Original Paper

Public Health Genomics

Public Health Genomics 2011;14:135–142
DOI: 10.1159/000317497

Received: November 9, 2009
Accepted after revision: June 21, 2010
Published online: October 8, 2010

Patient Perspectives on Group Benefits and Harms in Genetic Research

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Key Words
Biorepositories · Community consultation · Ethics · Genetic research · Group harm · Human subjects · Informed consent · Stored tissue

Abstract
Background: It is unclear how the possible effects of genetic research on socially identifiable groups may impact patient willingness to donate biological samples for future genetic studies. ***Methods:*** Telephone interviews with patients at 5 academic medical centers in the U.S. examined how patients' beliefs about benefits and harms to ones racial or ethnic group shape decisions to participate in genetic research. ***Results:*** Of the 1,113 patients who responded to questions about group harms and benefits, 61% of respondents indicated that potential benefits to their own racial or ethnic group would be a big or moderate part of their decision to donate a sample for genetic research. 63% of black respondents and 57% of white respondents indicated that they were 'very' or 'moderately concerned' about genetic research findings being used to discriminate against people by race or ethnicity. 64% of black and 34% of white respondents reported that their willingness to donate a blood sample would be substantially reduced due to these concerns. ***Conclusion:*** Our findings suggest that a key factor in many patients' decisions to donate samples for genetic research is how those studies may impact identifiable racial and ethnic groups. Given the importance of these considerations to many patients, our study highlights a need to address patients' concerns about potential group benefits and harms in the design of future research studies and DNA biobanks.

Introduction

The recent creation of several large sample collections to facilitate studies of genetic contributions to common diseases has intensified debates about the potential impact of genetic research on historically disadvantaged racial and ethnic groups [1, 2]. On one side of these debates are those who worry about the discriminatory potential of genetic research, particularly studies suggesting that certain genetic predispositions to disease may occur more frequently in some populations and not in others

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[3–6]. On the other side are those who worry that the benefits of genetic research will not be distributed fairly if members of historically disadvantaged groups chose not to participate in DNA biobanks due to concerns about discrimination [7].

Currently, there is little consensus on how best to take into account these divergent perspectives on the potential benefits and harms of genetic research in constructing new DNA biobanks to enable genetic research. In the United States, Institutional Review Boards (IRBs) are charged with protecting the rights and welfare of individuals who volunteer to donate biological samples for research but are discouraged from considering the indirect impact of research on others outside the investigator-subject relationship [8]. Although, critics have challenged this narrow understanding of the responsibilities of IRBs to protect identifiable social groups that may be affected by research [9], it is unlikely that IRBs have either the resources or requisite expertise to conduct systematic reviews of the long-term impact of genetic studies on members of racial and ethnic groups [10, 11].

As an alternative to expanded IRB review, commentators on genetic research have proposed supplemental oversight mechanisms designed to minimize the potential for group harm, to build trust and to promote community engagement [3, 12–15]. These mechanisms include forms of community consultation, structured researcher-community partnerships and formal Community Advisory Boards [12, 16–18]. However, there is little agreement about which criteria should be used to decide when these additional oversight mechanisms are necessary or what form they should take for any particular study.

In the absence of established regulatory mechanisms for assessing potential group benefits and harms resulting from genetic research, investigators and individual volunteers are left to assess these matters for themselves. Currently, it is unclear to what extent patients' beliefs about the potential effects of genetic research on identifiable social groups may influence their decisions about research participation. Although, numerous studies suggest that members of historically disadvantaged racial or ethnic groups are less willing to participate in genetic research due to concerns about discrimination [19–25], this tendency may reflect concerns about the potential for personal harm rather than worries about the impact of genetic research on social groups.

We report results from a study of patient perspectives on genetic research and DNA biobanking. This multi-site study examined multiple factors associated with patient willingness to donate clinical samples for genetic research, including beliefs about the potential benefits and harms of genetic research for others. A primary aim of the study was to characterize factors that influence patients' willingness to allow clinical samples to be used for future genetic research. In this paper, we report findings on patients' beliefs about the potential impact of genetic research on racial and ethnic groups, including the extent to which patients' beliefs about potential group benefits and harms influence their willingness to participate in genetic research.

