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THE ROLE OF RACE AND TRUST IN TISSUE/BLOOD DONATION FOR GENETIC RESEARCH

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Abstract

Background—Public willingness to donate tissue samples is critical to genetic research. Prior work has linked minority status and mistrust with less willingness to provide specimens. Some have suggested recruitment of prior research participants to address these barriers. We present data from a genetic epidemiology study with a request for blood and/or saliva specimens to: 1) measure willingness to donate tissue/blood samples, 2) identify demographic, trust, and other factors associated with willingness to donate samples, and 3) measure willingness to participate in future genetic research.

Methods—We surveyed participants in the North Carolina Colorectal Cancer Study (NCCCS), which included biologic sample collection from consenting participants. Participants were later asked about sample provision; trust in researchers, and future research participation.

Results—African Americans were less likely to give a blood sample when compared to whites (21% vs. 13%, $p<0.05$). After controlling for "trust," this difference was no longer statistically significant (17% vs. 13%, $p=0.27$). Those who had given samples were more likely to express willingness to participate in future research.

Conclusion—Despite prior participation in a genetic epidemiology study, factors associated with provision of tissue samples reflected many previously identified demographic factors (race, trust). Interventions to improve and demonstrate the trustworthiness of the research team as well as recruitment of subjects with a record of sample donation might enhance future study participation.

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Keywords

Trust; Research Participation; Biologic samples; Genetics

BACKGROUND

Public approval of and willingness to participate in studies that collect and store biological specimens are crucial for the viability of genetic research. Prior work demonstrates a general support for and favorable views of genetic research.[1–4] However, while general support appears high, less than half of individuals are willing to donate when a specific request for blood donation and storage is made.[5] Further, a number of studies have demonstrated that minority status and mistrust regarding potential outcomes of genetic research, among other factors, have been linked to lower rates of participation in genetic research and less willingness to provide specimens.[1, 6–9]

General endorsement of, participation in, and donation of biological specimens for genetic research likely represent a continuum of views that may overlap or diverge even in the same individual. Some have suggested a strategy of recruiting prior research subjects in order to increase the likelihood research participation and minimize the impact of the aforementioned barriers. Those with a history of participation in research studies may be more positive about requests for biological specimens and more willing participants in future genetic studies than the general population.[10–13] Yet even among participants in research that requests biological specimens, the response may be variable, and this variability may impact future recruitment. Few studies have examined the extent of that variation and the factors that may underlie different choices made by participants. Some explored only *theoretical* consent to donation and use of biological specimens.[4, 5] Others examined *actual* tissue donation but did not explore factors associated with consent[14] or focused only on conventional demographic factors.[1]

We report here on interviews that explore this issue for participants in a genetic epidemiology study which included an actual request for blood and/or saliva specimens. We evaluate their responses to this request and explore demographic variables, trust, and other factors associated with willingness to donate samples and how likely they would be to participate in a genetic research study in the future. Finally, we utilize responses to open-ended questions to contextualize our quantitative findings. We focused primarily on the characteristics and reservations of those unwilling to donate to facilitate discussions about future interventions designed to overcome reluctance to donate and participate.

METHODS

Learning About Research in North Carolina (LeARN) and North Carolina Colorectal Cancer Study Sample

Learning About Research in North Carolina (LeARN) is a cross-sectional study of African American and white participants who had recently participated in a case-control genetic epidemiology study of colon cancer risk factors, the North Carolina Colorectal Cancer Study (NCCCS). The methods are fully described elsewhere.[15] In brief, in the NCCCS study, cases had an initial diagnosis of invasive rectosigmoid cancer. Age, race, and sex matched controls were selected from two sources: Division of Motor Vehicles records for those under the age of 65 and Center for Medicare and Medicaid Services (CMS) tapes for those 65 years and older. Race/ethnicity was initially obtained from cancer registry records and DMV or CMS files and further confirmed by self-identification during the interview. In the case of conflicting data, the participants' self-identified race was used. The NCCCS participants

completed a two-hour in-person interview that collected data on demographics, dietary, lifestyle and environmental exposure, and health care access and utilization. Blood and/or a mouthwash sample were obtained from consenting participants at the conclusion of the interview. DNA and serum were stored for future analyses.

