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If I Could in a Small Way Help”: Motivations for and Beliefs about Sample Donation for Genetic Research

Marsha Michie, Gail Henderson, Joanne Garrett, and Giselle Corbie-Smith

University of North Carolina–Chapel Hill

Abstract

Human genome research depends upon participants who donate genetic samples, but few studies have explored in depth the motivations of genetic research donors. This mixed methods study examines telephone interviews with 752 sample donors in a U.S. genetic epidemiology study investigating colorectal cancer. Quantitative and qualitative results indicate that most participants wanted to help society, and that many also wanted information about their own health, even though such information was not promised. Qualitative analysis reveals that donors believed their samples contributed to a scientific “common good”; imagined samples as information rather than tissues; and often blurred distinctions between research and diagnostic testing of samples. Differences between African American and White perspectives were distinct from educational and other possible explanatory factors.

Keywords

genetic research; genetic sample donation; genetic variation research; colorectal cancer; tissue samples

Understanding the motivations and perceptions of donors and potential donors of genetic samples is crucial to genomic research, especially since previous research has shown that some populations are less willing than others to give samples and/or to authorize their storage for future use (McQuillan et al., 2003; Wang et al., 2001). Quantitative studies have examined both public support for genetic research and differences in levels of support among groups with differing demographic characteristics and differing beliefs about genetics and research. However, few studies have explored these attitudes qualitatively to better understand why some people choose to participate in genetic research and how they understand that participation. To address these issues, we adopted a mixed methods approach to understanding the motivations and perceptions of people who donated biological samples for genetic research. Using structured interviews with 752 participants who previously gave samples for a study of possible genetic factors in colorectal cancer, we present a theoretically grounded exploration of why donors choose to give samples for genetic research, and how they believe their samples will be used.

Background

Some aspects of genetic research participation, such as informed consent and the use of stored samples, have received considerable attention (see Chen et al., 2005; Ducournau, 2007; Ludman et al., 2010; Skolbekken et al., 2005). A small number of studies have

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Address correspondence to: Marsha Michie, Campus Box 8040, University of North Carolina, Chapel Hill 27599-8040. michie@unc.edu.

empirically examined the motivations of actual or potential genetic sample donors and their notions of how samples might be used, presenting quantitative data about group differences in motivations and views. These data reveal both general support for genetic research and differences in support associated with demographic and other group characteristics.

Wang et al. (2001), for example, used data from the 1998 American Healthstyles Survey and found that 79 percent of respondents favored blood donation for genetic research, long-term storage of samples for genetic research, or both. Those who favored both donation and storage (42 percent) also tended to believe that genetic research would prevent disease, to hold genetic deterministic views, and to be willing to participate in government research. This group was more likely to be White, to be more highly educated, to live in the mid-Atlantic or Mountain/Pacific regions, and to have a family history of a genetic disorder. Similarly, Mezuk, Eaton, and Zandi (2008), in a Baltimore-area survey in the U.S., found that 83 percent of participants were willing to donate biological samples for genetic research. Younger participants were more likely to donate than older ones, as were those with a family history of related genetic conditions. African Americans were as likely as Whites to donate, but less likely to agree to DNA storage for future research. A community-based study in Sweden (Hoeyer et al., 2004) found that while 71 percent of respondents would approve of genetic research on their biobanked samples, 62 percent disapproved of researchers examining their medical records without specific consent. About a third saw informed consent as an important issue, but most saw larger-scale justice issues as more important, especially insuring that all population groups have equal access to research results, and that research be readily applicable.

Fewer studies have conducted in-depth explorations of attitudes and motivations of genetic sample donors that would provide a more nuanced understanding of differences identified in quantitative reports. Treloar et al.'s (2007) pilot study interviewed 16 endometriosis study participants and found that most described their motivations in altruistic terms, and few noted any concerns for consent or privacy. Participants also expressed a desire for more information from the researchers about the condition under study. Another particularly interesting qualitative study is Reddy's (2007) ethnographic examination of International HapMap Project sample collection from the Houston-area Indian American community. Reddy documented conflicting narratives among sample donors and researchers, though each group employed similar language about the "good," the "public," and the "community." Divergent articulations of scientific progress, the gift, and the common good reflected fundamentally different understandings of the purpose and use of donated samples. Following on this finding, Reddy argued that HapMap scientists could never fully honor the donors' desires that their blood be used by scientists in the spirit of public service in which it was given. While these findings have profound implications for understanding the meaning of genetic research for a particular population, it is less clear how they can be translated into practical recommendations for recruiting genetic research participants who are asked to donate biological specimens. This study attempts to bridge these gaps between quantitative and qualitative study results, using a theoretically grounded, mixed methods approach.

Theoretical Frameworks for the Study

Our analysis draws on sociological theories of exchange and on related anthropological studies of the gift relationship. We also look to recent theorization on new formations of selfhood in an era of increased genetic information.

Exchange Theory: Sources of Trust and Social Solidarity

Exchange theory, which has benefited from years of experimental research, offers a useful framework for analyzing the motivations and beliefs of tissue sample donors (see Molm,

2000 for a summary). With an emphasis on mutual benefits, sociologists distinguish between *direct* and *generalized* exchange. The process of donating biological samples includes features of both types. Superficially, donation is a direct exchange in which participants give samples to a research project in return for monetary compensation, and for other direct emotional rewards that may far outweigh the small sum of money donors receive. However, there is a clear sense in which donors are also participating in a generalized exchange, one in which the potential beneficiaries of research using those biological samples may include innumerable people, perhaps many years into the future. Research has demonstrated that while generalized exchanges offer fewer certainties of benefits, they promote trust and social solidarity more than direct exchanges (Kollock, 1994; Molm, Collett, & Schaefer, 2007). Based on these studies, in our analysis we expected mixed indicators of trust and strong indicators of social solidarity to emerge in tissue sample donors' discussion of their donation.