Methods

Study Population

In 2002–2003, 1,193 patients at 5 academic medical centers were interviewed via telephone for this study [Duke University (n = 255), Johns Hopkins University (n = 139), University of Arizona (n = 234), University of North Carolina (n = 403), and University of Utah (n = 162)]. Participants were recruited from a sample of adult patients with appointments at clinics in internal medicine, thoracic surgery, medical oncology, and family medicine. In addition, approximately 1/3 of respondents were drawn from patients enrolled in an existing DNA biobank (UNC). Overall, 1,393 patients were approached and gave permission to be contacted regarding this study. Average participation rate from this initial sample was 86%. The 5 sites and individual clinics selected were part of a sampling strategy that was intended to reflect the diversity of adult patients at academic medical centers who might be recruited to participate in genetic research or donate clinical samples to a DNA biobank. A more detailed description of the study's design was reported previously [26].

Survey Instrument

The survey instrument consisted of 21 open-ended and 78 closed-ended questions (available upon request). An initial instrument was developed with expert guidance by the authors (S.C.H., R.R.S. and B.S.W.) and based, in part, on previous research [27–29]. The instrument was evaluated and refined through a focus group, 16 in-person cognitive interviews, and 29 pretest telephone interviews.

The survey instrument was administered using a computer-assisted telephone interviewing system. The survey examined respondents' familiarity with disease-oriented genetic research and level of enthusiasm for genetic research. The survey examined factors hypothesized to be associated with respondents' willingness to donate a blood sample for genetic research, including respondents' concerns about the privacy of medical information, trust of biomedical researchers and study sponsors, interests in learning more about personal health, and interests in helping others.

Respondent willingness to participate in future genetic research was assessed in several ways. Near the beginning of the survey, respondents were asked about their willingness to give a blood sample and release information from their medical records 'to a genetics researcher studying diseases'. Approximately one-

third of the way through the survey, respondents were asked '… how much of your willingness to provide a blood sample for genetics research would you say comes from your interest in finding out something about your own health?' This question was followed by similarly phrased questions examining respondents' interests in helping researchers learn more about 'diseases that might affect your family' and 'diseases that might affect people of the same race or ethnicity as you.' A related question asked about respondents' interest in 'helping people in general' and its impact on their willingness to provide a blood sample for genetics research. Finally, near the end of the survey, respondents were asked 3 questions that examined attitudes about group discrimination as a result of genetic research (fig. 1). Demographic data and information about health status were obtained at the end of the survey. Data on race and ethnicity were collected through 2 questions in the demographic section of the survey. Participants were asked whether they would 'consider themselves as Hispanic or Latino'. Participants were also asked 'Which of the following racial categories fits you best?' and were given the choices of 'black or African American', 'white or Caucasian', 'Asian', 'American Indian or Alaskan native', 'pacific islander or Hawaiian native', or 'other'.

Data Analysis

Descriptive statistics were used to describe frequencies of responses to the individual items described above. Additionally, differences between black and white respondents were examined using a chi-squared statistic. Responses to the items about group discrimination were examined independently and were used to identify a subset of respondents who were especially concerned about prospects of group discrimination. That subset included 125 individuals who reported that: (1) they had previously thought about group discrimination, (2) they regarded the possibility of group discrimination as a result of genetic research as a 'very' or 'moderately' serious concern and (3) their willingness to participate in genetic research was reduced substantially by concerns about group discrimination.

Human Subjects Protections

The study was approved by the Institutional Review Boards of the National Human Genome Research Institute, University of Massachusetts at Boston, University of Utah, University of Arizona, Johns Hopkins University, Duke University, and UNC Chapel Hill. A written description of the study was given to all subjects during recruitment. Oral consent was obtained before each interview.

1. Previously thought about group discrimination
Some people worry that the research results could be used to discriminate against selected groups. Is this something you have thought about?
1. Yes
2. No

2. Seriousness attributed to concerns about group discrimination
How seriously do you take the concerns expressed by others about research information being used to discriminate against people by race or ethnicity?
1. Very seriously
2. Moderately seriously
3. Not very seriously
4. Not seriously at all

3. Reduced willingness due to concerns about group discrimination
By how much, if any, is your willingness to provide blood samples for research reduced by these concerns?
1. Big part
2. Moderate part
3. Small part
4. No part at all

Fig. 1. Primary outcome variables and related survey questions.

Results

Demographic Characteristics

Of the 1,393 patients approached for the study, 1,193 completed the survey (86% response rate). A majority of the respondents were female (70%) and over the age of 50 (59%) (table 1). Most had some college education (72%), with nearly half reporting a bachelor's degree or higher (45%), and sixty-one percent reported having a serious or chronic medical condition. Seventy-six percent of respondents (n = 903) identified themselves as white or Caucasian, 16% (n = 192) as African American or black, and less than 5% as either Asian, American Indian or Alaskan native, or pacific islander or Hawaiian native. Four percent described their racial group as 'other'. Additionally, 5% (n = 57) identified themselves as either 'Hispanic or Latino'.