Participants for the LeARN telephone interviews were identified through the NCCCS database of participants interested in hearing about other studies. They were eligible if they met the following criteria: 1) self-reported race of African American or non-Latino white, 2) completed the entire interview required of the 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.

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 Participants were given a toll-free number to call the NCCCS offices and invited to call with questions or if they did not wish to be contacted. Potential participants were contacted on average 4 months after completing the NCCCS interview. During the initial phone call, the nature and purpose of the LeARN study was explained and verbal consent was sought. Each participant was offered an incentive of $25, which was mailed after completion of the interview. We contracted with a professional survey group, FGI, Inc., to conduct the telephone surveys, using Computer Assisted Telephone Interviewing (CATI) methods. The surveys consisted of both closed- and open-ended questions. For those who refused, interviewers made at least 10 attempts to contact each person and performed one refusal conversion attempt per refusal. All interviews were audio-taped and transcribed for content analysis of the open-ended questions. All procedures were approved by the UNC Institutional Review Board.

Measures

Included in the LeARN survey were questions on whether or not a participant had given a blood and/or mouthwash sample for NCCCS. For those who had not given a sample, we asked open-ended questions to determine why they had not. In addition, we asked several questions on attitudes about trust of research and researchers, and perceptions of potential discrimination that could occur by participating in a genetic research study. We also asked participants “If you were asked to take part in a genetic research study, the kind that looks at whether genes that are passed down through families put people at risk for diseases or illnesses, how likely would you be to take part in such a study in the future?”

Analysis

We used frequencies to describe demographic information (e.g., race, gender, education) and other characteristics, such as case/control status and perceived health status. We then used Pearson’s chi-square tests to assess associations between each of the participant characteristics and the responses to whether or not they had contributed a blood and/or a mouthwash sample for NCCCS. In addition, to explore whether trust was a factor in participants’ decision to provide a sample, we used Pearson’s chi-square tests to compare each of nine questions about lack of trust of medical research and researchers to whether or not a participant donated a sample. Each question was coded as 1 for “agree” with a statement about lack of trust and 0 for “disagree” or “don’t know”. We also examined the association of each of the trust questions to race. Given that our hypothesis was that African Americans would be less likely than whites to donate samples and that they would also be likely to have less trust in research and researchers, we used a logistic regression model with donating a blood sample as the outcome (yes/no) and race as the main study factor,

controlling for the questions on trust. Our goal was to see if any observed association between race and sample donation was confounded by lack of trust. We were also interesting in seeing whether participants who had contributed a sample were more likely to expressed willingness to participate in future genetic research studies. Because a large majority of participants said they were at least somewhat likely to participate in future studies (89%), we dichotomized this response into "very likely" vs. all other responses. We used Pearson's chi-square tests to compare sample donation to percent likely to participate in future studies, first overall, and then stratified by race. Finally, we examined the open-ended questions to further explore respondents' reasons for not giving a blood or mouthwash sample.

Qualitative Analysis—Qualitative analysis was performed to more fully understand the views and responses of the 112 participants who refused to provide at least one type of biological sample. We analyzed qualitatively responses to the open-ended question "What were your reasons for not giving blood?" Codes were initially developed a priori by the team of LeARN investigators, applied, and validated through an iterative process. Seven coders applied the codes to all responses to open-ended questions; periodic checks were undertaken to assure uniformity of application and accuracy of coding by the LeARN investigators. Additionally, there was a final review of each of the transcripts by race to determine if African Americans and whites to determine whether there were different patterns of responses.

RESULTS

The overall response rate in the LeARN study was 73%. The final sample of 801 had a mean age of 64 years. Respondents included 19% African Americans and 81% whites; 57% were male (Table 1). The majority had at least a high school education, and 28% had a college degree. About half the sample had an annual income of less than $40,000. Most were "very" (53%) or "somewhat" (42%) religious.

