Asking the Right Questions: Views on Genetic Variation Research Among Black and White Research Participants

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BACKGROUND: Genetic variation research (GVR) may raise concerns about misuse of information and discrimination. Seemingly contradictory positive views about GVR have also been reported.

OBJECTIVE: To dissect this inconsistency, our objectives were to: (1) explore open-ended views of GVR and (2) quantify views of and willingness to participate in GVR by race.

DESIGN: Cross-sectional study.

PARTICIPANTS: 801 African-American and white prior participants in a case-control genetic epidemiology study of colon cancer risks (NCCCS).

MEASURES: Qualitative measures evaluated responses to questions about good and bad things about GVR. Quantitative measures evaluated positive and negative perceptions, perceptions of discrimination, and likelihood of future participation by race.

RESULTS: Open-ended queries about GVR resulted in few "negative" responses. In closed-ended questions, however, African Americans were more likely to feel that such research would: result in higher insurance (41% vs. 30%, p=0.008), not benefit minorities (29% vs. 14%, p=<0.001), reinforce racism (32% vs. 20%, p=0.002), and use minorities as guinea pigs (27% vs. 6%, p< 0.001). Overall, after adjustment for potential confounding factors, African-American race remained inversely associated with feeling "very positive" about GVR (46% vs. 57%, p=0.035). In contrast, African Americans were as likely as whites to express willingness to participate in future GVR studies (46%).

CONCLUSIONS: Open-ended questions about GVR were unlikely to spontaneously generate "negative" responses. In contrast, when presented specific examples of potentially negative implications, more respondents agreed, and minorities were more likely to express concerns. This suggests that while participants appear generally positive about GVR, their inability to articulate views regarding these complex concepts may require that researchers engage lay audiences, ensure accurate understanding, and provide them with language to express concerns.

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BACKGROUND

Researchers have increasingly focused efforts on genetic variations research (GVR), research that seeks to understand genetic differences by racial/ethnic group, often in the hopes of addressing racial and ethnic diparities. Supporters of such work suggest that it may lead to improved health for individuals and populations, proposing that a better understanding of disease risk and targeted pharmacogenomic innovations are examples of this potential.[1,2] However, others express concern about the lack of clarity and consistency around the assignment of racial categories, along with fear of increased bias, discrimination, and reinforced stereotypes that may shift focus away from important social determinants of health.[3–8] One study, in fact, demonstrated that lay audiences exposed to messages about genetics that are linked to either 'Whites' or 'Blacks' were more likely to endorse higher levels of racism, beliefs about a genetic basis for racism, and genetic discrimination.[4]

To date, the bulk of this debate is in the academic arena and focuses on genetic research in more general terms. Sterling et al. recently performed a systematic review of studies examining public opinions on GVR and found only one study that prompted discussion about research *specifically* on the relationships of race, genes, and health.[9] Much less is known about the public perception of this type of investigation. While relevant cautions and concerns regarding general genetic testing and research have been elicited from researchers, minority organizations, and the public,[10–15] seemingly contradictory positive views about genetics research have also been reported.[10,15]

To dissect this inconsistency, we examined views of GVR among African-American and white participants in a genetic epidemiology study, using a mixed method approach – with both qualitative and quantitative components. We present findings from this study that evaluate qualitative open-ended responses to queries of the "good" and "bad" of GVR; quantify participant positive and negative views of and willingness to participate in GVR by race; and offer insight and implications for public discourse about this complex and controversial topic.

METHODS

Study Sample

Learning ***A***bout ***R***esearch in ***N***orth Carolina (LeARN) is a cross-sectional study of African Americans and whites who had previously participated in a case-control genetic epidemiology study of colon cancer risk factors, the North Carolina Colorectal Cancer Study (NCCCS). In NCCCS, cases had a diagnosis of invasive colorectal cancer. Controls were drawn from DMV records and Medicare beneficiary lists. Race was initially obtained from cancer registry records and DMV or HCFA files and further confirmed by self-identification during the interview. When there were conflicting data, the participants' self-identified race was used. We used the NCCCS database to identify participants interested in participating in other studies. Those who expressed interest were contacted to take part in the LeARN telephone interviews. They were eligible to participate if they met the following criteria (1) self-reported race of African American or non-Latino white, (2) completed the entire interview required of NCCCS, (3) agreed to be contacted about future studies, (4) lived in the state of North Carolina at the time of the LeARN study, and (5) had sufficient cognitive functioning, as assessed by the interviewer, to allow successful completion of the telephone interview.