Respondents who indicated that they would not be willing to allow a blood sample to be used in genetic research under any circumstances (n = 80) were not asked how concerns about potential group benefits or harms would affect their willingness to donate a biological sample for future genetic research. As a result, a total of 1,113 respondents were asked the survey questions reported in this paper (93% of all respondents). A chi-squared test confirmed that the sub-sample of 1,113 participants who answered the series of questions about discrimination was not statistically different from the demographics of the overall sample of 1,193 participants described in table 1. Additionally, we preformed a chi-squared analysis comparing the demographics of participants who responded to the questions about group harms and benefits (n = 1,113) and the individuals who

Table 1. Characteristics of survey respondents (n = 1,193)

Gender	
Male	30%
Female	70%
Age	
18–29	9%
30–39	13%
40–49	20%
50–64	36%
65+	23%
Education	
Less than high school	8%
High school	20%
Some college	28%
College graduate or beyond	44%
Race	
White/Caucasian	76%
Black/African American	16%
Asian American	2%
American Indian	2%
Other	4%
Religious affiliation	
Protestant	48%
Catholic	14%
Baptist	12%
Mormon	6%
Jewish	3%
Other	3%
None	9%
Household income previous year (USD)	
<20,000	18%
20,000–39,999	22%
40,000–59,999	18%
60,000–79,999	10%
≥80,000	23%
Not reported	9%
Have a serious or chronic medical condition	
Yes	61%
No	39%
Would not allow a sample to be used for future genetic research under any circumstances	<1%*

* This represents the 80 participants not in our sub-sample for the analysis reported in this paper, yielding a sample n = 1,113. A chi-squared test confirmed that there were no significant demographic differences between these two samples.

indicated that they would not donate biological materials for genetic research in any circumstance (n = 80). This analysis showed that self-reported racial affiliation was significantly different in these 2 groups, with African Americans accounting for 47% of the 80 'never donators' as opposed to just 16% of our overall sample ($p < 0.0001$).

Interest in Helping Others as a Factor in Patient Willingness to Participate in Genetic Research

Most respondents indicated that a personal interest in helping others was a large part of their overall interest in donating biological materials for genetic research (table 2). When asked whether their willingness to donate a blood sample for genetic research was influenced by an interest in helping their own family, 92% of respondents said that this consideration was a 'big' or 'moderate part' of their decision. Similarly, 97% of respondents indicated that an interest in helping people in general was a big or moderate part of their willingness to donate a blood sample. There were no statistically significant differences between white and black respondents regarding their respective levels of interest in helping their own families or people in general by participation in genetic research.

When respondents were asked whether helping researchers 'learn about diseases that might affect people of your race or ethnicity' would affect their willingness to donate a sample for genetic research, 61% of all respondents indicated that this consideration was a 'big' or 'moderate' part of their decision. With regard to this item, there were statistically significant differences between black and white respondents, with 83% of black and 56% of white respondents indicating that helping researchers learn about diseases that might affect people of the same race or ethnicity was a big or moderate part of their willingness to donate a sample for genetic research ($p < 0.0001$).

Concerns about Group Discrimination as a Result of Genetic Research

Thirty percent of respondents reported that they had previously thought about the possibility that results from genetic research might be used to discriminate against selected groups (table 3). This result was consistent across both white and black respondents. When asked how seriously respondents regarded this possibility of discrimination, 63% of black respondents and 57% of white respondents indicated that they were 'very' or 'moderately concerned' about genetic research being used to discriminate against people by race or ethnicity.

