

Jane Bahnson. A Survey of the Attitudes of Public Library Patrons on Submitting a Personal DNA Sample for Genetic Research. A Master's Paper for the M.S. in L.S. degree. November, 2009. 58 pages. Advisor: Brad Hemminger.

Research into genetic patterns and disease association has led to new understanding of disease etiology and medical treatment breakthroughs. Genetic research utilizes databases that include personal genetic information. People both support and fear having personal genetic information included in a research database. To understand reasons for supporting or opposing donating genetic samples, a survey of 120 library patrons was conducted on their attitudes toward contributing DNA for medical research. The results show that the fear of insurers learning their DNA results outweighs any other concern. Fear of law enforcement and employers learning the results were also highly ranked. Helping oneself and the public were highly ranked motivators for contributing DNA. The results suggest fear about the loss of confidentiality and anonymity remain impediments to the creation of large genetic databases, and legal protections against discrimination may not be adequate. Nonetheless, there remains strong support for genetic research among the public.

Headings:

Genetic privacy
Genetic research
Health attitudes

A SURVEY OF THE ATTITUDES OF PUBLIC LIBRARY PATRONS ON
SUBMITTING A PERSONAL DNA SAMPLE FOR GENETIC RESEARCH

By

Jane P. Bahnson

A Master's paper submitted to the faculty of the School of Information and Library
Science of the University of North Carolina at Chapel Hill in partial fulfillment of the
requirements for the degree of Master of Science in Library Science.

Chapel Hill, North Carolina

November, 2009

Approved by:

Brad Hemminger

Table of Contents		Page
1.	Introduction	5
2.	Review of the literature	8
	A. The Ethics of DNA Testing	8
	B. Government Efforts to Protect Against Genetic Discrimination	12
	C. Studies on the Attitudes of Targeted Populations On DNA testing	15
	i. Attitudes Toward Genetic Testing Among Those with a Known Genetic Risk	15
	ii. Attitudes Toward Genetic Testing Among Foreign and Minority Populations	16
	iii. The Effect of Religious Beliefs on Attitudes toward Genetic Testing	19
	iv. Attitudes Toward Genetic Testing in the United States General Public	21
3.	Methodology	23
	A. The survey population	23
	B. The survey questions, format and administration	25
4.	Results	27
	A. Summary Tables	27

Table 1: Demographic Data, Past Participation in Medical Research, and Willingness to Donate a DNA Sample as a Percentage of Total Survey Respondents	28
Table 2: Total number of each ranking assigned by Chapel Hill library patrons to each negative and positive attribute	29
Table 3: Total number of each ranking assigned by Durham library patrons to each negative and positive attribute	31
Table 4: Willingness to Donate DNA Sample Based on Demographic Criteria (Chapel Hill)	31
Table 5: Willingness to Donate DNA Sample Based on Demographic Criteria (Durham)	32
Table 6: Individual Participant Comments	33
Table 7: Number of each factor ranked as 1 or 2 (the most important factors) by age group (Chapel Hill)	34
Table 8: Number of each factor ranked as 1 or 2 (the most important factors) by education (Chapel Hill)	34
Table 9: Number of each factor ranked as 1 or 2 (the most important factors) by age group (Durham)	35
Table 10: Number of each factor ranked as 1 or 2 (the most important factors) by education (Chapel Hill)	35
5. Statistical Analyses	36
Table 11: Average Rankings of Concerns and Motivations by Chapel Hill Library Patrons	37
Table 12: Average Rankings of Concerns and Motivations by Durham Library Patrons	37

Table 13: Correlation between education and willingness to contribute a DNA sample as a function of age in Chapel Hill patrons	38
Table 14: Correlation between education and willingness to contribute a DNA sample as a function of age in Durham patrons	38
Table 15: Correlation between interest in curing one's own disease and willingness to donate a DNA sample as a function of age in Chapel Hill patrons	38
Table 16: Correlation between interest in curing one's own disease and willingness to donate a DNA sample as a function of age in Durham Patrons	39
Table 17: Correlation between interest in testing for family planning and willingness to donate a DNA sample as a function of age in Chapel Hill patrons.	39
Table 18: Correlation between interest in testing for family planning and willingness to donate a DNA sample as a function of age in Durham patrons.	40
Table 19: Most significant negative factors for Chapel Hill library patrons who would be unwilling to donate a DNA sample	40
Table 20: Most significant negative factors for Durham library patrons who would be unwilling to donate a DNA sample	40
Table 21: Most significant positive factors for Chapel Hill library patrons who would be willing to donate a DNA sample	41
Table 22: Most significant positive factors for Durham library patrons who would be willing to donate a DNA sample	41

	Table 23: Logistic regression analysis of influence of demographic factors on willingness to donate a DNA sample among Chapel Hill patrons	41
	Table 24: Logistic regression analysis of influence of demographic factors on willingness to donate a DNA sample among Durham patrons	42
6.	Discussion	42
	A. Willingness to Participate in a Genetic Database	42
	i. Deterrents to Participation in a Genetic Database	44
	ii. Primary Motivators to Participation in a Genetic Database	45
	iii. Age and Education Sub-group Trends	46
	iv. Demographic Predictors of Willingness to Donate a DNA Sample	47
	B. Study Limitations	48
	i. Survey Design	48
	ii. Responding population	49
7.	Conclusions and Implications for Future Genetic Studies	50
8.	Appendix	51
9.	References	53

1. **Introduction**

“This is not just an academic exercise by a bunch of nerdy gene hunters. This is the engine that will transform medicine.” (Dr. Francis Collins, leader of the successful effort to map the entire human genome and the current Director of the National Institutes of Health.)

The discovery of a connection between genetic patterns and disease has led to a new understanding of disease etiology, and the list of diseases identified as having a genetic factor is growing rapidly. Genetic research has shown not only patterns of disease susceptibility, it has facilitated the development of more effective, targeted medical treatments and offered tremendous hope for people suffering from diseases once considered untreatable. New fields of study, including pharmacogenetics, have arisen from the rapid expansion of genetic databases worldwide. Currently, the countries of Iceland, the United Kingdom, Canada, Singapore, Estonia, and others are working on developing national genetic databases in the hope that this information will lead to improved, and ultimately cost-efficient, health care. Commercial interests are increasingly involved as gene-targeted drug discoveries enter clinical trials. The potential public health benefits are enormous.

In the United States, there is intense interest in genetic research. Ongoing private projects are seeking participants to expand their database of genetic and associated phenotypic information. The U.S. Surgeon General initiated a campaign in 2004 to encourage families to track and record their family health histories in order to look for inherited disease risks. Thanksgiving is now “National Family History Day,”

and families are encouraged to take this day “to talk about, and to write down, the health problems that seem to run in their family” (Surgeon General’s Family Health Initiative, 2009). Private companies offer personal DNA analyses. For a cost of about \$400, an individual can send in a simple saliva sample on a cotton swab and receive a profile identifying those diseases he or she is at risk for developing, based on currently known genetic pattern associations gleaned from a genetic database, along with lifestyle and sometimes medical treatment advice.

The information collected by families and most private companies, however, is usually not available for scientific research and is kept confidential; thus, it is of no help in tracking disease patterns or identifying gene-disease links in the general population. In order to maximize the utilization of genetic information to benefit public health, information regarding the frequency of genetic susceptibility occurrences, disease associations, and environmental influences from as large a sample of the population as possible is essential.

Not everyone has been willing to participate in a genetic research database. In the past, DNA information has been misused by employers and insurers to discriminate against those individuals who are likely to develop certain diseases. One research group is directly addressing the risks an individual incurs in publicizing their genetic traits. Ten researchers conducting the Personal Genome Project have already agreed to have their own DNA profiles as well as personal health information available for access by anyone, and one researcher’s results so far have already been posted. These researchers hope to recruit over 100,000 members of the public to do the same. This study should illuminate not only future phenotypic/genotypic links, but

also the impact on the individuals who have made their genetic information public (Personal Genome Project, 2009).