Gift Theory: Relationships and Obligations

Anthropologies of non-state societies generated complex theories of the gift and its social and economic implications (Malinowski, 1922; Mauss, 1954 [1925]). While these theories gave rise to exchange theory within sociology and its insights into trust and social rewards, theories of the gift are valuable here mainly for their understanding of the character of the gift in complex social systems and, in particular, how the inalienability of gifts forms relationships between giver and receiver. A basic tenet of gift theory is that a gift always entails a relationship, because gifts, unlike commodities, are never completely alienated from the giver. They always entail giving part of oneself; thus the receiver is compelled to reciprocate and complete the social bond. Richard Titmuss (1971) extended this logic to argue against the selling and buying of human blood. Titmuss's contention, that blood donation promoted social cohesion by creating a cycle of interdependence among citizens, while commoditization of blood promoted social fragmentation by severing the relationship between seller and receiver, greatly influenced the development of blood banking in the U.K. and the U.S. Indeed, blood (and, more recently, other bodily substances such as DNA samples) could be the ultimate form of inalienable gift, or "keeping-while-giving" (Weiner, 1992). Unlike blood donation for transfusion, however, in DNA sample donation it is not the substance (of saliva or blood) that is the crucial gift: instead, it is the gift of information that is precious and inalienable—both completely unique to an individual and an identifier of kinship and ancestry. Bodily substances decay and are renewed; while losing too much of them causes weakness or even death, giving of them in small amounts is simple, even inconsequential. The information that resides in these substances, however, is never fully separable from the individual, family, and larger kin group from whom it is obtained. An expectation that this gift entails a relationship with, and obligations on the part of, researchers is likely inherent in the act of gifting such an intimate component of self (Fisher, 2008). With these principles in mind, in our analysis we expected genetic research participants to talk about their sample donation often in terms of its information content, rather than in terms of its physical substance. We also expected that many participants would feel that the researchers were obligated to them in some sense, a point we expand upon below.

Genetic Responsibility: Self-Knowledge and Mitigating Risk

The emergence of genetic technologies has led to new possibilities for diagnosis and treatment, but also to new dilemmas, including the creation of the person "genetically at risk." These new forms of self-knowledge have given rise to a "somatic individual," constrained in novel ways by the possibilities and limitations encoded in his or her genome, and expected to take responsibility for these. This newly generated "genetic responsibility" obliges an individual to calculate future risks and re-evaluate relationships with actual or

potential genetic kin (Novas & Rose, 2000). These emergent forms of selfhood, within a political climate emphasizing personal responsibility for one's future, have also been described as a "neoliberal medical subjectivity," one that seeks to maximize future health through risk aversion and informed decision making (Waldby & Mitchell, 2006). Given these trends, in our analysis we expected that many who agreed to donate biological samples for genetic research would look for medical benefits to themselves. Such overestimation of benefit from research participation is often called a "therapeutic misconception" (Appelbaum, Roth, & Lidz, 1982) and has given rise to appeals for more thorough processes of informed consent. But more recent studies have shown that research participants are active co-creators of their understandings of these documents (Dixon-Woods et al., 2007), and of their multiple, overlapping roles in the research setting (Morris & Balmer, 2006), suggesting that varying interpretations of participation in the research endeavor are, to some degree, inevitable. In addition to diverse interpretations, given the particular historical context of race relations in the U.S., we expected that African Americans might look for individualized benefits more frequently, due to well-documented distrust that they will benefit equally from medical advancements (Corbie-Smith, 1999; Corbie-Smith, Thomas, & St. George, 2002; Schulz, Caldwell, & Foster, 2003).

Methods

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

Learning About Research in North Carolina (LeARN) is a cross-sectional study of African Americans and Whites who had recently participated in a case-control genetic epidemiology study of colon cancer risk factors, the North Carolina Colorectal Cancer Study (NCCCS) (see Corbie-Smith et al., 2008, for full description). In NCCCS, cases had an initial diagnosis of invasive rectosigmoid cancer. Age, race, and sex matched controls were selected from the Division of Motor Vehicles (DMV) records for individuals under the age of 65, and from the 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. 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. After the interview, all NCCCS participants were asked if they were interested in hearing about other research studies ("From time to time other research studies become available. Should such a study become available, may we contact you?" yes/no).

Participants for the LeARN telephone interviews were identified through the NCCCS database of participants interested in hearing about other studies. An average of four months after the NCCCS interview, NCCCS investigators mailed potential participants a letter that introduced the LeARN study, described the telephone interview, and alerted them to expect a follow-up telephone call, in which an interviewer explained the nature and purpose of the LeARN study and sought verbal consent. An incentive of \$25 was mailed after completion of the interview. A professional survey group, FGI, Inc., conducted the 45-minute telephone surveys, consisting of both closed- and open-ended questions, using Computer Assisted Telephone Interviewing (CATI) methods. All interviews were audio-taped and transcribed for content analysis. Of the 1257 NCCCS participants who indicated they were willing to be re-contacted, 1196 agreed to hear further about the LeARN study, and 810 gave verbal consent at the start of the phone interview and participated (a response rate of 73%). Due to technical problems such as tape errors, we analyzed slightly fewer interviews qualitatively (N = 752), compared to those analyzed quantitatively (N = 772). All procedures were

approved by the University of North Carolina and Emory University Institutional Review Boards.