Respondents were asked to what extent concerns about research findings being used to discriminate against people by race or ethnicity would be a factor in their overall willingness to donate a blood sample for genetic research. Forty-one percent of all respondents stated that these concerns would be a 'big' or 'moderate factor' in reducing their willingness to donate biological materials for re-

Table 2. Patient interests in helping others as a big or moderate factor in willingness to donate biological materials for genetic research

	Total sample (n = 1,113)	Black (n = 155)	White (n = 870)	Difference between Black and White respondents (p value)
Own family	92%	94%	91%	0.428
Others of the same race or ethnicity	61%	83%	56%	<0.0001
People in general	97%	95%	97%	0.144

Table 3. Patient attitudes about group discrimination based on genetic research results

	Total sample (n = 1,113)	Black (n = 155)	White (n = 870)	Difference between Black and White respondents (p value)
Have previously thought about group discrimination based on research results	30%	30%	30%	0.998
Take concerns about potential discrimination very or moderately seriously	58%	63%	57%	0.149
Concerns about potential discrimination as a big or moderate factor in reduced willingness to donate biological materials for research	41%	64%	36%	<0.0001
Participants who had previously thought about group discrimination took concerns about potential discrimination seriously and had reduced willingness due to concerns about group discrimination	12%	21%	11%	<0.0001

search. Differences were observed between white and black respondents, with 64% of black and 34% of white respondents reporting that their willingness to donate a blood sample for genetic research would be reduced substantially due to concerns about genetic research findings being used to discriminate against people by race or ethnicity.

A subgroup of respondents who were especially concerned about prospects of group discrimination was defined using the criteria described above. This subgroup consisted of respondents who had previously thought about group discrimination, had higher levels of concern about group discrimination and were less willing to donate biological materials for genetic research due to concerns about group discrimination. Twelve percent of all respondents fell into this category (n = 125). Among these respondents with heightened concerns about group discrimination as a result of genetic research, we observed differences between white and black respondents, with 21% of black respondents and 11% of white respondents falling into this subgroup of individuals who were especially concerned about discrimination on the basis of race or ethnicity ($p < 0.0001$).

Discussion

Results from our study suggest that in deciding whether to participate in genetic research, patients often engage in benefit-to-risk assessments that include not only direct individual benefits and harms but broader benefits and harms to the social groups with which they identify. When asked about factors that influence their decision to donate samples for genetic research, a majority of patients considered how that research might benefit their families, members of their racial or ethnic communities and the general public. Similarly, our results suggest that in deciding to participate in genetic research, most patients consider how that research could potentially harm the larger social groups with which patients identify. The majority of the patients we surveyed reported that they took concerns about potential discrimination based on findings from genetic research seriously and that their willingness to donate biological samples for future genetic research would be decreased as a result of these concerns. Together, these findings suggest that potential group benefits and harms are important to patients who are considering participation in genetic research.

This broader approach to weighing the potential benefits and risks of research participation is out of step with regulatory guidelines in the U.S. Current guidelines for the protection of research subjects focus narrowly on the risks of the research process itself and its potential impact on individual participants rather than the potential impact of research on socially identifiable groups such as racial or ethnic communities [8, 11]. Current research regulations and policies encourage investigators, IRB members and others to exclude assessments of potential benefits and risks to others, particularly to the extent that such a broader focus may detract investigators and IRB members from serving as responsible advocates for individual research volunteers [11]. Similarly, in examining the informational needs of patient-subjects, ethicists and commentators on clinical research have tended to emphasize the disclosure of potential benefits and risks of research to individual subjects during the informed-consent process rather than on broader disclosures of the potential implications of a study for identifiable social groups and the communities in which a study takes place [30, 31].

Our findings that patients often assign a great deal of importance to group-level considerations – and make decisions about their personal participation in a research study based in part on an assessment of the risk-to-benefit ratio of that study for the racial or ethnic groups with which they identify – has important implications for how investigators frame their studies when recruiting subjects. Our data suggest that researchers should be prepared to discuss potential group-level harms and benefits with research subjects. It also may be helpful to incorporate a discussion of the impact of genetic research on identifiable social groups into informed-consent documents and other informational materials used to enroll subjects.

The potential implications of our data for IRBs are less clear. IRBs may not be well positioned to assess the long-term impact of genetic research on heterogeneous social groups. There may be circumstances in which IRBs can anticipate potential group harms and suggest ways of addressing those risks, for example where a local community is both clearly defined and directly affected by a research study, but routine evaluation of group-level considerations in all research studies would place a substantial burden on IRBs. Concerns also might be raised about the extent to which IRBs possess the appropriate expertise to engage in these group-level assessments of benefits and risks of research. IRBs should be sensitive to these matters but candid in acknowledging their limitations.