Recruitment Procedures and Data Collection

Potential participants were mailed a letter by the NCCCS investigators that introduced the LeARN study, described the telephone interview, and alerted them to expect a follow-up telephone call. We contracted with the professional survey group, FGI, Inc., to conduct the telephone interviews using Computer Assisted Telephone Interviewing (CATI) methods. Potential participants were contacted on an average of 4 months after completing the NCCCS interview. LeARN interviewers were racially diverse and trained to address barriers to research participation. We used a follow-up protocol with at least ten attempts made at different times of day and different days of the week to maximize response rates.

Participants provided verbal consent to participate in the telephone interview. All interviews were audio-taped and transcribed for content analysis of the open-ended questions. The final LeARN participant questionnaire took on average 45 min to complete. After completion of the LeARN interview, each participant was mailed an incentive of $25. All procedures were approved by both the UNC and Emory University Institutional Review Boards.

Quantitative Analysis

Views of GVR were assessed by examining the Likert responses to two questions, "How positive or negative do you feel about genetic research that looks into why different racial groups get different diseases?" and "How likely would you be to take part in such a study in the future?" Because a large majority of participants answered positively to both these questions, we dichotomized each response at the highest category, i.e., "Very positive" versus the other responses for the first question, and "Very likely" compared to the other responses for the second question. We examined racial and other participant characteristics for differences in responses to these two questions using Pearson's chi-square tests. In addition, participants were given a list of five potential concerns about minority participation in genetic research and were asked whether they agreed or disagreed with these statements. We used Pearson's chi-square tests to examine whether these responses differed by race. We were particularly interested in racial differences in responses to views of GVR. To examine this in more depth, we used logistic regression models to see if any observed differences remained after adjustment for potential confounding factors, including concerns about minority participation. We developed a separate model for each of the two outcomes. Each initial model included race as our main study factor and the other participant characteristics as potential confounding variables (case status, age, gender, education, income, how religious, health status, family history of cancer, how much they had heard about GVR, and concerns about minority participation). We used a "change in effect" elimination strategy to reduce the models. We considered dropping potential confounders when removing them from the model caused little change (<10%) in the estimate of the relationship between race and each outcome. The estimates for the differences between African Americans and whites were reported as adjusted percents, based on the beta coefficients from the final logistic regression models. We chose to report adjusted percents rather than odds ratios because of the common occurrence of both outcomes (54% and 45%); odds ratios would over-estimate the size of the effect.

Qualitative Analysis

Qualitative analysis was performed to more fully understand the views and responses of participants. Since our original sample was too large for an in-depth qualitative analysis, a smaller sub-sample (N=194) was created. We included the first 51 African-American cases and 46 African-American controls. We then matched participants by case status, age, education, and sex to an equal number of white cases and controls. Most of the 97 African-American participants had only one clear match among the white participants. In cases where there was more than one potential match, a match was randomly chosen.

For this sub-sample of 194, we analyzed qualitatively responses to four open-ended questions, (1) "What are the good things for *yourself* and your *family* about participating in genetic research that looks at why different racial groups get different diseases;" (2) "what are the good things for *society* about participating in genetic research that looks at why different racial groups get different diseases?" These two questions were then repeated for a list of the "*bad* things." Codes were initially developed by the team of LeARN investigators, applied, and validated through an iterative process. Two coders applied the codes to all responses to open-ended questions; periodic checks were undertaken to assure uniformity of application. Four LeARN investigators worked to further refine and validate codes for the four questions used in this paper. Additionally, there was a final review of each of the transcripts by race to determine if African Americans and whites articulated their responses differently even when coded similarly.

RESULTS

Participant Characteristics

The overall response rate for the LeARN study was 73%. This represents the percent of NCCCS participants who were eligible for LeARN and responded to our survey. There were 801 respondents in the sample, of which 153 were African Americans (19%). The mean age was 64.3 years (SD=9.90). Cases from NCCCS made up 55% of the LeARN sample, 57% were male, and most had at least a high school education (Table 1). African Americans and whites were comparable in age and reported similar perceived health status. African Americans, however, were somewhat more likely than whites to have been cases in the NCCCS study (55% of African Americans vs. 43% of whites; p=0.008), to be female (51% vs. 41%, p=0.026), to report less education (31% vs. 11% had less than high school), to have lower income (48% vs. 15% made less than $20,000), to be more religious (64% vs. 51% were very religious), and to have heard more about GVR (29% vs. 16% heard "a lot"). A large majority of both African Americans and whites felt positive about GVR (84% and 93%), although African Americans were less likely to feel very positive (43% vs. 56%). Both groups expressed that they would be very likely or somewhat likely to participate in future studies (82% and 87%), and these responses did not differ by race.