Measures

This paper is based on the section of the LeARN survey about donation of blood and/or saliva, asked only of the 772 participants who provided a sample for NCCCS. This section was preceded by questions about participants' understanding of the purpose of the NCCCS study; their beliefs about the causes of colorectal cancer and the sources of those beliefs; and their understanding of genetic research and its advantages and drawbacks for them, their families, and society. Following the section on sample donation, interviewers asked closed-ended questions eliciting participants' opinions about participating in genetic research and their trust in researchers, followed by a series of demographic questions. Interviewers began the section on sample donation by asking whether the interviewee had given blood, saliva, or both to the NCCCS study. The small number who had refused to donate one or both were asked their reasons (see Bussey-Jones et al., 2010, for analysis of these results). To those who agreed to donate one or both samples, interviewers stated, "People who provide a blood or mouthwash sample for research may do so for a variety of reasons," and then asked, "Could you tell me the reasons why you were willing to give mouthwash and/or blood for the colorectal study?" Next, participants were told, "Now I'm going to read some reasons people might be willing to give blood or mouthwash. Please tell me if each of these was a reason for you in that study. Please answer yes or no for each." These reasons were offered in random order: (1) "You were interested in finding out something about your own health"; (2) "You were interested in being a part of research on diseases that might affect your family in the future"; (3) "You were interested in being a part of research on diseases that might affect people of the same race as you"; and (4) "You were interested in helping people in general." They were then asked, "How do you think the blood and/or mouthwash that you provided for the colorectal study will be used?"

Analysis

Our analysis combines data from interviewees' responses to both the open-ended and closed-ended questions described above. We used frequencies to describe demographic information (e.g., race, age, education) and case/control status for participants who contributed blood and/or mouthwash. Next, we explored participant characteristics for those who chose each of our four suggested reasons for giving the blood and/or mouthwash. To further explore our hypotheses about those who look for individual benefits from research participation, we used Pearson's chi-square tests to examine individual characteristics of those who chose "own health" as a reason for participation. To assess which characteristics were independently associated with choosing "own health" vs. any other responses as the outcome, we fit a logistic regression model using race, education (in four categories), age (in four categories), and case status (colorectal cancer case vs. control) as independent variables. We also used a likelihood ratio test to determine whether there was any significant interaction between race and education, i.e., to assess whether the race by "own health" relationship differed by level of education. Final results from the logistic regression were estimated as adjusted proportions (presented as adjusted percents) using the beta estimates from the model and solving the logistic regression equation for each variable, adjusted for the other variables in the model.

In the second stage of our analysis, we analyzed the texts of participants' responses to further explore and understand their reasons for donation and their understanding of sample use. In our analysis we included both responses to open-ended questions and any extra comments (beyond basic affirmatives or negatives) made in response to the closed-ended question. Based on the study's guiding questions and a preliminary reading of transcripts,

we agreed on an initial list of descriptive content codes for all open-ended questions in the survey, including the subset of questions asked only of donors, described above (Miles & Huberman, 1994). Using ATLAS.ti qualitative analysis software, two independent coders applied these content codes to all interviews, and reconciled all discrepancies by consensus. The first author then developed interpretive content codes for the subset of questions analyzed in this paper, based on a full reading of interview content and earlier descriptive coding (Miles & Huberman, 1994). The first author applied and refined these interpretive codes in successive readings of the interview texts. A second coder confirmed accuracy and consistency of these additional codes for a ten-percent sample of interviews.

Results

Quantitative Results

Of the 801 LeARN study participants, 772 provided biological samples. Eighteen percent of those who donated were African American, and 82% were White (Table 1). The majority had at least a high school education and 28% had a college degree. The mean age was 64.3 years and 45% were colorectal cancer cases. There were no significant differences between those who donated samples and those who did not for any of these participant characteristics.

Reflecting our expectation that participants would express strong indicators of social solidarity, almost everyone in our sample (99.7%) expressed interest in donating a blood or mouthwash sample to help people in general, and almost as many (93.1%) wanted to be involved in research on diseases that might affect their family in the future. A smaller, but still fairly large percent wanted to be part of research that affected their own race (75.3%) or wanted to find out something about their own health (70.8%). We found no differences in responses for the first two questions (to help people in general and affect their family in the future) by participant characteristics. For the question about research that affected their own race, those with less education were slightly more likely to answer positively, but there were no other differences by race, age, or case status. However, race, education, and case status were all significantly associated with selecting own health as a reason to contribute to research (Table 2). African Americans were more likely than Whites to choose “own health” (88% vs. 67%). Those with the least education chose “own health” 83% of the time vs. only 56% for those with a college degree or higher. People with colorectal cancer also chose “own health” more frequently than controls. No age differences were observed. The estimated adjusted percents from the logistic regression model showed similar results to the unadjusted percents (Table 2). The associations between choosing “own health” with race, education level, and case status remained statistically significant. The differences in adjusted percents narrowed only slightly compared to the unadjusted bivariate results, even after controlling for the other variables in the logistic regression model. This was particularly of note for the race and education effects; the estimated effect for race was not confounded by education, and the estimated effect for education was not confounded by race. There also was no significant interaction between race and education.

Qualitative Results

Several themes emerged in our qualitative analysis of LeARN sample donors’ motivations and understandings (see Table 3 for the frequencies with which these themes appeared). We present them in three topical groupings that correspond to the theoretical frameworks (the exchange, the gift, and genetic responsibility) described above.