Our data have more significant implications for the design and governance of biobanks. The salience of group-level concerns for many patients suggests that biobank policies should address the potential impact of studies using stored biological materials on participant groups. Even though the potential impact on larger social groups may be unknown or difficult to assess for unspecified future research, the salience of these issues for some patients supports discussion of group-level considerations with potential donors. Given that many biological samples are collected and stored in biobanks for very long periods of time, many researchers using these samples will never have direct contact with the original sample donors. Nonetheless, investigators using these materials can have direct interactions with other individuals who share many of the same cultural and social values as the original donors. These discussions are not only an important step in building trust between participants and researchers but may have the potential to mitigate the negative effects of biobanking research on specific populations by increasing awareness among community members and enhancing public dialogue about the use of stored biological materials.

The development of 'group focused' informational materials will require researchers and biobanks to recognize that some populations are more concerned about group-level considerations than others. While our study found that a majority of patients consider the impact of genetic research on individuals and social groups outside of the immediate researcher-subject dyad, we observed differences between black and white participants with respect to beliefs about group harms and benefits. While considerations of potential benefits to their families and to the public in general were taken into account equally by black and white patients in deciding whether to donate a sample for genetic research, potential benefits to one's own racial or ethic group appeared to be a stronger factor in the decision-making of black patients. While these data show that both black and white patients were concerned about potential group discrimination based on genetic research results, the impact of these concerns on willingness to participate in research was greater among black patients. Sixty-four percent of black patients said that concerns about potential discrimination would be a significant factor in their willingness to donate a sample, compared to only 36% of white patients. There may be multiple explanations for these differences, but it is not surprising that members of historically disadvantaged racial or ethnic groups conceptualize the benefits and harms of research in broader terms and thus

take concerns about the potential impact of genetic research on their communities more seriously in deciding whether to participate in research. Additionally, it is important to note that while these data concerning the effects of potential group discrimination are significant, they reflect only the concerns of patients who would agree to donate biological materials for research in at least some circumstances. These data do not capture the concerns of African American patients who indicated that they would never provide biological materials for genetic research. Future studies might explore why some populations have higher levels of group centered concerns about research and seek to clarify the nature of these concerns in greater detail. Given the difficulty of assessing group-level concerns about research, these data will help researchers better prepare to engage communities in discussions about the broader social impact of their work.

This study has several limitations. First, because participants were asked to comment on their general attitudes about the hypothetical donation of a biological sample for research, these data do not assess actual willingness to enroll in particular genetic research studies. Our sample is not representative of the U.S. population, nor even all patients seeking health care at academic medical centers. Nevertheless, these data can shed light on the types of patient perspectives found at academic medical institutions engaged in genetic research or DNA biobanking. Secondly, because patients who would not allow a sample to be used in future genetic research under any circumstances were not included in this sample, our analysis may not reflect the attitudes and opinions of those patients who are most concerned about the impact of genetic studies on groups. Consequently, our data may underestimate the prevalence these group-level concerns among patients. Additionally, this study only assessed concerns about discrimination in relation to patients' self-reported racial or ethnic group and did not collect data on other kinds of social groups with which our respondents may have identified. Lastly, these data were collected before the passage of the Genetic Information Nondiscrimination Act (GINA) in the U.S. Patient attitudes regarding the donation of clinical samples for genetic research, and concerns about potential discrimination based on genetic research results, may be affected the passage of this legislation. However, the effectiveness of the protections established through GINA, and its overall impact on patient attitudes, is not yet known [32].

Conclusion

Efforts to minimize research-related harms have focused on the protection of individual research volunteers, which has made it difficult to achieve consensus on how best to address potential concerns about the long-term impact of research on identifiable social groups, especially historically disadvantaged racial and ethnic communities. Given the increase in population-based studies that assess genetic variation between groups, the broader impact of this work has become a significant issue for researchers, ethicists and policy makers [3, 33]. Our results demonstrate how, for many patients, the manner in which genetic research may affect others outside the immediate investigator-subject dyad is a key factor in personal decisions about research participation. Given the salience of these concerns for individual volunteers, these broader group-level implications of genetic research should be taken into consideration by those engaged in comparative genetic research or planning for the creation of DNA biobanks to facilitate such studies. Those involved in genetic research should be prepared to discuss the potential impact of their work on the socially identifiable groups from which study participants are recruited and, to the extent that specific harms can be anticipated, take steps to mitigate group harms.

Acknowledgements

The authors thank Jeff Botkin, Mark Brown, Mark Hughes, Debra Schwinn, Pamela Sankar, Jeremy Sugarman, Dragana Bolcic-Jankovic, and Brian R. Clarridge for their help in developing and recruiting patients for the Patient Attitudes about Genetics Research Survey, supported by intramural research funds from the National Human Genome Research Institute.

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