NCCCS blood or mouthwash samples

Overall, 15% of the participants did not give a blood sample, 8% did not give a mouthwash sample, and only 3.5% did not give either. African Americans were less likely to give a blood sample when compared to whites (21% vs. 13%, $p<0.05$) (Table 1). Other than this observed racial difference, there were no significant differences in blood or mouthwash donation by any of the other demographic characteristics.

We did, however, observe several associations when we compared responses to LeARN survey questions on trust in medical research to providing blood and/or a mouthwash sample during NCCCS. Those who felt less trust for research and researchers were less likely to have given a sample (Table 2). For example, when asked whether they agreed with the statement, "The government cannot be trusted to regulate the use of genetic information," 18% who agreed had not given a blood sample vs. 12% of those who did not agree. There were pronounced differences between African Americans and whites in their responses to the trust questions, with African Americans consistently showing less trust (Table 3)

We used a logistic regression model *to examine* the relationship between race and blood donation adjusted for the trust variables, *and found the estimated differences between African Americans and whites was smaller when compared to the unadjusted estimates, This adjusted difference (17% no blood sample in African Americans vs. 13% no blood sample in whites)* was no longer statistically significant ($p=0.27$). None of the other participant characteristics, including case status, confounded the original racial differences. Although African Americans were still somewhat less willing than whites to donate blood after

controlling for the trust variables, much of the unadjusted discrepancy might be explained by less trust in research and researchers.

Willingness to Participate in Future Genetic Studies

When we asked participants about how likely they would be to take part in future genetic research studies, those who had given samples in NCCCS were more likely to express willingness to participate. These differences were particularly evident among the African American participants (Table 4). Controlling for participant characteristics and the trust variables in a logistic regression model did not change any of these results.

Qualitative Responses

There were 112 participants who refused to provide at least one type of biological sample (32 provided a blood sample but no mouthwash and 80 provided mouthwash but no blood). Additionally, 26 participants provided neither. Of the 80 participants who did not give a blood sample but did give a mouthwash sample, 36 responded to the open-ended question: "What were your reasons for not giving blood?" Responses to the open ended question were brief with the average response of 3.6 sentences. There were several common themes. More than a third reported offering to have blood drawn, but there was a problem finding a vein. Others, primarily cancer cases or those with debilitating medical conditions, said they did not feel well enough to have another blood draw. Several admitted to not liking needles. Some were vague and said they "just didn't want to do it" or planned to do it another time. A few expressed concerns about "privacy" by responding with answers such as "Because they couldn't tell me when and how they were going to use it" and "I just didn't want to give, I didn't want anybody I didn't know sticking me."

Fourteen of the 26 participants who did not give either a blood or mouthwash sample answered the open-ended questions. Some respondents (5 of 14) said they did not recall a request for samples ("I wasn't asked to give any"). The majority (9 of 14), however, gave responses that suggest concerns – from general unease to unambiguous suspicion. Sample responses include, "I'm very careful though [about] who puts anything in my mouth, you know? I don't know you people …" Another respondent stated, "I don't donate blood. It's my opinion. What I want for my body or what I want for me is entirely up to me. … I'm very skeptical because doctors make so many mistakes." When examining the responses by race we were unable to identify a clear pattern of responses.

DISCUSSION

In this study, we were able to explore factors associated with refusals to provide blood and/or mouthwash samples among genetic research study participants and its relationship to future research participation. We found that respondents who were unwilling to provide biological specimens were more likely to be African American and less trusting of medical researchers, and were also less likely to be willing to participate in future genetic research. Further, the discrepancy between African Americans and whites for blood sample donations was explained in part by less trust in medical research and researchers. Thus, despite prior participation in a genetic epidemiology study (NCCCS), factors associated with willingness to provide tissue samples reflected many demographic factors previously identified in research on public attitudes toward genetic research. This study enhances this prior work by adding trust to an examination of traditional demographic variables, and adding open-ended questions that provide more detailed explanation of participant refusals. In these open-ended queries, we found generic concerns about needle sticks and inconvenience as well as themes of discomfort and mistrust.