Helping Out “Down the Line”: Altruism, Trust, and Social Solidarity—“I just thought, if it would help, I’d be willing to do it.” This statement, by a LeARN study

participant in her seventies, sums up the most common reason that donors offered for their willingness to give tissue samples to NCCCS. Similar to the quantitative results, most donors, regardless of age, race, or other factors, said they were motivated by a desire to help their families, to help other people, to help the study, and often just “to help” in general. Participants who said that they were motivated by a desire “to help” spoke most often about helping the study, or helpfulness in a nonspecific sense. Emily, a 61-year-old woman who said she felt very positive about participating in a genetic research study, stated that she was willing to donate samples because “I was hoping in some small way I could help with the research.” Also commonplace in interviews were statements indicating that donors wanted to help people who have or might get cancer or other health problems, and minimizing any negative aspects of tissue donation, especially in comparison to the perceived benefit of helping others. Frank, a White male colorectal cancer survivor, saw genetic research as an opportunity to prevent or eliminate “inherited diseases” such as diabetes or poor eyesight. When asked why he agreed to give samples, Frank mused, “I didn’t see any good excuse not to, because what would it accomplish if I said, no, I’m not going to participate? I mean, that don’t help nobody.”

Most donors spoke of the benefits of their donation as generalized to all people rather than directly accruing to themselves (but see the later discussion of donors who also looked for direct benefits). The future-oriented language of Arthur’s interview reflected his understanding of research benefits as long rather than short term. A White male in the NCCCS control group, Arthur agreed when presented with a suggestion that research participants could be misled by researchers; nonetheless, when asked why he gave samples, Arthur asserted, “If they can learn anything to help somebody in the future, I was for it.” In a phrase echoed by other respondents, Joyce (a 57-year-old African American cancer survivor) hoped that her contribution would help someone else “down the line.” Some participants took this sense of social benefit even further, speaking about their participation in terms of their duty as a citizen, a Christian, or simply as a human being. “If something so simple could aid in research, if it improves one disease or one person having disease, or if it contributed to a cure or a vaccine or something, why wouldn’t you do this?” said one donor. “It would be a terrible world to live in if people didn’t take part in, and do whatever little bit they can to help somebody at large.”

Perhaps related to this sense of duty to contribute to a common social good, over a quarter of sample donors (203 of 752) made extraneous comments when asked to respond “yes” or “no” to the question, “Were you interested in being part of research on diseases that might affect people of the same race as you?” Many were bewildered by the question or even offended, and many took pains to state that they did not limit the desired recipients of benefits of research to just one race, but wanted to help all people. Similarly, donors rarely mentioned racial or ethnic groupings in their responses to the open-ended questions (see Table 1). Somewhat fewer interviewees (151 of 752) commented on a similar closed-ended question that asked, “Were you interested in finding out something about your health?” However, these comments were more mixed; many people noted that they did not expect to find out about their own health, but participants frequently expressed a desire to receive such information if it were available (see below).

Like many other participants, for Tom (a 48-year-old White male) tissue donation was motivated by a desire to see causes, cures, treatments, or preventions found for cancer. A colorectal cancer survivor, Tom “nearly died” from two surgeries and chemotherapy, and said of his donation, “I want them to figure what really does cause it, to help come up with a cause or prevention and new drugs.” A theme of scientific research as a long-term undertaking again emerged from discussions of curing and treating cancer. George, a 75-year-old who laughed that he gave samples to be “a guinea pig,” nonetheless spoke of

studies like NCCCS as important contributors to medical advancement: “That’s the way medicine is progressed these days, by these various types of tests and surveys and whatnot. Each year it gets better and better.” But although Tom, George, and other participants focused on the hope that their tissue donation would help scientists find causes or cures for cancer, Linda and other interviewees were less specific. Fifty-one and cancer-free, Linda simply stated, “I just felt like I could help others. I felt like it was for a good cause.”

This sense of social solidarity had its limits, however. While it was rare to hear concerns in interviews about giving tissue samples to the study, Bill (a White, 54-year-old cancer survivor) hinted at some ambivalence about his trust in the NCCCS researchers when he noted, “All I can do is take them at their word for it. We only had a handshake.” Ruth, a 72-year-old White female, had recently had surgery for her colorectal cancer at the time she gave samples. When asked how she thought her samples would be used, she wondered, “I don’t know whether I should have or not, but at that time I was still kind of not with it, you know. But hopefully they [are] using it right.” The mention of topics related to trust, consent, and confidentiality did not always indicate distrust; donors with more formal education tended to bring up these topics more often (see Table 3), perhaps due to a greater awareness of their significance in scientific research. For the group in our study, however, who all elected to donate tissue samples to NCCCS, the potential benefits clearly outweighed their concerns. This feeling was aptly expressed by Walter, a 66-year-old cancer survivor, who recalled with some bitterness and irony that he had been in the first class of African Americans allowed (by court order) to attend the very same university that had gladly accepted his tissue samples. Despite his distrust of historically White institutions, Walter did give those samples, saying, “I was very apprehensive but I just put my trust out there, and said, I’ll just give it a shot. It’s just a gamble to make to see if it helps.”