Governmental bodies in the United States have taken legislative steps to alleviate the concerns of those who fear the consequences of publicizing their genetic information. At the federal level, the recently enacted, and as yet untested, Genetic Information Nondiscrimination Act (GINA) forbids discrimination by employers and certain insurers based on genetic information. However, many members of the public remain reluctant to contribute their DNA samples to a medical research database for a variety of practical and personal reasons. Some consider genetic information more sensitive and deserving of greater protection than other types of medical information. This principle has its own term: genetic exceptionalism (Green, 2003).

The purpose of this research is to add to the body of knowledge regarding the most significant reasons why members of the public both support and remain reluctant to contribute their own DNA samples to a national genetic database. A survey was presented to local library patrons in a manner unconnected with the participants' medical caregiver or a medical institution. This survey did not target those whose health or whose families' health has already been affected by a genetic disease. Participants were asked to assign a rank order to those common concerns and motivations regarding genetic testing that were identified by other research subjects in prior studies that are also of importance to them. The results reported here may ultimately help those working on building genetic databases to target those concerns that are the most important deterrents to participation to the greatest number of people,

or to capitalize on the most important motivations, with the overall goal of increasing participation in a national genetic database in order to promote public health.

2. Review of the Literature

Much has been written by the medical and legal communities on the ethics of genetic testing and on legislative efforts to protect study participants. These scholarly analyses help illuminate those aspects of genetic testing that worry the general public. Research surveys already conducted on the attitudes of different groups toward DNA testing also reveal broad-based concerns that sometimes differ among demographic groups, and these studies identify common concerns and motivations included in the current survey.

A. The Ethics of DNA Testing

Several authors voice strong concern that the science of genetic testing is on a trajectory that is already too far ahead of the laws necessary to protect individuals from loss of privacy and exploitation. In an article discussing the legal and social implications of genetic research, Tyshenko, et al. tracked the development of the science and clinical applications of genetic research. These researchers observed that databases of genetic information have become increasingly large, public and interlinked. As genetic research is rapidly progressing into therapeutic development, with the potential for pre-symptomatic disease treatment and gene therapy, care must be taken to address the social, moral, and legal issues surrounding the use of genetic information. Specifically, scientists must recognize the right of individuals to protect their information, including the freedom not to know of their disease risks, and society

must protect individuals from discrimination based on genetic disease risks if this technology is to accomplish its potential (Tyshenko, 2005). Similarly, Austin et al. conducted an electronic search and literature review of publications involving genetic database research and characterized five categories of ethical, legal, and social issues unique to the development of genetic databanks: database sponsorship, the function and powers of ethics committees, public input, consent, and protection of the data. These authors found existing policies governing databanks to be nonspecific and generally unenforceable. The authors conclude that developing comprehensive and widely applicable guidelines governing the creation of genetic databanks would be beneficial, with special attention paid to privacy protection and consent, and that an international advisory group should ultimately monitor the development of gene banks (Austin, 2007).

Concern has also been raised over the impact on groups characterized by certain genetic traits or predispositions. Eltis, et al. argue that the broader social consequences of potential genetic discrimination have been insufficiently addressed, and that emphasis has been placed too narrowly on the rights of the individual and not enough on the potential effects of discrimination on entire groups. There are human rights implications that extend beyond insurance and employment discrimination. For example, certain entire groups have been stigmatized as less intelligent, more violent, or prone to develop cancer based on genetic analyses. Biobanking may inadvertently negatively impact ethnic or other vulnerable groups, and these potential consequences must be considered by lawmakers as the field of genetic research expands (Eltis, 2007). Joan McGregor, the director of the Bioethics, Policy and Law Program at the

University of Arizona, raises a similar concern. She points out in her essay that biological differences among ethnic groups has been used in the past as an excuse for discrimination and stigmatization. It is unclear whether standards for the protection of individuals who participate in research are applicable and sufficient to protect entire groups of people who participate in genetic research. The moral aspects of genetic determinism, that is, the belief that genes determine physical and behavioral traits, must also be considered. McGregor recommends treating research populations more as collaborators who have a say in what is done with their genetic information than as research subjects (McGregor, 2007)

Some authors feel the use of genetic testing may already be causing more potential harm than good. Author Nancy King criticizes the “medicalization” of non-disease states, and argues that the potential for discrimination and stigmatization based on genetic testing makes it an improper basis for making clinical recommendations and public policy. A large gap still exists between most genetic disease predisposition identifications and effective prophylaxis, and there is great potential harm if a risk is misinterpreted as a foregone conclusion. King further argues that the public already understands the importance of diet, exercise, and limiting environmental risks in avoiding disease, and that adding genetic risk analysis contributes little to individual health (King, 2007).

Of course, King’s points could apply to the early stages of most scientific research, and one could argue that King unfairly ignores the advances already made in pharmacogenetics and other gene-specific therapies. Yet, a discussion of how genetic information is to be used to benefit individuals should be the subject of debate and

careful decision. Family members can be seriously affected by implications to their own health (and insurability) as the result of learning one member's genetic analysis (Suter, 1993). Cullen, et al. point out that society must also address who should receive gene therapy if resources are limited, a prescient observation in light of the current healthcare reform debate. Stereotyping of groups based on genetic information, the rationale for genetic testing for diseases that have no cure, the difficulty of interpreting genetic tests, and the possible misuse of genetic information are among many issues that must be addressed (Cullen, 2006).

The issue of who really benefits from genetic testing was raised by Merz, et al., who looked at the ethical issues surrounding the development of a national genetic database in Iceland, which has an "opt out" policy for inclusion in the national genetic database. The authors conclude that Iceland's approach may serve the interests of the pharmaceutical industry more than the general public, and they feel that informed consent should be obtained before inclusion of an individual's genetic data in any database. The authors point out many concerns with the Icelandic system, including the fact that individuals will be identified because genetic data is inherently identifiable, that children are included who lack capacity to opt out, and that families cannot prohibit the collection of genetic information from their dead relatives (Merz, 2004).

The "inherently identifiable" aspect of genetic information is a factor not addressed with potential subjects by many researchers, but as technology advances and information databases become interlinked, it is an aspect that cannot be ignored. With the proper analytical research tools, efforts to disassociate a donor from his or

her DNA may become largely pointless, as individual identities can be determined from the DNA sample itself. Even complicated encryption tools can be circumvented with the proper research techniques. Recognizing this arguable inevitability, Lunshof, et al. have proposed an “open consent” model of informed consent for genetic research participants. Lunshof points out that most participants’ confidentiality expectations when it comes to medical research are already unrealistic. In the authors’ own project, the Personal Genome Project, researchers advise participants that, among other things, they cannot guarantee anonymity, privacy, or confidentiality, there may be harm to themselves or relatives as a result of participation, and it may not be possible to completely remove data once it has become part of the public domain (Lunshof, 2008).

If one accepts the arguments of Lunshof, et al., that efforts toward protecting privacy and confidentiality of genetic information will ultimately fail, the solution arguable lies in governmental policies that prohibit the use of genetic information in a manner that could harm participants in genetic research. To date, however, no other large-scale researchers or governmental bodies advocate total abandonment of attempts to keep genetic information confidential, and it is doubtful that total abandonment of confidentiality protocols will ever be widely accepted by the public.

