, East/South Asian, Multiracial	Facilitators: Researcher control over how findings are used by other researchers, policymakers, etc. Accurate dissemination of findings Potential for genetically at risk to be stigmatized and ostracized	Concerns: Cannot separate genetic and environmental influences on teen mental health/behavior Hard to attribute behavior to specific race given mixed heritage Potential for increased racial prejudice Misuse of research by third parties Premature treatment after diagnosis
Hoyo et al. 2003[30]	Identify barriers and facilitators of Black male participation in prostate cancer genetic research	North Carolina (n = 55, 5 focus : groups) Black Some college/higher 64% Family history cancer 50%	Facilitators: Feedback about use of samples and research outcomes Community gatekeepers and female partners as recruiters Black investigators and historically Black college/university involvement Shorter, more frequent vs long surveys Specimen collection during routine care	Barriers: Mistrust of research/medical institutions Lack of disease knowledge Extent of involvement (study duration, long surveys, rectal exams culturally inappropriate)
Schulz et al. 2003[31]	Identify concerns regarding the Human Genome Project and related activities	Michigan (n = 62, 7 focus groups) Hispanic 53%, Black 47% College or higher 60%	Benefits: Individual- and social-level benefits identified by most participants Facilitators: Wide dissemination of findings Increased minority involvement as human subjects, investigators, and advocates	Concerns: Disparities in who serves as research subjects vs who benefits from conducted research Racial discrimination Lack of government control over genetic information and technology

Note. Table presents 4 of 14 total studies identified in literature search.
[a]All 4 studies used nonrandom sampling and analyzed primary data from focus groups.
[b]Most frequently reported by study participants explicitly tied to genetics-related research. Proportions appear when provided by study.

Data Analysis

Studies providing the most detail about consent included frequencies and sociodemographic information by contact attempt, successful contact, and consent.[22,23] One of these 2 studies also provided racial/ethnic group information for the population from which the sample was drawn and reasons for nonresponse.[22] Seven consent studies included multivariate regression or stratified analyses to measure the significance of sociodemographic, attitudinal/behavioral, or health status variables. Three studies included covariates from all 3 variable categories.[18,22,25] Thematic analysis of focus group transcripts were presented in the 4 qualitative studies, 1 of which also presented quantitative data.[28]

The extent of variation in study design makes it difficult to draw strong conclusions across identified studies. Instead, we offer the following observations.

Willingness to Participate in Genetic Research

Studies reported public willingness to participate in genetic research with different measures of consent, including overall consent rates (number providing consent over total sample), responder consent rates (number providing consent

over responders), and eligible responder consent rates (number providing consent over eligible responders). The relative merits of each for understanding consent are not discussed explicitly by the authors. However, Royal et al.[27] noted that overall consent rates can serve as an indicator of recruitment challenges. In their study, successful enrollment of 43 families into genetic prostate cancer research was the result of more than 8000 initial contacts with potential participants—an overall consent rate of 0.5%. By contrast, the eligible responder consent rate for their study was 75%, providing information about participant willingness during later stages of recruitment.

Overall consent rates varied substantially in the 8 studies that included actual requests for participation, 5 of which had overall consent rates below 40%.[18,20,22,23,27] Responder consent rates were substantially higher than overall consent rates, largely because of reduced denominators.[18,21–23,26,27] The highest responder consent rates had majority White American responders.[21–23,26] Reported eligible responder consent rates[21,23,27] were relatively high (>75%). One of these high consent rates resulted from an African American sample.[27]

Study samples that included people with previous participation in health or genetic research reported overall consent rates ranging from 21% to 85%.[17,18,20,22] Studies in which potential participants were provided with specific information about the use of their DNA also had variable consent rates.[18,22,23,26,27] Lastly, studies that included people with a personal/familial history of a genetic condition reported lower overall consent rates, ranging from 28% to 53%,[20,22,25] the highest resulting from a hypothetical request.[25]

Variation of Willingness by Racial/Ethnic Group

Statistical tests and multivariate analyses conducted in 6 of the 7 consent studies found racial/ethnic group membership to be a significant predictor of consent. In particular, African American race was a significant predictor of lower levels of consent, with only 1 exception.[26]

Consent among subjects who had previously participated in health or genetic research varied by racial/ethnic group. Moorman et al.[22] found the lowest levels of consent among former research participants. In their study, only 37% of African Americans indicated willingness to enroll in a cancer genetics registry, compared with 58% of White Americans. In addition, exclusive or substantial (41%) African American samples that included people with personal or familial histories of a genetic condition also reported low levels of overall consent (<37%).[20,22]

By contrast, Wang et al.[25] found that those with a family history of a genetic condition in a largely White American sample reported significantly higher levels of consent. Finally, the highest responder consent rates (>85%) resulted from 2 studies with largely White American samples. The first of these 2 studies sampled within a population of older primary care patients[18] and the second involved in-home requests for consent.[21]