While participants across all demographic categories overwhelmingly endorsed the value of helping, some notable differences emerged between “cases” and “controls,” and between older and younger donors. (African American and White donors also had somewhat differing perspectives, discussed below.) Participants with a history of colorectal cancer (cases) were over twice as likely as those without such a history (controls) to say they believed or hoped their donation would help in the search for causes, treatments, or a cure for cancer. James, a White, 64-year-old cancer survivor, noted that the diagnosis “changes your attitude towards these things very quickly. If you had asked me these same questions a year and a half ago, I might have had different responses.” Controls, on the other hand, were more likely than cases to say that experience with a loved one’s cancer motivated them to give samples. Controls were also more likely to raise issues of confidentiality, consent, and trust in the study researchers (whether positively or negatively), though, as noted, these topics were infrequently mentioned overall.

“To Advance the Scientists’ Knowledge”: DNA and the Gift of Information—

The second most commonly cited motive for giving biological samples to the study, and the way most participants thought samples would be used, was the advancement of science and knowledge production, sometimes noting that information from samples was crucial for research. At 75 years of age, Donald had not noted any difference in lifestyle among his friends who had and had not developed colorectal cancer. So, he argued that collecting samples “helps in their study. They would have to have all the information. Just talking to somebody doesn’t give you the DNA and whatever else you might need.” Participants’ education level was directly associated with the likelihood of mentioning this sample use; those with at least a college education were nearly twice as likely to talk about scientific study as those who did not finish high school. Donors usually made few suppositions about what this study might look like, saying that their samples would be used “in some type of

research,” “to advance the scientists’ knowledge,” or, as another donor phrased it, “for the study, whatever they’re hunting for.”

Those participants who took the further step of imagining what the research might entail often focused on the information content of the samples. Helen, a White 75-year-old who felt “very positive” about genetic research, said that samples “provided them information which they would need, you know, to provide the information to us.” Also prominent was the idea of comparisons in research, perhaps between people who have had colorectal cancer and those who have not. “I imagine they will analyze it and compare it statistically to all the other samples they get, and look for groupings,” offered Paul, a 71-year-old White participant with a graduate degree. Karen, a 47-year-old White participant, mentioned genetic information that might be obtained from the samples: “Maybe they’re looking at some genetic markers that my blood might have that somebody else’s doesn’t have.” Pat, a 53-year-old White woman who has never had colorectal cancer, said of her sample, “Well it has my DNA in it, so they’ll get the DNA and look at the genes.” Larry, 56-year-old White interviewee with a bachelor’s degree, mentioned the possibility of comparative study between samples and the lengthy lifestyle interviews conducted by NCCCS researchers, noting that they would probably “look at the makeup of both of those samples and relate it back to the answers I gave to the question as far as diet, health issues, and lifestyle.”

“If there’s something wrong with me, they can catch it”: Individual Thinking and Desires for Diagnoses—Even if they did not expect to receive individual results from the study, participants sometimes spoke about the uses of their samples more in terms of diagnosis than of comparative study. Perhaps scientists would use samples to find out whether the donor had cancer. Perhaps, offered David (a White 65-year-old cancer survivor), they would “see if they find anything unusual about it.” Virginia, also surviving colorectal cancer at 68 years old, guessed that “they’ll go in there and find germs, and maybe where it comes from or why it’s in my system.”

For a few participants, this individualistic understanding of sample use led to an expectation that the results of those individual assessments would be returned to them, especially if there was “something wrong,” as Chuck (a 55-year-old White participant) put it. Mike, age 46, had already undergone treatment for colorectal cancer; but said that he gave samples to the study “because if they found [cancer], sure to God they would have told me.” While some interviewees specifically noted that they knew they would never receive individual results from the study, a few others believed that they were promised just that. Henry, a 73-year-old White participant without cancer, recalled that “they told me they would run it like it was an individual and said they would notify me if there was anything wrong. So I never got notified so I figured there wasn’t nothing wrong.”

Sample donors without a history of cancer gave more varied responses in regard to this topic than cancer survivors. On the one hand, controls were more likely to discuss how samples would be used in terms of their individual health; to say that they gave samples, at least in part, to find out something about their own health; and to say that they wanted individual results from the study. But they were also slightly more likely than cases to specifically note that they did *not* expect individual results.

African American study participants were more likely than their White counterparts to talk about their sample donation in ways that emphasized individual health assessment over comparative study. Mirroring results in the quantitative analysis, African American donors were more likely to say they were interested in finding out something about their own health from the study or, less frequently, that they expected or hoped for individual results to be returned to them. White participants were more likely to mention that they had no

expectation of receiving any information about their own health from the study; and they were somewhat more likely to refer to some notion of scientific research or generalized knowledge in discussing their sample donation and its use. Again, as we found in the quantitative results after controlling for race, participants with less education were more likely to talk about sample donation in terms of individual health, and less likely to specifically mention that they did not expect individual results from the study.

Discussion

We found that the quantitative and qualitative results from our sample met our expectations, which were:

- Strong indicators of social solidarity and mixed indicators of trust in discussions of sample donation;
- Frequent discussion of samples in terms of their information content, rather than their physical substance;
- A sense from many participants that researchers are obligated to them in some sense; and
- A desire on the part of many participants for medical benefits to themselves, particularly among African Americans.