Prior research on public attitudes toward requests for biological specimens for research and long-term storage has examined how responses might vary based on the request and the respondent. African American race, female gender, older age, lower income, less education, higher occupation category, and worse health status have been associated with less willingness to consent to donate and store specimens.[1, 16] Researchers have documented public belief in the potential of genetic research to contribute to improved health,[6, 7, 10] but consistently lower acceptance among minority groups.[1, 5, 6, 16, 17] One study analyzed consent forms and found that, while 87% of 1670 subjects authorized future use for any medical condition, fewer African Americans (75%) did so.[18] Our study mirrors these racial differences; however, further exploration of trust appears to be important in explaining these differences. Further, our study explicitly examines the role of race and trust among a population of prior research participants, presumed to be more receptive. Despite prior participation, some participants in our study expressed distrust of medical researchers and lower willingness for future participation.

Concerns previously identified among minorities that might explain differential participation include control of DNA, potential for misuse of genetic data, racial discrimination, stigmatization, and unequal access to potential benefits.[6–9, 19, 20] *Such negative views among African Americans 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 Tuskegee.*[21] The recruitment and participation of African Americans in research has been a topic of much discussion, given the aforementioned concerns and a continued push to include diverse groups in all human research and the scientific discourse about race and genetic variation. Some have suggested that, given the complexity of the biological specimen requests for genetic studies, decisions to donate may be based less on "informed consent" – that is, participant evaluation of the purpose[22] or assessment of the risks and benefits of the specific project.[4] Rather, general trust that those performing the research will act responsibly may be as important as informed consent.[4, 23]

These findings, and the concerns described in response to open-ended interview questions, represent potential barriers to recruitment and retention of participants from diverse backgrounds for genomics studies. Interventions that help educate researchers as well as potential study participants about genetic research and efforts to improve and demonstrate the trustworthiness of the research team might help encourage future study participation. While a high proportion endorsed interest in future participation, researchers should not assume that prior experience in genetic research completely removes participants' reservations about participation or willingness to donate biological specimens.

Our findings should be viewed in light of its limitations. First, because LeARN participants were drawn from the North Carolina Colorectal Cancer Study, the generalizability of its findings is limited to individuals who have joined similar research studies. NCCCS took many measures to demonstrate trustworthiness of the research team and build rapport with potential participants (e.g., 2 hour in home visits prior to requests for samples and a recruitment and consent process that involved multiple contacts). Individuals who have not joined such studies may have different and potentially less positive attitudes toward research participation. Additionally, while the LeARN response rate was quite good (73%), there are potential biases inherent in the sample that may further limit its generalizability. While the number of African Americans and whites who refused to participate in the LeARN study was similar, due to unusable telephone numbers the response rate differed by race.[15] It is possible that differences between African Americans and whites about how positive they felt about genetic research conceivably could have been larger than we observed had we been able to recruit both races equally.

Despite these limitations, the contributions of LeARN findings are highly relevant to current goals of recruiting genetic study participants. Similar to other reports in the literature, LeARN participants demonstrate a clear willingness for biological specimen donation. This willingness appears, in part, to be driven by trust. Mistrust and concerns about genetic research studies will need to be addressed to ensure diverse future participation.

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Table 1

Participant demographic characteristics and their associations with no blood and/or mouthwash samples given during NCCCS

Participant Characteristic	n (%)	% No Blood Sample	% No Mouthwash Sample	% No Blood or Mouthwash
Race				
African American	153 (19)	21*	9	6
White	648 (81)	13	8	3
Case status				
Case	363 (55)	15	9	3
Control	438 (45)	14	7	4
Race and Case				
Black cases	84 (10)	18	11	5
Black controls	69 (9)	24	7	6
White cases	279 (35)	14	8	3
White controls	369 (46)	12	7	3
Gender				
Male	457 (57)	14	8	3
Female	344 (43)	15	7	4
Education				
Less than high school	118 (15)	15	11	8
High school grad	197 (25)	13	10	3
More than high school	258 (32)	16	7	4
College and higher	228 (28)	13	6	2
Household income				
< $20,000	147 (21)	16	8	3
$20,000 – $40,000	183 (27)	16	9	4
> $40,000	361 (52)	14	7	3
Current health status				
Excellent	105 (13)	15	7	4
Very good	294 (37)	15	5	4
Good	235 (30)	14	10	5
Fair	113 (14)	16	11	2
Poor	45 (6)	14	9	0
How religious				
Not religious	40 (5)	19	8	8
Somewhat religious	326 (42)	17	9	4
Very religious	413 (53)	12	7	3