Concerns and Opinions About Genetic Research

Opinions about genetic research were presented in 7 studies (Tables 3 and 4). Identifying concerns was the primary focus of these studies; however, in 2 studies, the majority of participants reported benefits to genetic research.[28,31] Common themes appearing across studies included concerns about discrimination, confidentiality, or the misuse of information, perhaps in part because of a lack of confidence in researchers[18,27,30,31]; perceived disparities between the participants and beneficiaries of research[31]; and perceptions of being used by researchers.[27] Lack of interest and no perceived benefit from participation were reported in several studies as well.[18,26,27] This group of concerns is similar to concerns reported about medical research.[32–34]

More specific to genetic research were several concerns including the potential for those at risk of genetic conditions to be stigmatized and ostracized,[29] the initiation of premature treatment,[29] changes in familial expectations or interest in "designer babies,"[28] and religious objections.[28] In the only study that prompted discussion about research on relations among race, genes, and health, Fisher and Wallace[29] reported participant skepticism regarding researchers' abilities to separate genetic, environmental, and racial/ethnic group contributions to health, particularly in cases of mixed heritage. Identified facilitators to participation in genetic research were often reflections of reported concerns (e.g., taking more active control over the use of research by third parties[29]). Finally, although 5 of the 7 studies in Tables 3 and 4 included diverse samples, only 1 study compared opinions by racial/ethnic group membership.[28]

DISCUSSION

We searched for answers to several questions regarding public willingness to participate in and opinions about genetic variation research. We expected to find many more studies given the substantial controversy surrounding its advancement. Only 1 study in our review provided insights into the specific concerns people may have regarding participation in genetic variation research exploring relations among race, genes, and health.

Although there were some patterns by racial/ethnic group membership regarding consent, there were few systematic data across studies that would allow us to draw strong conclusions about the relative willingness of different groups to participate in genetic research.

Recommendations for Future Studies

Following are points for consideration in the design of future studies.

First, it is important to establish clear distinctions in the literature among research studies involving requests for genetic testing, genetic specimen donation, or genetic specimen storage. As discussed previously, the risks and benefits associated with these different requests can vary. Using "genetic research" in reference to all 3 can obscure important distinctions. Using a standard nomenclature when referencing these different requests and corresponding study designs will help ensure that findings regarding consent and public opinion are placed in their appropriate context.

Second, to facilitate cross-study comparisons, future studies

must include information needed to calculate overall, responder, and eligible responder consent rates, where applicable. Providing this information by racial/ethnic group membership, other sociodemographic variables, and other characteristics unique to the study (e.g., health, attitudinal/behavior indicators) will facilitate more accurate assessment of consent across studies. Information on the reasons for nonresponse is essential to interpret responder consent rates as well.

Third, researchers conducting qualitative studies should use appropriate probing techniques to identify both the benefits and the concerns participants associate with genetic research. Consent studies should include a qualitative component whereby recruited subjects are asked their reasons for consenting to or declining specific requests. Researchers should build on qualitative findings to measure the extent to which specific or thematic opinions are prevalent in larger diverse samples. When possible, authors should report findings by racial/ethnic group membership.

Fourth, we strongly recommend that future studies explicitly ask potential participants about their willingness to participate in and their opinions regarding genetic variation research, highlighting the exploration of relations among racial/ethnic group membership, genes, and health. Our literature review found only 1 such study. Researchers should make every effort to include Asian Americans, Native Americans, Alaskan Natives, and other groups currently underrepresented.

Finally, to enhance our understanding of how the lay public may perceive genetic variation research, we encourage investigation into parallel areas of research (some of which already appear in the literature[11,35,36]), including lay public understandings of race, ethnicity, genes, and health and the relations among them; the extent to which people hold views consistent with genetic determinism; and opinions about pharmacogenomics, gene therapy, and other innovations that may arise from genetic research.

Conclusions

Failure to address gaps in this literature will hinder the scientific and ethical advancement of genetic research in general, and genetic variation research in particular. Incomplete data regarding consent may inaccurately portray some groups as less willing to participate in genetic research than others. Furthermore, gaps in information about racial/ethnic group variation in perceived benefits, concerns, and other opinions may delay creative and culturally appropriate strategies to recruit and retain human subjects.

We must open the dialogue occurring within the scientific community about the use of racial/ethic group membership in genetic variation research to members of the general public who may serve as future study participants. As demonstrated by Fisher and Wallace[29] and others conducting parallel areas of research, the public can engage in meaningful dialogue about these issues and should be provided with more opportunities to do so.

POSTSCRIPT

During production of this article, 4 new studies satisfying the inclusion criteria for this review came to the authors' attention via the Centers for Disease Control and Prevention *Genomics and Health Weekly Update* (http://www.cdc.gov/genomics/update/current.htm).[37–40] Of note, Buchwald et al.[37] reported consent rates for participation in a hypothetical genetic study among 420 urban American Indian/Alaska Native patients and staff at an Indian health care facility. Associations between consent and different study characteristics (i.e., subject matter, risks and benefits, institutional sponsor, community involvement) also were reported. ■

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Contributors

G. Corbie-Smith and G.E. Henderson originated the study. R. Sterling led the systematic search and review of relevant literature and led the writing of the article. All authors helped to conceptualize ideas, synthesize findings, propose recommendations, and edit drafts of the article.

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