The overwhelming majority of tissue sample donors honed in on the idea of “helping,” suggesting that few donors conceived of their contribution as part of a negotiated, direct exchange of monetary compensation for their blood, saliva, energy, and time. Rather, most conceived of giving samples as an act of public altruism. By characterizing their donation as an act “for the good of human-kind,” participants expressed both motivation and expectation; researchers were recast not as direct exchange partners, but in a powerful sense as middlemen, facilitating an exchange between citizens (of a community, of a nation, of the world) and that of a larger society, however envisaged. It may be that researchers can play this facilitating role in the imagination of these tissue donors precisely because of the institutional context of a respected university research program; as Dixon-Woods and Tarrant (2009) have proposed, beliefs that such institutions are well regulated—bolstered by cues such as institutional credentials and consent forms as evidence of regulatory structures—underlie decisions to cooperate with research. It is tempting to view statements downplaying monetary compensation and foregrounding altruistic motives as, at best, self-congratulatory, and, at worst, self-deceiving. But a justified claim of altruism can and should be considered a major benefit that donors receive for their participation; pride in having given something to society is itself a motivator that, for most, likely outweighs that small sum of money. As one donor put it, “It makes me feel good about it that I have some part in it, you know?” This feel-good “benefit” from donating tissue samples is one among many potential benefits calculated by donors. Moreover, frequent disclaimers that their contribution was “simple,” “a small part,” or “no trouble,” and difficulty with questions that proposed more limited benefits (for “my individual health” or “people of my race”), suggest that most participants measured their donation against a much larger scale—as part of a cumulative social benefit that occurs when small individual contributions to the common good add up. A belief in helping others out “down the line” points to a notion of these contributions as continually returning to the individual via social advancements that eventually benefit everyone. However flawed and incomplete these common benefits may be in practice, a belief in the necessity of that continuing cycle of generalized exchange clearly plays a large role in motivating people to take on the inconvenience of needles, swabs, and lengthy interviews, and to downplay any risks of sample donation.

This expansive view of societal benefit was not unmixed with other motives, as we describe below; and it may also be experientially altered for some participants. Cancer survivors, who may be more likely, as Susan Sontag (1978) put it, to identify as citizens of “the kingdom of the sick,” focused more explicitly on benefits to their metaphorical countrymen: others who have or may one day get cancer. They were also less likely to be among the few participants who commented on consent, confidentiality, or trust in those traditional allies of the “kingdom of the sick,” doctors and medical researchers. Due to their history of medical treatment and perhaps involvement in clinical studies of their condition or patient advocacy organizations, cancer survivors are also more closely involved in networks of medical knowledge production than the general public. This factor may elevate their hopes and expectations for new biomedical technologies for cancer treatment (see Brown & Michael, 2003; Novas, 2006).

In any case, participants rarely expressed any concern for the substance of the samples themselves. Many were baffled by the idea that a mouth swab could be useful (one participant in her forties exclaimed, “It just blows my mind—and I watch ER!”); and very few mentioned storage of samples for future use, although an entire section of the consent process was devoted to this possibility. It was the information content of the samples that most donors understood as their real gift. When a tissue donor says that he gave to the study because “I want researchers to have information they need to find a cure for this problem,” he is expressing an equivalence in which his tissues *are* information. Nearly all donors seemed to conceive of the information they contributed as residing in a biomedical “information commons” available for the good of all (Waldby & Mitchell, 2006, pp. 135ff). Some, like the participant who gave samples “to help research and do my part,” referred to science as a collective endeavor that presumably works for the common good. Virtually no participants considered any commercial or entrepreneurial uses of their sample/information. Instead, they viewed their donation as a contribution to “help out” society as a whole. As Reddy has said of Indian American donors to the HapMap project, the vague term “research” is equivalent, for many, to that abstract “common good” for all of humanity that is part of the imaginarity of sample donation for genetic study (2007).

Unlike tissue donation for transfusion or transplantation, however, this donation of bodily information is indefinitely replicable; and it is forever tied to the identity of the donor, even more powerfully than the tissues themselves. Blood or organs that are put into another person’s body no longer fully belong to the donor, but DNA is always “my DNA,” never reducible to another person or to humankind in general. This truly inalienable gift demands reciprocation, whether through, in the broadest sense, the benefits of medical advancement extended to all people, or, in a narrower sense, acknowledgment of the giver and perhaps a return of some form of individual results. Fisher (2008) has argued that donors rightfully expect this latter kind of reciprocity, noting that “we donated parts of ourselves ... an almost sacred act. We entered a covenant, not a contract.” This formation of a relationship of reciprocity complicates the notion of “altruistic” sample donation, as Haines and Whong-Barr (2004) also noted in the case of a UK-based biobank. One LeARN participant clearly expressed this sense of reciprocity by saying, “We helped them with their study; looks like they could go a little further and give you the information.”

It is this desire for (and sometimes expectation of) individual results from biological samples given for research purposes that so often troubles researchers concerned with the informed consent process (Appelbaum et al., 1987; King et al., 2005). While it is crucial that researchers continue to work toward the clearest and most transparent consent processes possible for any study involving human subjects, several studies have also suggested that the perspectives of donors to genetic and other medical research will necessarily differ from those of researchers, due to their very different positionality vis-à-vis the research endeavor.

Few LeARN interviewees told us that they expected to receive diagnostic or treatment information from the NCCCS study, but many spoke of their samples being analyzed in an individual way. These results indicate a fundamental difference between what researchers believed they were communicating about the NCCCS study and the way many research participants conceptualized the research endeavor. As Dixon-Woods et al. (2007) have concluded, these latter differences may not be cause for concern unless they lead people to make decisions about research participation that they would not make if their misunderstanding were pointed out. The relationship of education level to this difference in understanding suggests that, as the proportion of Americans who have post-high school education continues to rise, misunderstandings of the implications of research participation may decrease.