Table 1. Participant Characteristics, Overall and by African American (AA) vs. White Presented as Percents*

Participant Characteristic	% Overall (n=801)	% AA (n=153)	% White (n=648)	p value†
Case status in NCCCS				
Case	45	55	43	0.008
Control	55	45	57	
Age				
40 to 54 years	20	21	20	0.662
55 to 69 years	42	44	42	
70 to 85 years	38	35	38	
Gender				
Male	57	49	59	0.026
Female	43	51	41	
Education				
Less than high school	15	31	11	<0.001
High school graduate	25	28	24	
Technical or some college	32	26	33	
College degree, graduate school	28	15	32	
Income				
Less than $20,000	21	48	15	<0.001
$20,000 to $40,000	27	26	26	
More than $40,000	52	26	59	
How religious				
Not religious	5	4	5	0.001
Somewhat religious	42	32	44	
Very religious	53	64	51	
Perceived health status				
Excellent	13	13	13	0.113
Very good	37	30	39	
Good	30	32	29	
Fair	14	20	13	
Poor	6	5	6	
Cancer Hx				
Case, family hx (relative)	6	8	6	0.027
Case, no family hx (relative)	39	47	37	
Control, family hx (self or relative)	18	11	20	
Control, no family hx (self or relative)	37	34	37	
How much heard about genetic research and race				
A lot	18	29	16	0.001
Little	71	59	73	
None	11	12	11	
How positive about genetic research about racial differences				
Very positive	54	43	56	<0.001
Positive	37	41	37	
Neutral or negative	9	16	7	
How likely to take part in genetic research about racial differences				
Very likely	45	44	45	0.284
Somewhat likely	41	38	42	
Neutral or unlikely	14	18	13	

Percents are column percents, e.g., 55% of African Americans are cases and 43% of whites are cases

†*p value for chi-square test comparing each characteristic to African Americans vs. whites*

Qualitative Analysis

In the qualitative analysis, several themes emerged. Respondents were positive about the potential for GVR to contribute to knowledge, determine causes, prevent, and find the cures for diseases. Some felt that GVR might help determine differential group risk and identify culturally/racially specific lifestyle risks. One said, "Different groups have different lifestyles, they eat different, they do things different, and, of course, some ethnic groups are more prone to diseases, such as diabetes and high blood pressure." Others discussed equity in research and felt it would allow researchers to prioritize research on certain groups to address prior inequalities. For example, "Well, it would benefit the racial groups who have not been targeted before." "It's like giving everyone the same starting block... Making sure that everyone has the same advantage."

Some people discussed dispelling racial myths through research as one potential positive consequence. "A good thing would be to give you honest answers ... There are certain myths and many perhaps untruths about genetic passing down. I feel very strongly that there are too many myths about it, and I believe this would expose and expel some of it." "You create a better understanding among all people. Then what you do if the research is genuine... you eliminate the greater chance of discrimination. Because you have actual facts."

In contrast, some respondents disagreed with the premise of race as the central issue. While the frequencies of these qualitative responses coded as "race is not the issue" did not vary by race, African Americans and whites articulated their responses differently in some cases. Whites in several cases reported that we are all the same, should be treated equally, and such distinctions should not be made. For example, "I feel like everybody's created equal." 'It doesn't make any difference the race... I know that scientists want to separate the racial groups... I don't know." "To me a man's a man whether regardless of his race... I think we're all one people even though African American, white, red, yellow, whatever."

While African Americans expressed similar views of equality, they also offered alternatives to race as grounds for disease disparities. Examples such as money, health care, and food were offered as more relevant issues than race. One person stated, "I don't think it has to do with race itself. I think it has to do with your access to proper foods and proper medical

attention more so than race. But I don't think it has to with the genetic makeup of those races." One respondent stated, "Uh, I think as being African American… that if we had the resources like money and good health-care provider we wouldn't have the genetic diseases like we would because we would know more about taking care of ourselves." Finally, one respondent explicitly offered bias as a cause. "And there are certain diseases that African Americans get that whites don't and it could be because of prejudice."

Few voiced concerns about the negatives of GVR. The respondents who did raised issues of abuse of information ("If this information was used against you for employment purposes or being able to get insurance coverage"); discrimination ("Whatever racial group had a particularly strong indication of a particular problem that may be discriminated against because of it"); stereotyping ("Sometimes people are stereotyped that they're bad because of the fact that maybe this race is affected by a certain disease more so than others"); and increased anxiety ("The only thing is knowing ahead of time that you're going to catch something or get something terrible").