B. Government Efforts to Protect Against Genetic Discrimination

Legislators at the state and federal level have scrambled to respond to the concerns of the public in protecting their genetic privacy, although efforts to protect the public against the misuse of genetic information actually predate the sequencing of the human genome. Protections also vary widely between countries (Hsieh, 2003-

2004). In the United States, the Health Insurance Portability and Accountability Act of 1996 (HIPAA)¹ lists genetic information as “protected health information” and forbids the use of genetic information that indicates a potential disease risk as a “preexisting condition” in determining eligibility for health insurance. However, HIPAA did not prohibit raising group insurance rates based on genetic information from its members or forbid its use in underwriting for those seeking insurance on the individual market. Later amendments protected the access to and disclosure of genetic information as private health information. Similarly, the Americans with Disabilities Act² may provide some protections against the discriminatory use of genetic information by employers, although the extent of the protections available under this act remain unclear and largely untested (Hudson, 2007).

States have placed a patchwork of protections against health insurer discrimination based on genetic testing, although none of these laws apply to employee-sponsored health plans, the primary way most Americans obtain health insurance, as these policies are exclusively governed by ERISA³ (Abiola, 2008). Those state protections that are in place vary widely from state to state. Some states only protect specific genetic conditions, for example, Alabama’s statute only addresses sickle cell anemia and cancer predisposition, and only about half of the states prohibit an insurer from requiring genetic testing (National Conference of State Legislatures, 2008). Roughly half of the states have no protections against the dissemination of genetic information without informed consent. Very few states

¹ HIPAA, Pub L 104-191, enacted August 21, 1996.

² ADA, 42 USC §§ 1201 et seq.

³ ERISA, Pub L 93-406, 88 Stat 829, enacted September 2, 1974.

prohibit genetic discrimination in life, disability, or long-term care insurance, although some require actuarial justification for use in life insurance policy discrimination.

In May, 2008, the Genetic Information Nondiscrimination Act (GINA)⁴ was signed into law to protect individuals from discrimination by employers and some insurers based on genetic predisposition to disease. GINA amends the Employee Retirement Security Act, the Public Health Service Act, the Internal Revenue Code and the Social Security Act to prohibit the use of genetic information to deny health insurance, adjust health insurance premiums or as the basis for personnel decisions. GINA was debated in Congress for over a decade before it was passed and signed into law, as it was delayed by many legislators who argued that incidents of documented genetic discrimination are low and the legislation therefore unnecessary. As it stands, GINA does not prohibit genetic discrimination in life insurance, disability insurance, or long-term care insurance (Abiola, 2008).

Enforcement of GINA's provisions lies with the Secretaries of Health and Human Services, Labor, and the Treasury, and enforcement is in the form of a fine that can be levied against any offending insurer or employer. This fine may be waived or reduced if the insurer or employer shows diligent efforts to avoid misuse of genetic information. GINA provides no enforcement rights by individuals even if they can show disparate impact on the basis of genetic information, and there is no specific provision establishing a private cause of action by affected individuals even if intentional genetic discrimination is shown (Abiola, 2008). The full provisions of GINA are scheduled to take effect by November 21, 2009 (Baruch, 2008) Whether

⁴ The Genetic Information Nondiscrimination Act of 2008, Pub. L. 110-233, 122 Stat 881, enacted May 21, 2008.

this legislation is sufficient to calm the fears of those Americans reluctant to undergo genetic testing or whether the remedies within GINA are sufficient to prevent the misuse of genetic information remain to be seen.

C. Studies on the Attitudes of Targeted Populations on DNA Testing

It is unclear whether the public is even aware of the legislative protections in place that govern the use of genetic information. Regardless, some concerns about genetic research are fundamental and personal, and they fall outside the protections current law provides. Concerns also vary between different populations.

i. Attitudes Toward Genetic Testing Among Those with a Known Genetic Risk

One might assume that those with a known or suspected risk of a genetic illness would be the most supportive of genetic database development and research, but studies of the attitudes of such individuals reveal a somewhat confusing and inconsistent picture. Balama, et al. looked at motivations and concerns regarding genetic testing among those already identified as being at risk for different hereditary cancer syndromes. The results showed that many individuals at risk for certain hereditary cancers viewed genetic testing as part of their medical management and the results of genetic testing to be important information for their children. The authors were surprised to find little concern by participants over their ability to cope with test results. However, those who were unaffected by disease and those who were at high risk of developing cancer were more concerned about possible discrimination from genetic testing results than those who were already diagnosed with cancer and those who were statistically at low risk of developing cancer (Balama, 2004).

In another study of the attitudes of those with a genetic disease history and those without a known history toward genetic testing, Cutler, et al. compared the attitudes toward genetic testing of 108 middle-aged children of parents with Alzheimer's disease with the attitudes of 140 middle-aged children whose parents had no such history. The authors asked participants whether they would be tested if the genetic test were 100 percent accurate, and their reasons for or against being tested. The survey found no statistically significant difference between the two groups as to whether they would submit to genetic testing, with 64.5 percent indicating they would be likely to take it. Of those who would submit to testing, getting the best treatment and planning for the future were listed as the most important reasons. Of those who would not submit to testing, the lack of treatment options and fear of discrimination by insurers and employers were listed as the most important reasons, although the lack of treatment options was a much more significant deterrent for those with affected parents (Cutler, 2003).

ii. Attitude Toward Genetic Testing Among Foreign and Minority Populations

Studies have been performed in many countries to gain insight into attitudes toward genetic testing. Wong, et al. studied public attitudes in Singapore toward donating blood for DNA analysis. The researchers conducted focus groups and questioned participants on their attitudes and concerns about DNA testing. Of those responding, about half were willing to give blood samples for genetic research. Those willing to give samples generally expressed belief in a benefit to the general public, lack of concern about needles or the loss of confidentiality, and a positive attitude toward government-led studies. Those unwilling to give samples generally cited fear

of pain, lack of any personal benefit, fear of discovering they had a disease, and fear of discrimination as the most common reasons. The authors concluded their population had a lower rate of willingness to donate than the general public in the United States or Europe (Wong, 2004).

In a study by Matsui, et al., researchers looked at the factors affecting the participation rate in genetic studies by members of the general public in several rural areas in Japan. The authors found that providing extensive information about genetic research actually decreased the participation rate among the general public, but reduced the number who withdrew from studies once they had enrolled. They also noted “intrinsically strong negative attitudes” toward genetic research, and warned that failing to protect personal genetic profiles and privacy could result in strong opposition to genetic research (Matsui, 2005). Another survey and analysis by Goddard et al summarizes the reported concerns of the public in developing large-scale genetic databases in the United Kingdom, Iceland, Estonia and Quebec. Concerns across all groups include the need for confidentiality, worry about the way employers or insurers may use genetic information, concerns for privacy, and the desire to know why samples are collected and how they will be used. The public was more willing to participate if they could access research results (Goddard, 2004).

In a study targeting minority populations within the United States, Singer et al. conducted a telephone survey to gain insight into the reasons why genetic testing is not as widely used by African-Americans and Latinos as it is by non-Hispanic whites. The authors found that Latinos and African-Americans were more likely to be of the opinion that genetic testing would do more harm than good, and of these participants

who expressed this view, most cited religious or ethical beliefs as the primary reason. All three groups expressed strong privacy concerns. The authors concluded that the lower utilization of genetic testing by minority groups stemmed from fewer resources, less access to information, and greater concern for possible negative consequences of such tests (Singer, 2004).

Similarly, Laskey et al. surveyed undergraduate premedical majors participating in a summer science minority and disadvantage student enrichment program on their attitudes toward genetic testing before and after taking the program. Sixty-six participants answered the initial survey, and 87 answered the post-course survey. The majority supported genetic testing for preventive care and presymptomatic detection of disease. However, the study also found that students were more concerned about privacy and about genetic testing leading to eugenics and discrimination after they received a week of genetics lectures than before. The authors theorize this may be due to the students' greater understanding of the issues surrounding genetic testing after the lectures. There was a greater negative response toward genetic testing among African American students than among other minorities (Laskey, 2003).