However, the relationship of race to a belief that research participation may lead to individual health outcomes may point to a more complicated set of historically based issues. While race and education were related in our sample, they also varied independently in our quantitative data. African Americans were nearly as likely as White participants to espouse altruism or “helping” as a motive for giving samples, but over twice as likely, at the same time, to look for individual benefits for their participation. Corbie-Smith et al. (2002) found that African Americans were significantly less trusting of doctors than Whites, even after controlling for other markers of social class; and, in another study, found that African Americans in focus groups believed that signing an informed consent document meant that “you don’t have any legal rights” (Corbie-Smith et al., 1999, p. 540). These results reflect a long history of racially based discrimination in the U.S. in which African Americans have been institutionally disadvantaged under the law as well as in medicine, education, housing, and employment (Smedley, Stith, & Nelson, 2003). The LeARN interviewees, having already participated in a genetic research study, were more positive about medical research and researchers than Corbie-Smith et al.’s focus group participants; however, they likely share similar community memories of past abuses such as the well-known Tuskegee syphilis study by the U.S. Public Health Service, in which Black participants were deprived of life-saving information about their condition for many years, and many died (Brandt, 1978; Corbie-Smith, 1999). Their willingness to participate and overall positive view of research may not conflict with a belief in the possibility of reciprocation through individual results so much as they are contingent upon it.

Best Practices

By combining qualitative and quantitative data on a sizable group of sample donors, this study illuminates some of the complex and overlapping hopes and concerns of genetic research participants. Genetic researchers can improve their communications with research participants by taking these hopes and concerns into account and recognizing that the needs, desires, and understandings of different populations may vary.

The Therapeutic Misconception and the Return of Results

This study found that a large percentage of genetic sample donors, even in a study that took place outside a clinical environment, did not make a clear distinction between research and diagnostic testing, leading some to expect individual results despite being informed (at least in the consent form) that they would not receive such results. Researchers should recognize when recruiting participants that the common conception of genes as powerful determinants of health may prevent potential subjects from recognizing subtle language about the lack of individual benefit from research, particularly when such language is embedded in a multi-page consent form. Verbal statements in clear language about the intent of the study and its benefits and risks may deter some misconceptions, but not all. If the return of individual results is at all feasible, it is preferable, as the opinions of participants in this and many other

studies have shown. If it is completely unfeasible, researchers should consider a follow-up communication with participants summarizing the overall results of the study and clearly stating again that individual results will not be offered. Barring this communication, researchers should at the very least be prepared to receive and respond clearly to later questions from participants who may have misunderstood the terms of their participation.

African Americans' Participation in Research

Both quantitative and qualitative results from the LeARN study show the importance of historical differences between African Americans and Whites in relation to clinical research. African Americans' doubts about the research enterprise will likely remain for years to come. Researchers who seek to include African Americans in genetic research will likely continue to need to work harder to gain their trust, and may need to offer incentives (such as the return of individual results) to make research participation more attractive. Engaging with minority populations on a community basis (through religious institutions, community groups, and the like) may yield an ongoing research relationship in which researchers and participants are more likely to understand and accommodate one another's goals; such relationships can both encourage research participation and increase mutual satisfaction with the research partnership (see Corbie-Smith et al., 2010).

Doing Good for Science and One Another

The idea of "helping" was overwhelmingly present in the motivations of genetic research participants in this study, as in similar ones with other studies and populations. Research participants repeatedly echo the belief that scientific research contributes to the common good of society and, therefore, that their participation benefits not only the scientific enterprise, but one's own family, neighbors, and community. Because of this, as Hoeyer and Lynoe (2006) have noted, research participants must place their trust in researchers, research institutions, and the scientific community as a whole to further their interests in the common good. The standard of informed consent is a good first step toward ethical relationships with research participants, but it does not address these larger issues for which participants (and, to some extent, even individual researchers) cannot possibly take responsibility. To more fully meet the expectations of research participants, research institutions and the funders who support them must advance ethical standards on a broader scale, by working to insure that genetic discoveries are translated into clinically relevant technologies, and that these are made accessible to all segments of society.

Research Agenda

In this study, we present results from interviews with a large number of participants in a colon cancer research study regarding their motivations for donating and expectations of how their sample would be used. It is not a nationally representative sample. Rather, it is a study of former research participants, likely representatives of future targets of recruitment efforts as more genetic research builds on existing cohorts (SACGHS, 2007).

Our quantitative results reflect those of other studies on sample donation. Yet our qualitative analysis give these findings context and depth. In particular, our finding that genetic research participants in this study viewed their samples primarily as information rather than as physical substances illuminates the lack of concern on the part of most participants for the long-term storage of their samples. Further research into the ways that genetic research participants in other study populations view their samples may lend further support to these findings, or may alter or refine them in significant ways.

Our quantitative results demonstrate that differences between African Americans and Whites cannot be reduced to economics or education, and our qualitative findings offer

intriguing glimpses into some of the complex ways that African Americans relate to medical research, even when they have agreed to participate in it. Research comparing African American attitudes among research participants and decliners may illuminate these issues even further.

Educational Implications

Our finding that many genetic sample donors did not clearly distinguish between giving samples for research and for clinical testing reflects the findings of many other studies. This result reinforces the importance of very clear consent processes, but it also reminds us that even those consent processes may not prevent participants from reaching their own conclusions, a point that researchers and IRB members must keep in mind when considering the motivations and incentives for research participation.

Genetic studies that ask for donations of biological samples involve many of the same ethical and practical issues as any medical research study, among them the need for recognizing and addressing the complexity of the consent process for research participants, discovering and overcoming barriers to participation, and finding an ethical balance between these two. These issues are compounded in the genomic era, as hopes for genetic discoveries and therapies bring with them additional risks of loss of confidentiality or insurability, stigmatization, and even challenges to self-perception and community identities. Perceptions among actual and potential genetic sample donors of researchers as facilitators of their desires to help improve society as a whole call for conscientious response on the part of scientists who recruit and utilize tissue donations, for transparency in the former endeavor and accountability in the latter. Researchers can enhance both of these aspects of their relationships with research participants by recognizing that very relationship, one that, for sample donors, does not end with their gift of DNA, but only just begins.