Finally, when our sample of respondents who had participated in a study collecting genetic data were asked open-ended questions about the positives or negative about GVR, many expressed limited knowledge. When asked about the positives and negatives of GVR for themselves, their family and society, 20% reported "did not know" of any positives/negatives. Similarly, 10% of the sample said they did not understand these questions or responded in a manner that made us doubt their comprehension.

Quantitative Analysis

In contrast to our open-ended questions, in which many were unable to articulate either general responses or specific negatives, when given a list of potential implications of research that collects information about genes, most were able to articulate concerns in response to closed-ended questions. African Americans were more likely than whites to feel that such research would: result in higher insurance premiums (41% vs. 30%, p=0.008), not benefit minorities (29% vs. 14%, p=<0.001), reinforce racism (32% vs. 20%, p=0.002), and use minorities as guinea pigs (27% vs. 6%, p<0.001) (Table 2). African-American controls were the most likely to express concerns about minorities' participation in genetic research when compared to African-American cases, white cases, and white controls.

Table 2. Concerns About Minority Participation in Genetic Research by Race

	African American (n-153)	White (n=648)	P value*
% Discrimination against minorities	33	29	0.277
% Higher insurance to minorities	41	30	0.008
% Minorities less likely to benefit	29	14	<0.001
% Research could reinforce racism	32	20	0.002
% Minorities used as guinea pigs	27	6	<0.001

**P value for chi-square test comparing race (African Americans vs. whites) to each concern about minority participation question*

Overall, African Americans were less likely than whites to feel very positive about GVR (43% vs. 56%; p=0.003) (Table 3). Other participant characteristics associated with feeling very positive about GVR were older age, male gender, more education, higher income, not being religious, better perceived health status, having heard more about GVR, and disagreeing that minorities are used as guinea pigs. When we included these other factors in a logistic regression model, they had a neglible effect on the relationship between race and feeling very positive. Even after adjustment, African-American race remained inversely associated with feeling "very positive" about genetic research (46% AA vs. 57% white, p=0.035). In contrast, in both the bivariate analysis and in the logistic regression model adjusting for potential confounding variables, African Americans were as likely as whites to express willingness to participate in future studies "that look at why different racial groups get different diseases" (45% for both groups in the bivariate analysis; 46% for both groups in the logistic regression model).

DISCUSSION

Our research indicates that the majority of participants in a genetic epidemiology study of colorectal cancer in North Carolina were generally positive about GVR. In fact, when asked open-ended questions about their views of GVR, participants were unlikely to spontaneously generate "negative" responses. Additionally, despite having previously participated in genetic research that examined differences in genetic and other risk factors by race (NCCCS), a surprising number reported having no knowledge of GVR or did not understand the question. In contrast, when presented with specific examples of potentially negative implications of such research, more respondents endorsed these views, and minorities were significantly more likely to express concerns.

Broad views on GVR among a diverse study sample should not be unexpected given the complexity of this material. Our sample of prior participants in a genetic study expressed views that demonstrate both remarkable insight as well as limited understanding in some cases. Participants were often affirmative and optimistic on the one hand yet guarded on the other. These differing responses seem inconsistent, but may instead characterize multifaceted and emerging views on this challenging topic. The inability to freely articulate responses to open-ended queries, even among those that have previously participated in genetic research, points to the difficulty lay audiences may have communicating the concepts and language of genetic research. The complexity of genetic concepts for lay audiences has been corroborated in prior survey research that found that very few respondents (11%) considered themselves "very informed" about scientific discoveries. In this survey, 48% had not heard of the Human Genome Project.[16] Conversely, other researchers have demonstrated that the public is capable of articulating complex views of genetic research irrespective of advanced education or coursework.[10,17] Importantly, our work suggests that the content of questions and method of inquiry may also play a role in the responses generated.