News reports have also turned up some unanticipated objections to genetic testing among native indigenous populations. In Alaska, National Geographic researchers hit a road block in their efforts to collect DNA from some Native Alaskan tribal members as part of a project to track ancient human migration patterns. Some tribal leaders fear that DNA evidence may clash with long-held beliefs as to tribal origins that are vital to preserving their culture. On a more practical level, they fear that land rights, and even their right to health care under through the Indian Health

Service may be jeopardized. One tribal representative expressed concern that if the results show their people descended from another country it may undermine their moral basis for sovereignty and jeopardize their legal claims. “It’s a benefit to science, probably, but I’m not sure it’s a benefit to the tribes” (Harmon, 2006).

A biotechnology company ran into a similar snag in Tonga in their efforts to establish a database of genetic information on Tonga’s population, in part because the extended family of participants had not been included in the consent procedure. As one official noted, “what we are talking about is not only the genetic information from that one individual but the genetic material from that extended family” (Canberra, 2002). Similarly, in Canada, members of an indigenous tribe who had donated blood for research into genetic causes of rheumatoid arthritis became angered and raised privacy concerns when researchers used the samples for other research, including a study of the spread of a disease contracted through intravenous drug use, arguing that it could lead to negative stigmatization of the tribe as a whole (Dalton, 2002).

iii The Effect of Religious Beliefs on Attitudes toward Genetic Testing

Most Americans claim to have religious or spiritual beliefs, and for many, these beliefs influence their attitudes toward genetic research (Bartlett, 2009). Disapproval of genetic testing may arise from concerns about “tampering with nature” (Goddard, 2004), from doubts about the theory of evolution and the heritability of traits, or from opposition to abortion. In a study of North Carolina residents by Henderson, et al., researchers found that being “non-religious” was one factor significantly associated with a “very positive” feeling toward the benefits of genetic testing. Although the number of study subjects in this “non religious” group was

admittedly small, researchers concluded that more attention to the role of religion in forming attitudes toward genetic testing is needed (Henderson, 2008).

Religious opposition to certain uses of genetic test results does not always translate to objection to conducting genetic tests. In an in-depth study on the potential conflicts between religion and genetic testing, Bartlett, et al. conducted a focus-group study on health care workers and religious clergy to explore issues surrounding religion and genetics and how they typically arise. The study results showed little conflict between religious teachings and the ethics of genetic testing per-se, but conflict frequently arose when it came to interpreting or making decisions regarding genetic test results (Bartlett, 2009). Those groups voicing the most strong opposition to genetic testing were concerned that prenatal genetic testing would lead to abortion (Bartlett, 2009). Some participants did make “a direct leap from discussions of genetic testing to genetic manipulation” and found this and other practices to be “immoral” and “points of conflict between science and faith” (Bartlett, 2009). In the Canadian study referenced above, researchers reported objections by a conference of churches to “the conversion of God-created life forms, their molecules or parts into corporate property through patent monopolies,” (Canberra, 2002), although these participants did not specifically object to genetic testing itself.

Not all religious groups are hostile toward genetic testing and some even see it as a means for achieving religious goals. In an article analyzing the teachings of Christianity and their application to the pursuit of genetic testing, author David Smith argues that “vigorous genetic research” and its use to improve health and treat disease are supported by Christian beliefs, and that Christians have a duty to seek care for

those suffering from genetic disorders (Smith, 2009). Perhaps the most public and rigorous advocate of genetic research to profess strong religious beliefs is Dr. Francis Collins, the current director of the National Institutes of Health and the former director of the human genome project. Some scientists nonetheless responded with misgivings to his appointment due to fear these beliefs may impede certain areas of research (Harris, 2009).

iv. Attitudes Toward Genetic Testing In the United States General Public

Surveys of attitudes among the general public in the United States toward genetic testing have also been conducted and have reached varying conclusions about public support for DNA research. Researchers from the National Center for Health Statistics surveyed participants in an ongoing health and nutritional status (NHANES) study about their willingness to participate in genetic research. Roughly 60 percent of the participants agreed to submit samples in 1999, and that number increased to about 68 percent in 2000. The lowest consent rate was for non-Hispanic black participants, and females were significantly less likely to participate than males. The youngest and lowest age groups had the lowest consent rates. The authors concluded there is broad-based general acceptance of genetic research across all demographic groups, and that population-based genetic studies can achieve high consent rates if they employ appropriate methods and outreach efforts (McQuillan, 2003).

Kaufman et al. conducted a nationwide online survey of 4569 Americans regarding their willingness to participate in a proposed genetic study and found similar support for genetic research. Eighty percent of those surveyed supported the proposed study, and 60 percent of those stated they would be willing to participate. Those

factors that most directly increased willingness to participate were monetary compensation and return of individual genetic testing results. The study did not look specifically at reasons why people did not want to participate (Kaufman, 2008). Sanner, et al. approached hospitalized cardiac patients with a request that they participate in a genetic study. Approximately 50 percent agreed, and those who refused cited confidentiality, fear of blood drawing, and stress as their main reasons for refusing. The authors also noted that minorities and older adults had a lower rate of participation than others (Sanner, 2007). Kaufman, et al. conducted an online survey of Veterans Affairs patients to assess the attitudes of veterans toward building a genetic database, including their willingness to participate. Results showed that 83 percent approved of the creation of the database, and 71 percent expressed willingness to participate. Researchers found that veterans who were registered organ donors and blood donors were more likely to participate, but many expressed a desire to retain control over what was done with their DNA samples. The researchers conclude that appealing to altruistic tendencies may be important in recruiting participants (Kaufman, 2008).

Whether further consent must be obtained for genetic testing of leftover biological samples originally collected for another purpose is an ongoing debate. In the Canadian study discussed above, in which researchers utilized available specimens to test for another condition related to drug use, they were surprised by the resulting harsh criticism and admitted that getting further consent to perform additional research on specimens they already had “didn’t cross anyone’s mind” (Dalton, 2002). Conversely, in another study regarding donors’ attitudes on the use of their leftover

specimens for genetic testing that had been previously collected for other purposes, Pulley et al. found that over 90 percent felt that leftover blood and tissue samples should be available for anonymous medical research. However, a small group strongly opposed such use based on privacy concerns and discomfort with the proposed DNA database project itself. The authors concluded that the general beliefs of the public regarding DNA testing still require further exploration and study (Pulley, 2008).

Based on these studies, insurance and employment bias, fear of discrimination, fear of blood drawing, and fear of what might be done with genetic samples all appear to be significant concerns to some groups. Conversely, an overall positive feeling among the public toward genetic research and optimism that results could help participants or the public cure disease has also been demonstrated. Those having altruistic motivations have also been shown to be the most likely participants in a general DNA database. These concerns and motivations were incorporated into the current survey.

3. Methodology

A. The Survey Population

The populations selected for this survey were chosen for their accessibility and because they were not affiliated with a known medical institution or university, so that underlying loyalty to a facility would not influence their opinions. By selecting a public library as the study venue, as opposed to a medical or university setting, it was hoped that participants would more closely demographically represent the general communities of which they are members. The initial study targeted patrons of the Durham Public Library located in Durham, North Carolina. According to the 2000

National Census, the most recent published population data, the population of the County of Durham at that time was over 223,000, with the average age was approximately 30 years. The median per capita income in 2000 was \$22,526. Approximately 18.3% of the population over age 25 had a graduate or professional degree. The population was approximately 39 percent Black or African American, 50 percent White, 7 percent Hispanic or Latino, and 3 percent Asian. (Durham, North Carolina Population Profile, based on 2000 Census Data, <http://www.durhamnc.gov/departments/planning/pdf/demographics.pdf> , accessed 7/27/09.) The current (2009) average home price in Durham is \$155,100 (Zillow.com, accessed 9/25/09, http://www.zillow.com/local-info/NC-Chapel-Hill-home-value/r_17386/)

The study population was subsequently expanded to include patrons of the Chapel Hill Public Library in order to increase the number of responses. According to demographic data from the 2000 National Census, the latest available published data, the population of Chapel Hill at that time was approximately 49,000, with the average age approximately 32 years. The median per capita income in 2000 was \$24,133. This low per-capita income average undoubtedly reflects a substantial percentage of graduate and other advanced-degree students, who make up a large proportion of the population. Chapel Hill is the home of the University of North Carolina at Chapel Hill, a large public university that offers advanced degrees in many fields and supports many professional schools. In 2000, approximately 40.5% of the population over age 25 had a graduate or professional degree. The population was approximately 11 percent Black or African American, 78 percent White, 7 percent Asian, and 3 percent

Hispanic or Latino. (Chapel Hill Demographics, citing 2000 Census data, <http://chapelhill.northcarolina.com/demographics.html> , accessed 7/29/09). The current (2009) average home price in Chapel Hill is \$332,800. (Zillow.com, accessed 9/25/09, http://www.zillow.com/local-info/NC-Chapel-Hill-home-value/r_17386/).