* $p<0.05$

Table 2

Associations between no blood and/or mouthwash samples given during NCCCS and participant responses to questions on trust and discrimination

General Questions on Trust/Discrimination	n	% No Blood	% No Mouthwash	% Neither
Lose insurance coverage by taking part in study				
Agree	153	17	10	5
Do Not Agree/Don't Know	608	14	7	3
Lose privacy when giving a sample for research				
Agree	179	18	12[2]	8[1]
Do Not Agree/Don't Know	585	13	7	2
Shouldn't do research until we know how info used				
Agree	368	18[1]	9	4
Do Not Agree/Don't Know	391	11	7	3
Government can't be trusted to regulate use of genetic info				
Agree	287	18[2]	8	5
Do Not Agree/Don't Know	468	12	8	3
Trust medical researchers				
Agree	707	14	7[1]	3[1]
Do Not Agree/Don't Know	56	18	17	11
Research participants may be deceived by researchers				
Agree	226	19[2]	8	5
Do Not Agree/Don't Know	533	13	7	3
Researchers want to know more than they need to know				
Agree	145	21[1]	11	8[1]
Do Not Agree/Don't Know	619	13	7	2
Researchers do harmful experiments w/o pt's knowledge				
Agree	194	16	7	5
Do Not Agree/Don't Know	569	14	8	3
Medical researchers use minorities as guinea pigs				
Agree	77	23[2]	10	11[1]
Do Not Agree/Don't Know	684	13	8	3

[1] $p<0.01$

[2] $p<0.05$

Table 3

Associations between race and participant responses to questions on trust and discrimination

General Questions on Trust/Discrimination	n	% African American	% White	p value
Lose insurance coverage by taking part in study				
Agree	153	28	19	0.014
Do Not Agree/Don't Know	608	72	81	
Lose privacy when giving a sample for research				
Agree	179	29	22	0.067
Do Not Agree/Don't Know	585	71	18	
Shouldn't do research until we know how info used				
Agree	368	67	44	<0.001
Do Not Agree/Don't Know	391	33	56	
Government can't be trusted to regulate use of genetic info				
Agree	287	49	35	<0.001
Do Not Agree/Don't Know	468	51	65	
Trust medical researchers				
Agree	707	87	94	0.007
Do Not Agree/Don't Know	56	13	6	
Research participants may be deceived by researchers				
Agree	226	44	27	<0.001
Do Not Agree/Don't Know	533	56	73	
Researchers want to know more than they need to know				
Agree	145	36	15	<0.001
Do Not Agree/Don't Know	619	64	18	
Researchers do harmful experiments w/o pt's knowledge				
Agree	194	40	22	<0.001
Do Not Agree/Don't Know	569	60	78	
Medical researchers use minorities as guinea pigs				
Agree	77	27	6	<0.001
Do Not Agree/Don't Know	684	73	94	

Table 4

Association between blood and/or mouthwash samples given and being very likely to participate in future genetic research studies

Type of Sample	Overall			African American			White		
	n	% Very Likely	p	n	% Very Likely	p	n	% Very Likely	p
Blood									
Yes	628	51	0.019	113	47	0.042	515	52	0.170
No	106	39		30	27		76	43	
Mouthwash									
Yes	679	50	0.010	127	48	0.011	552	51	0.118
No	56	32		14	14		42	38	
Blood and Mouthwash									
Yes	687	50	0.008	130	45	0.051	557	51	0.062
No	23	22		8	13		15	27	