Table 3. Bivariate Comparisons of Participant Characteristics and Percent "Very Positive" About GVR, and Percent "Very Likely" to Participate in Future GVR Studies

Participant characteristic	% Very positive About GVR	p value*	% very likely To participate in GVR	p value*
Race				
African American	43	0.003	45	0.942
White	56		45	
Case status in NCCCS				
Case	51	0.171	41	0.068
Control	56		48	
Age				
40 to 54	42	0.006	41	0.142
55 to 69	60		49	
70 to 85	58		42	
Gender				
Male	57	0.037	48	0.043
Female	50		41	
Education				
Less than high school	42	<0.001	40	0.065
High school grad	48		41	
Technical or some college	53		43	
College degree, graduate school	65		52	
Income				
Less than $20,000	48	0.009	36	0.014
$20,000 to $40,000	50		50	
More than $40,000	61		49	
How religious				
Not religious	65	0.028	63	0.002
Somewhat religious	49		38	
Very religious	58		49	
Perceived health status				
Excellent	67	0.028	54	0.105
Very good	56		48	
Good	49		39	
Fair	49		44	
Poor	48		40	
Cancer Hx				
Case, family hx (relative)	43	0.325	37	0.223
Case, no family hx (relative)	52		42	
Control, family hx (self or relative)	55		50	
Control, no family hx (self or relative)	56		47	
How much heard about genetic research and race (GVR)				
A lot	65	<0.001	62	<0.001
Little	53		43	
None	37		29	
Discrimination against minorities				
Agree	55	0.555	43	0.429
Disagree	53		46	
Higher insurance to minorities				
Agree	54	0.966	43	0.515
Disagree	54		46	
Minorities less likely to benefit				
Agree	55	0.687	40	0.188
Disagree	53		46	
Research could reinforce racism				
Agree	53	0.848	44	0.876
Disagree	54		45	
Minorities used as guinea pigs				
Agree	38	0.003	36	0.110
Disagree	56		46	

**P value for chi-square tests comparing each characteristic to each outcome*

In addition to the complexity of the subject matter by itself, wide-ranging individual perspectives—shaped by experiences, media, and other cultural influences—have also been reported. Prior research suggests that the public is positive about the potential of genetic research to contribute to improved health.[10,11,15] Our work parallels prior findings that these generally optimistic public perceptions are often multifaceted, nuanced, and may not be equally expressed by all groups.[10] Earlier studies of lay perceptions of genetic research have demonstrated increased concerns among minorities regarding potential loss of privacy, genetic discrimination, and potentially undesirable or dangerous genetic research.[12,18] African Americans' negative views are often considered in the context of a historical legacy of discrimination often based on the assertion of genetic inferiority as well as government-funded research, such as the Tuskegee study.[19] Even so, African Americans and whites generally share similar optimism regarding the promise of genetic research.[10,15,18,20]

Limitations

This study does have limitations that should be noted. First, while the overall NCCCS sample is large, it still represents one state; regional variations may limit generalizability. Next, we chose to examine African-American and white views only. It is likely that other groups may have differing concerns and views. This sample represents the opinions of subjects that had previously participated in genetic research. Their willingness to participate in at least two research projects (NCCCS and LeARN) suggests an openness to genetic research that, perhaps, would exceed that of the general population. Additionally, while the LeARN response rate was quite good (73%), there are biases inherent in the sample that further limit its generalizability. The response rate differed by race: 65% of African Americans participated compared to 75% of whites. It is likely that African Americans who agreed to participate in LeARN were more likely to feel positive toward genetic research then those who did not agree to participate. Differences between African Americans and whites about how positive they felt about genetic research conceivably could have been larger than we observed had we had been able to recruit both races equally. Even so, the difference between these groups in LeARN was still statistically significant.

Implicatons/Future Research

Despite these limitations, a number of relevant themes and information emerged that may have implications and add direction to future work in this area. The aforementioned discussions of genetic research in general terms has generated complex opinions from lay audiences.[20,21] As greater attention is focused on population-specific genetic variation research, additional questions will emerge about the application and implications of the results of this work. Given historical abuses[18] and concerns about collective risks, such as disease associations, stigmatization, and discrimination for socially identifiable groups,[22] explorations of lay perceptions of population-specific genetic variation are likely to heighten this complexity. As funding and eventually treatment and clinical practice recommendations are considered, assessing the public's and particularly minority groups' concerns, fears, and perceptions of GVR is critically important.

Given the paucity of literature examining lay perceptions of GVR, this work, demonstrating wide-ranging views within one diverse study population, begins to lay the foundation for further investigation of public perceptions. Importantly, it suggests that ongoing queries of opinions of GVR are likely to generate diverse, occasionally conflicting views that should be expected, accounted for, and explored. To that end, unidimensional research models may become increasingly inadequate. Rather, research models should utilize a range of approaches and be communicated in a variety of forums. Approaches that combine quantitative and qualitative responses can be expected to enhance researchers' understanding of public opinion regarding risks and benefits of GVR — the former allowing a deeper canvasing of public perceptions in their own words and the latter providing them with the language to express their concerns.

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