Those responding to the survey were typically older and better educated than a representative cross-section of either the Durham or Chapel Hill population would have produced. (Table 1)

B. The Survey Questions, Format and Administration

Survey questions were developed based on concerns identified by the published research studies described in the foregoing section, as well on concerns obtained from informal polling conducted in the months preceding the study. Effort was made to abbreviate the length of the survey and keep it to one page in order to decrease the burden of responding and increase the number of participants. Questions of racial or ethnic background, religion, and income were omitted, in order to avoid questions that may be sensitive and thus deter some patrons from participating. A trial of the web-based survey performed before the formal survey was launched showed an average completion time of 2 minutes and 12 seconds for answering the survey questions. An incentive in the form of a chance to win a \$25 VISA gift card was offered for participation.

The directors of the Durham County Library and the Chapel Hill Public Library were contacted and permission was obtained to conduct the survey in the manner described below. This study was approved by the University of North Carolina Chapel Hill Office of Human Research Ethics- Institutional Review Board as one that

constitutes no more than minimal risks to subjects. General information, including the purpose of the study and an explanation of participants' rights, was given in an introductory letter. Participants were required to acknowledge their understanding of the survey and consent before proceeding with the survey. (Appendix A, Figure 1).

The Durham County Library survey was conducted in web-based form using Qualtrics web survey software. The survey initially required completing basic demographic information regarding age, education, gender, and past participation in studies, then placing in the order of numerical importance those factors both encouraging and discouraging DNA testing that were of significance to the participant. Open text fields were included to allow participants to provide any other reasons or information regarding DNA testing significant to the participant. See Appendix A, Figures 2, 3.

The shortened URL for the survey was advertised on small red cards stacked at the Durham Public Library reference desk and on red flyers posted at the entrance to the library with pull-off tabs. On the cards, patrons were invited to log on and take a quick survey on DNA testing. The option of entering into a drawing for a \$25 VISA gift card was offered after completion of the survey. Contact information was collected through a link to a second questionnaire. Contact information was optional and recorded independently of the survey responses. The survey remained active for approximately two months.

In order to increase the number of responses, the survey was subsequently printed out in paper form for the Chapel Hill library. Paper flyers were prepared advertising the study, and on two successive weekends, a table was set in front of the

library foyer with stacks of flyers and letters explaining the purpose of the study and its sponsorship, identical to the first page of the online study (See figure 1, above). Participants were offered clipboards with the survey attached and provided pencils for responding. For those wishing to participate in the drawing for the \$25 gift card, contact information was collected separately on index cards which were placed in a box with a slot cut in the top.

After completion of the online and paper surveys, all participants who provided contact information were assigned a number, and a computerized random number selector was used to select the winner. The winner was contacted through an email address provided, and the gift card was mailed to the provided address. After the card was awarded, all participant contact information was destroyed.

4. Results

A. Summary Tables

The web-based survey posted at the Durham County Public Library drew a total of 39 responses from library patrons during the two months the link remained active. Eighty-one Chapel Hill Public Library patrons responded to the paper survey during the two afternoons the survey was offered. The large table holding paper flyers, which was located at the entrance to the Chapel Hill library and visible to everyone entering the library, attracted significant attention and was undoubtedly more effective in stimulating participation than the small cards placed at the reference desk of the Durham County library. A summary of the demographics of those responding is set forth in table 1, below.

	Durham Public Library (total n=39)	Chapel Hill Public Library (total n=81)
Participated in medical research before?		
Yes	45% (18)	43% (35)
No	55% (21)	57% (46)
Willing to Give a DNA Sample?		
Yes	51% (20)	32% (26)
No	26% (10)	32% (26)
Depends	23% (9)	36% (29)
Gender		
Male	31% (12)	28% (23)
Female	69% (27)	72% (58)
Age		
65+	3% (1)	10% (8)
40-65	59% (23)	48% (39)
25-40	18% (7)	30% (24)
<25	20% (8)	12% (10)
Education (not all responded)		
Some high school	13% (4)	0
High school graduate	13% (4)	5% (4)
Some college	48% (15)	14% (11)
College graduate	26% (8)	29% (23)
Post-graduate	0	52% (42)

Table 1 : Demographic Data, Past Participation in Medical Research, and Willingness to Donate a DNA Sample as a Percentage of Total Survey Respondents.

Table 2 shows the total combined number of each rank assigned by patrons in Chapel Hill to each attribute.

Chapel Hill

<i>Negative Attributes</i>	1	2	3	4	5	Blank (no rank assigned)
Fear re employer	3	15	10	6	3	44
Fear re insurance	43	10	4	1	1	23
Hurts	9	4	2	9	12	45
Family discovers	0	1	8	10	13	49
Law enforcement	5	18	14	4	2	38
<i>Positive Attributes</i>						
Cure myself	25	20	17	12	3	4
Cure public	24	29	14	7	4	3
Help Kids	21	15	19	7	6	13
Curious	5	7	17	27	12	13
Family planning	5	6	8	11	29	22

Table 2: Total number of each ranking assigned by Chapel Hill library patrons to each negative and positive attribute. 1= most important, 5= least important, blank = unimportant.

Table 3 shows the total combined number of each rank assigned by patrons in Durham to each attribute.

Durham

<i>Negative Attributes</i>	1	2	3	4	5	Blank (no rank assigned)
Fear re employer	4	10	4	6	1	14
Fear re insurance	13	8	4	1	1	12
Hurts	5	2	4	5	5	18
Family discovers	1	3	4	9	7	15
Law enforcement	2	2	9	3	7	16
<i>Positive Attributes</i>						
Cure myself	12	12	3	5	2	5
Cure public	12	7	12	3	2	3
Help Kids	8	7	12	3	3	6
Curious	5	3	5	15	4	7
Family planning	3	5	3	3	15	10

Table 3: Total number of each ranking assigned by Durham library patrons to each negative and positive attribute. 1= most important, 5= least important, blank = unimportant.

Table 4 shows the percentages Chapel Hill library patrons, organized by demographic information, who indicate a willingness to contribute a DNA sample.

Patron Demographics	Number	Percent of total Within sub-grouping
Age		
65+	3	37%
40-65	11	28%
25-40	8	33%
<25	4	40%
Education		
Some HS	0	0
HS graduate	1	25%
Some College	4	36%
College graduate	6	26%
Post-college education	14	33%
Gender		
Male	7	30%
Female	19	33%
Past participation in Medical research study		
Yes	13/35	37%
No	13/46	28%

Table 4: Willingness to Donate DNA Sample Based on Demographic Criteria (Chapel Hill)

Table 5 shows the percentages Durham library patrons, divided by demographic information, who indicate a willingness to contribute a DNA sample.