Biographies

Marsha Michie is a Postdoctoral Fellow at the Center for Genomics and Society at the University of North Carolina–Chapel Hill. She is a cultural anthropologist whose research interests include the ethical and social implications of genetics and genomics, genetic identities and moralities, and religion in everyday life. She conducted the qualitative analyses for this manuscript and prepared it in collaboration with the three co-authors.

Gail Henderson is Professor and Chair of the Department of Social Medicine at the University of North Carolina School of Medicine. She is also Director of the UNC Center for Genomics and Society. Her work addresses the social and ethical implications of conducting and participating in genomic research, often combining qualitative and quantitative methods. This present study is based upon data from the Learning About Research in North Carolina (LeARN) project, for which she was a co-investigator. She contributed to the study design, data analysis, and manuscript preparation.

Joanne Garrett is a researcher at the Center for Women's Health Research and a Professor in the Department of Obstetrics and Gynecology at UNC. She is an epidemiologist and biostatistician who has been a co-investigator on many research studies with a focus on ethical issues in health care. She contributed to the study design, statistical analysis, and manuscript content and revisions.

Giselle Corbie-Smith is Associate Professor in the Department of Social Medicine and the Department of Medicine at the UNC School of Medicine. She is also Director of the Community Engagement Core of the NC Translational and Clinical Science Institute and co-

Director of the Program on Health Disparities at the Sheps Center for Health Services Research. Her work addresses the practical and ethical approaches of engaging communities of color and underserved communities in research. She was principal investigator for the Learning About Research in North Carolina (LeARN) project. She led and designed the study, obtained funding, and contributed to the current manuscript's design, data analysis, and preparation.

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TABLE 1

Sample Characteristics for Participants Who Contributed Either Blood or Mouthwash (n=772).

Characteristic	N(%) or Mean(SD)
Race	
African American	142 (18%)
White	630 (82%)
Education	
Less than high school	111 (14%)
High school	190 (25%)
More than high school	249 (32%)
College+	222 (29%)
Age in years (SD)	64.3 (9.93)
Case status	
Case (colorectal cancer)	350 (45%)
Control	422 (55%)

TABLE 2

Unadjusted and Adjusted Proportions of “Interested in Own Health” as a Reason for Giving Blood or Mouthwash Sample by Participant Characteristics.

	n	% Interested in Own Health (Unadjusted)	% Interested in Own Health (Adjusted) ^a
Race			
African American	142	88 ^b	87 ^b
White	615	67	69
Education			
Less than high school	116	86 ^b	83 ^b
High school	195	76	76
More than high school	255	73	75
College+	224	56	60
Age			
43–55	175	68	70
56–65	198	71	74
66–75	271	70	72
76–82	91	79	79
Case status			
Case (colorectal cancer)	342	76 ^b	77 ^b
Control	415	66	69

^aBased on results from a logistic regression model, adjusted for race, education, age, and case status

^b $p \leq 0.01$

Note: No interaction effect between race and education.

TABLE 3

Textual Themes in Participant Interviews.

Theme Groupings	Altruism, Trust, and Social Solidarity			DNA and the Gift of Information		Individual Thinking and Desires for Diagnosis		Other Notable Themes		
	Altruism: Wanted to help the study, other people, downplayed negatives	Addressing cancer: Want to find cause/prevention	Familiarity with cancer: Motivated by own cancer, or cancer in loved ones	Trust and consent: Discussed consent process, or trust in researchers	Advancing scientific knowledge: Talked about research, DNA, need for samples	Individual results: Samples about individual health	No individual results: Did not expect individual results would be returned	Don't know: No ideas about how samples will be used	They asked/ It was part of study: Gave samples simply because asked to	Race and ethnicity: Mentioned racial or ethnic groupings
Total % (n=752)	70.6	26.6	8.2	17.6	66.5	22.3	6.4	29.5	13.4	2.3
Case (338) *	73.7	38.2	12.4	12.4	63.3	18.0	5.6	31.1	10.1	1.2
Control (412)	67.7	17.0	4.9	21.8	69.4	25.7	7.3	28.4	16.3	3.2
Age: <70 (469)	70.8	30.5	10.2	16.0	71.6	22.0	7.0	24.5	10.0	2.3
Age: 70+ (283)	70.3	20.5	4.9	20.1	58.0	23.0	5.7	37.5	18.7	2.1
Race: African American (142) †	64.8	28.9	10.6	9.9	57.0	41.5	1.4	24.6	12.0	4.2
Race: White (606)	72.3	26.1	7.8	19.5	68.8	17.8	7.8	30.5	13.7	1.7
Education: Less than high school (107)	65.4	25.2	2.8	12.1	46.7	31.8	0.0	41.1	12.1	0.0
Education: High school (187)	72.7	28.9	10.7	12.8	61.5	26.2	3.2	31.6	11.8	2.1
Education: More than high school (242)	72.7	25.6	8.7	17.8	69.4	19.4	6.6	25.2	14.9	2.9
Education: College and up (216)	69.4	26.9	8.3	24.1	78.2	17.1	12.5	26.4	13.9	2.8

* The study did not have information on case status for 2 participants.

† The race of 4 participants was neither African American nor White.