Patron Demographics	Number	Percent of total within sub-grouping
Age		
65+	1	100%
40-65	12	52%
25-40	5	71%
<25	2	25%
Education		
Some HS	2	50%
HS graduate	1	25%
Some College	8	53%
College graduate	5	62%
Post-college education	0	0
Gender		
Male	8	67%
Female	12	44%
Past participation in Medical research study		
Yes	10/17	59%
No	9/21	43%

Table 5: Willingness to Donate DNA Sample Based on Demographic Criteria (Durham)

Patrons were offered an open field to offer any concerns or motivations regarding submitting a DNA sample they deemed important that were not included in the survey. Table 6 displays those individual comments.

Survey Population	Comments
Chapel Hill	
	Would want to agree to the ultimate use of the sample
	Now knowing who will use it and for what purposes and what security protocols; For immediate personal medical treatment that required such a test or sample.
	Kept on file somewhere
	Not sure what would be done with it
	Don't know enough about it
	Invasion of privacy
	Not worried at all
	Afraid that if a needle was used, I might get sick or get a disease if it was done improperly
	But over reliance on genetic "answers" to diseases diverts research from other causes (environmental, etc.) Genetics are important but not the sole cause of disease.
Durham	
	Results of illness in my family
	Cost
	Discouraged by family members
	It depends on what kind of research I am supporting
	Prospective mates would get information
	I would not want to know that somebody else has my DNA and use(d) it for other reasons than they have given me.

Table 6: Individual Participant Comments

Tables 7, 8, 9 and 10 show the most important factors within each demographic group, as indicated by a ranking of 1 or 2.

Age group	Employer Discovers	Insurer discovers	hurts	Family discovers	Law enforcement	Help self	Help public	Help kids	curious	Family Planning
65+ (8)	2	3	0	0	1	5	7	2	1	0
40-65 (39)	8	24	4	1	9	22	23	16	8	6
25-40 (24)	7	18	7	0	8	12	16	14	2	3
<25 (10)	1	8	2	0	5	6	7	4	1	2
Total (81)										

Table 7: Number of each factor ranked as 1 or 2 (the most important factors) by age group (Chapel Hill)

Education Level	Employer discovers	Insurer discovers	hurts	Family discovers	Law enforcement	Help self	Help public	Help kids	Curious	Family planning
Some High School (0)	-	-	-	-	-	-	-	-	-	-
High School Graduate (4)	2	3	0	0	1	2	2	2	0	1
Some College (11)	0	6	2	1	5	6	7	6	1	2
College Graduate (23)	7	17	5	0	5	11	16	12	5	1
Post Graduate (42)	9	27	6	0	12	25	28	16	6	7
Total (80*)										

*one respondent declined to provide information regarding education level

Table 8: Number of times each factor received a ranking of 1 or 2 (the most important factors) by education (Chapel Hill)

Age group	Employer Discovers	Insurer discovers	hurts	Family discovers	Law enforcement	Help self	Help public	Help kids	curious	Family Planning
65+ (1)	0	1	0	0	0	0	1	1	0	0
40-65 (23)	10	13	4	1	1	15	12	7	5	5
25-40 (7)	1	4	1	2	1	5	3	4	2	0
<25 (8)	3	3	2	1	2	4	3	3	1	3
Total (39)										

Table 9: Number of times each factor received a ranking of 1 or 2 (the most important factors) by age group (Durham)

Education Level	Employer discovers	Insurer discovers	hurts	Family discovers	Law enforcement	Help self	Help public	Help kids	Curious	Family Planning
Some High School (4)	1	1	2	1	1	2	3	0	0	1
High School Graduate (4)	2	1	0	1	0	1	2	1	1	1
Some College (15)	6	8	3	1	2	8	4	9	6	4
College Graduate (8)	1	5	2	1	1	7	4	3	1	0
Post Graduate (0)										
Total (31)*										

*Eight respondents declined to provide information regarding education level

Table 10: Number of times each factor received a ranking of 1 or 2 (the most important factors) by education (Durham)

The survey results indicate that concern about insurers finding out the results was the highest ranked (ranking of 1 or 2) negative factor regarding DNA testing. This was true across all age and education groups, with the exception of the four Durham respondents who were not high school graduates. Curing the public, curing oneself,

and helping their own children were the most highly ranked (ranking of 1 or 2) positive factors regarding DNA testing.

Fear of an insurer finding out the results is the only negative reason in which a ranking of one (most important) outweighed blank responses (no importance). For all other negative reasons, “blank” (no importance) was the most common response. Conversely, of the positive reasons for donating DNA samples, blank was not the most common response for any category. Those who previously participated in medical research expressed only a slightly greater willingness to contribute a DNA sample than those who had not previously participated.

6. Statistical Analyses

All data were entered into spreadsheets and data averages and correlation analyses were performed using Microsoft Excel. The average rankings assigned by Chapel Hill respondents for each motivation and concern in the survey are set forth in Table 11, and those for Durham respondents are set forth in Table 12.

Concern	Average ranking	Number of blank spaces left (indicating factor is unimportant)
Employer discovers	2.87	42
Insurer discovers	1.42	22
Fear of pain	3.47	41
Family discovers	4.15	47
Law enforcement discovers	2.53	38
Motivation	Average ranking	Number of blank spaces left (indicating factor is unimportant)
Cure own disease	2.32	4
Help the public	2.21	3
Cure children	2.441	13
Curious	3.52	12
Family planning	3.92	21

Table 11: Average Rankings of Concerns and Motivations by Chapel Hill Library Patrons (lowest average corresponds to most important factor)

Concern	Average ranking	Number of blank spaces left (indicating factor is unimportant)
Employer discovers	2.73	13
Insurer discovers	2	11
Fear of pain	3.6	14
Family discovers	3.92	13
Law enforcement discovers	3.77	13
Motivation	Average ranking	Number of blank spaces left (indicating factor is unimportant)
Cure own disease	2.21	5
Help the public	2.33	3
Cure children	2.58	6
Curious	3.31	7
Family planning	3.76	10

Table 12: Average Rankings of Concerns and Motivations by Durham Library Patrons (lowest average corresponds to most important factor)

The correlation between education level and willingness to contribute a DNA sample showed an increase with age in the Chapel Hill participants.

	Correlation between education and willingness to contribute a DNA sample
Age 65+	.7628
Age 40-65	.2058
Age 25-40	.1158
Age <25	-.1799

Table 13: Correlation between education and willingness to contribute a DNA sample as a function of age in Chapel Hill patrons.

This trend was also evident in the Durham participants.

	Correlation between education and willingness to contribute a DNA sample
Age 65+	n/a
Age 40-65	.2319
Age 25-40	-.0831
Age <25	-.2342

Table 14: Correlation between education and willingness to contribute a DNA sample as a function of age in Durham patrons.

There was also an increase in the correlation between interest in curing one's own disease and willingness to give a DNA sample with age among Chapel Hill patrons, although this trend was not observed in the Durham patrons.

	Correlation between interest in curing disease and willingness to donate DNA sample
Age 65+	.2894
Age 40-65	.0352
Age 25-40	.0269
Age <25	.017

Table 15: Correlation between interest in curing one's own disease and willingness to donate a DNA sample as a function of age in Chapel Hill patrons.

	Correlation between interest in curing own disease and willingness to give sample
Age 65+	n/a
Age 40-65	.428
Age 25-40	.2582
Age <25	.4201

Table 16: Correlation between interest in curing one's own disease and willingness to donate a DNA sample as a function of age in Durham patrons.

One might expect a relationship between the age of a patron and the importance of family planning in deciding whether or not to submit a DNA sample for testing, as one could theorize that those of childbearing age may be the most interested in this potential purpose for testing. This trend was weakly evident in the Chapel Hill respondents, although it was not evident among the Durham respondents.

	Correlation between interest in testing for family planning and willingness to donate DNA sample
Age 65+	0
Age 40-65	-.09
Age 25-40	.2954
Age <25	.375

Table 17: Correlation between interest in testing for family planning and willingness to donate a DNA sample as a function of age in Chapel Hill patrons.

	Correlation between interest in family planning and willingness to give DNA sample
Age 65+	n/a
Age 40-65	.2524
Age 25-40	-.4961
Age <25	.1336

Table 18: Correlation between interest in testing for family planning and willingness to donate a DNA sample as a function of age in Durham patrons.

The following tables show the most highly ranked deterrents among those who indicated unwillingness to donate a DNA sample:

Fears/ Negative Motivators Category	Percentage of those unwilling to donate ranking each group 1 or 2 (most important)
Fear employer would discover	11%
Fear insurer would discover	54%
Fear it would hurt	11%
Fear that family would discover	4%
Fear that law enforcement would discover	35%

Table 19: Most significant negative factors for Chapel Hill library patrons who would be unwilling to donate a DNA sample

Fears/ Negative Motivators Category	Percentage of those unwilling to donate ranking each group 1 or 2 (most important)
Fear employer would discover	56%
Fear insurer would discover	78%
Fear it would hurt	0%
Fear that family would discover	0%
Fear that law enforcement would discover	11%

Table 20: Most significant negative factors for Durham library patrons who would be unwilling to donate a DNA sample

The following tables show the most highly ranked motivators among those indicating willingness to donate a DNA sample:

Motivators/ Positive Factors Category	Percentage of those willing to donate who rank each group 1 or 2 (most important)
Cure self	56%
Help the public	76%
Help children	28%
Curious	4%
Family planning	28%

Table 21: Most significant positive factors for Chapel Hill library patrons who would be willing to donate a DNA sample

Motivators/ Positive Factors Category	Percentage of those willing to donate who rank each group 1 or 2 (most important)
Cure self	75%
Help the public	60%
Help children	40%
Curious	10%
Family planning	20%

Table 22: Most significant positive factors for Durham library patrons who would be willing to donate a DNA sample

Tables 23 and 24 show logistic regression analyses for Chapel Hill and Durham patrons, respectively, examining the influence of the demographic measures on individual patrons' expression of willingness to give a DNA sample.

Parameter	Df	Regression coefficient	χ^2	Prob> χ^2
Age*	1	.3982	2.3571	.1247
Education	1	.2837	1.3393	.2471
Gender**	1	-.2836	.3671	.5446
Prior research participation	1	.1334	.0998	.7521

Table 23: Logistic regression results for willingness to give a DNA sample as a function of age, education, gender and past participation in medical research for Chapel Hill participants.

* indicates slight inverse relationship between age and willingness to donate a sample due to numerical assignments of age groups

** indicates slight trend toward women expressing a greater willingness to donate a sample

Parameter	Df	Regression coefficient	χ^2	Prob> χ^2
Age*	1	-.2101	.2174	.6411
Education	1	.4095	.8146	.3668
Gender**	1	1.3682	1.6822	.1946
Prior research participation	1	-.7527	1.0137	.3140

Table 24: Logistic regression results for willingness to give a DNA sample as a function of age, education, gender and past participation in medical research for Durham participants.

*indicates slight relationship between age and willingness to donate a sample due to numerical assignments of age groups

** indicates a trend toward men expressing a greater willingness to donate a sample.

6. Discussion

A. Willingness to Participate in a Genetic Database

The data suggests some ambivalence among respondents toward donating personal DNA samples for research. While just over half of the Durham patrons indicated a willingness to donate, patrons of the Chapel Hill public library were almost evenly split between those willing, those unwilling, and those unsure (Table 1). These are lower percentages of those reporting willingness to participate than were reported in prior studies of the general public in the United States. This could be the result of increased awareness of the issues surrounding genetic testing. It could also be a reflection of new skepticism about the use of genetic technology due to reports of questionable applications. For example, recent stories have reported a genetic

company offering a test to see what sports a child is genetically predisposed to excel at (Macur, 2008), and another group of researchers reported a genetic component to the inability to commit to a partner (BBC, 2008). The possibility of genetic links to socially stigmatizing conditions such as mental illness may make some wary of having their genetic information potentially accessible in the future, even if they are assured anonymity or personally never learn the results. As prior studies have also theorized, increased education about the potential uses of and issues surrounding genetic testing can cause a paradoxical decrease in the number of those willing to participate in genetic research as medical, legal, and ethical discussions enter the public forum.

Individual comments largely focused on concern about what will ultimately be done with the samples and loss of privacy (Table 6). Patrons' worries about their genetic material being "kept on file somewhere" and "not sure what would be done with it" suggest an unwillingness to allow scientists unfettered use of their DNA samples. Expressed worries about "potential mates" discovering this information and "invasion of privacy" underscore the importance of assuring participants that their samples will be kept secure, and perhaps offer a warning to those groups advocating abandonment of all attempts to keep the information secure that they may run into trouble recruiting subjects. (See Lunshof, 2008) New questions about information security seem to arise daily, for example, what happens to the data and the samples when a DNA testing company goes bankrupt? (Vorhaus, 2009). Guaranteeing privacy and anonymity appear to remain the most important challenges to gaining broad public participation in genetic databases. The remaining expressed concern, fear that the test

would hurt or cause infection, could be alleviated with the simple explanation that modern testing techniques do not require blood samples.

Despite this uncertainty, overall respondents ranked the positive reasons for donating a sample more often and more highly than the negative reasons for not donating a sample (Tables 2, 3). This may be due to the optimistic news stories of medical advances and treatment options DNA testing has facilitated. Americans generally embrace new medical treatments and value state-of-the-art medical care. While reluctance to donate a personal sample despite ranking positive aspects of genetic testing highly may seem inconsistent, it may show that the public is overall optimistic about the potential benefits of DNA research but remains concerned about the potential consequences of loss of privacy in or control over the personal information obtained.

- i. Deterrents to Participation

Fear of insurers finding out the results of a DNA test was the highest ranked negative factor among the Chapel Hill and Durham patrons. (Tables 2, 3, 7, 8, 9, 10, 11, 12). This finding is consistent with other studies described above. This was also the factor most commonly ranked as most important among the subset of respondents who express unwillingness to donate a DNA sample (tables 19, 20). Concern that employers would find out was also ranked highly both among all respondents and among the subset who indicate unwillingness to donate a DNA sample. Since most Americans still get their health insurance through their employers, this finding is also not surprising, although it may indicate people are also concerned about discriminatory actions an employer might take if they discover an employee or

potential employee is genetically predisposed to an undesirable condition. Informing the public of GINA and of other legal protections through outreach programs or as a part of the solicitation materials when recruiting genetic database donors may help alleviate this particular concern.

One surprising result from the survey is the large percentage of respondents who ranked “afraid law enforcement would find out” as an important concern about genetic testing (Tables 19, 20). News reports of perpetrators found through DNA linkage to relatives might have influenced some respondents, who may be worried they could become involuntary informants on family members (Nakashima, 2008). This fear could be further enhanced by news reports of botched DNA testing resulting in erroneous convictions (See Dao, 2005, in which the author discusses the review of 150 criminal cases in Virginia after it was shown the state crime lab had improperly performed DNA testing.) Informal polling of some respondents in the present study revealed some may be unduly influenced by the manner in which genetic testing is portrayed in television crime dramas; others voiced vague and unspecified concerns about homeland security or “big brother” tracking their genetic information.

ii. Primary Motivators to Participation

A desire to help the general public was the highest ranked motivator among the Chapel Hill library patrons, with only three participants out of 81 failing to give this factor any importance rank (Tables 2, 11). Similarly, among the Durham library patrons, helping the general public was ranked as the second-highest motivator, with only three patrons failing to rank this factor as important (Tables 3, 12). Looking only at those patrons who expressed a willingness to submit a DNA sample (Tables 21, 22),

again, this factor was the most highly ranked by the Chapel Hill patrons and was second most highly ranked among the Durham patrons. Studies reported above show consistent results and support the conclusion that an appeal to altruism may be effective in recruiting genetic study participants.

One potential motivator that did not rank highly was an interest in genetic testing for family planning, which received the greatest number of “blank” (no importance) responses of all of the positive attributes, and the highest number of least important (rank 5th out of 5) rankings among those respondents who did rank this factor. (Tables 2, 3). This was true for both Chapel Hill and Durham participants. Of those willing to donate a DNA sample, this factor was ranked second to last among both Chapel Hill and Durham populations (tables 21, 22). There was a weak correlation between age, willingness to donate a DNA sample, and a ranking of family planning among those of child-bearing age in the Chapel Hill patrons, but this pattern was not evident among the Durham Patrons (Tables 17, 18). This result was somewhat surprising, and could be due to many factors, including the religious beliefs of the respondents. The absence of treatment options for most genetic diseases at the pregnancy planning or prenatal stage, leaving abortion as the only therapeutic alternative, may also be a factor.

iii. Age and Education Sub-Group Trends

Of those willing to donate a DNA sample, the raw percentages show no strong correlation between age or education and willingness to donate a sample in either the Chapel Hill or Durham participants (Tables 4, 5). Ignoring the influence of those who responded “depends,” there was a slight trend among those who had previously

participated in medical research to indicate a willingness to submit a DNA sample among both the Durham and Chapel Hill participants. These results are inconsistent with studies discussed above which found a strong association between prior participation in medical research and willingness to submit personal DNA samples for a genetic database. This observation may reflect increasing public awareness of the unique issues surrounding DNA research and a resulting hesitation to participate despite the altruistic motivations that led to participation in other types of medical research.

There was an increasing correlation between education level and willingness to contribute a DNA sample as age increased in both the Chapel Hill and Durham populations (Tables 13, 14). This could be evidence of increasing knowledge with age and education of the potential benefits of genetic testing in treating disease, or perhaps an increasing desire to help the public as potential donors gain education and life experience. One hypothesis, that with age and education comes an increasing interest in participating in genetic research to advance one's own health, was not supported by the data. There was an increase in the correlation between interest in curing one's own disease and willingness to give a DNA sample with age among Chapel Hill patrons, but this trend was not observed in the Durham patrons (Tables 15, 16).

iv. Demographic Predictors of Willingness to Donate a DNA Sample

Tables 23 and 24 show the results of logistic regression analyses measuring the impact of age, education, gender, and past participation in medical research on willingness to donate a DNA sample. Unlike tables 4 and 5, these analyses take into account those expressing ambivalence (“depends”), not only those indicating

willingness to submit a sample. While there appeared to be a slight trend for those younger, better educated, and female to express willingness to donate a DNA sample in the Chapel Hill group, none of these values were statistically significant. The logistic regression results for the Durham group, as set forth in Table 24, also showed a slight trend for those better educated to express willingness to donate a DNA sample. Unlike the Chapel Hill results, however, increased age and male gender showed a slightly positive trend toward willingness to participate. No values were statistically significant. Prior experience with research studies was also not significantly predictive of who would express willingness to donate a DNA sample. Chapel Hill patrons with prior research experience showed a slight trend toward willingness to donate a sample, while Durham patrons with prior research experience showed a slight negative trend. Again, in both cases, the data was not statistically significant.

B. Study Limitations

i. Survey Design

Some respondents had difficulty ranking items in order of importance and the complexity of this task likely deterred some potential participants. Three Chapel Hill surveys were discarded due to the ranking of all of the factors, both positive and negative, as “1.” Two others were discarded as they responded by simply checking off all of the factors—a response not allowed by the web-based survey. Information regarding the respondents’ race, religious affiliation and income would have been interesting to factor in to the analysis of the data. However, these questions were deliberately omitted to avoid offending participants or deterring participation due to

the sensitivity of the questions. There may be research venues in which this information could be more comfortably solicited and the impacts of race, religion and income on participants' views toward genetic research would be an interesting area for future research.

ii Responding population

The web-based survey conducted on Durham library patrons produced a disappointing response rate, despite heavy advertising in the form of flyers and cards and a gift card incentive. Part of the difficulty in gaining web-based participation was the need for respondents to manually type in the URL for the survey. Even though the URL was shortened, this approach necessarily limited respondents to those with sufficient computer knowledge to know how to do this. A link to the survey on the library's website would have been preferable and would have reached distant users; however, this was not permitted by library administrators. The Durham library would also not permit a paper survey to be conducted on or around the library premises, due to concerns about congestion and traffic flow outside of the library. Consequently, the computer literate and more educated patrons of the Durham public library were likely over-represented and there was no way to reach those uncomfortable with computer use.

The Chapel Hill library survey was conducted on the weekend of the annual book sale and on another weekend when cookie sales were taking place, in the hope that those patronizing the library on those days would represent a broad section of the Chapel Hill public. Nonetheless, the Chapel Hill respondents were heavily weighted toward those with advanced degrees. Selecting a library as a research venue in itself

likely skews those respondents toward those who are better educated. The subject matter of the survey also seemed intimidating to some library patrons.

7. Conclusions and Implications for Future Research

These results suggest that guarantees of confidentiality and anonymity remain essential to gaining broad scale participation in genetic databases. Laws that prohibit discrimination by insurers and employers are likely insufficient to calm the fears of those who worry their information may be disclosed to others or used for types of research for which they have not given permission. Convincing assurances of confidentiality and anonymity would resolve the vast majority of concerns among potential donors. Limiting use of the samples to those purposes agreed to, and education of those fearful of pain or infection on current sample collection techniques such as cheek swab would virtually eliminate the remaining expressed concerns.

These results also suggest broad interest in and positive attitudes toward genetic research, and a common desire to help advance the health of the general public through genetic research. These motivations far outranked the negative aspects of genetic testing. If potential donors could be assured of adequate security and confidentiality and that the use of their genetic information would be confined to those purposes agreed to, the vast majority of objections to donating DNA samples would appear to be satisfied, and could result in broad public participation in this frontier of medical science.

8. Appendix

Qualtrics

Take This Two-Minute Survey and Get a Chance to Win a \$25 Gift Card!

Dear Library Patron,

I am a graduate student at UNC-Chapel Hill in the School of Information and Library Science, and I am studying how people in the community feel about contributing their personal DNA information to a genetic database for medical research. I would like for you to complete an opinion survey on this subject. This survey is not connected with any ongoing genetic data gathering or registry enrollment. You can skip any question or quit at any time, and participation in this survey is entirely voluntary. This is a quick (one page) survey and I hope you'll take a few minutes to fill it out.

A genetic database is a large collection of information about the genes people carry. The information is arranged in a way so that scientists can look for patterns. By comparing these patterns to an individual's health, scientists can develop better ways to diagnose and treat many common diseases. Genetic databases need a lot of people to contribute their DNA information to them to make them useful. By answering these questions, you will help us understand how people feel about giving their DNA information for research.

If you decide to answer this survey, your answers will not be traced back to you. We will collect your contact information at the end of the survey so that we can contact you if you win the gift card. You do not need to give us any contact information if you do not want a chance to win the gift card. One gift card will be awarded. Once the \$25 gift card has been awarded, all contact information will be destroyed.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have any questions or concerns about your rights as a research subject, you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu. If you contact the IRB, please reference study number 08-2174.

Questions? Please contact Jane Bahnsen at jbahnsen@email.unc.edu or her advisor, Brad Hemminger, PhD, at bmb@unc.edu

I understand my rights as explained above and I wish to take this survey. Please click on the arrows at the bottom of the screen (>>) to continue.

yes
 no

>>

Figure 1: Survey Cover Letter

Qualtrics

Studying human genetic data promises to uncover important information that could help cure many diseases. We would like to know how you feel about potentially contributing your DNA sample for medical research.

First, please let us know:

I am;

age 65+ age 40-65 age 25-40 under age 25

I have the following education (please check your highest level of education):

some high school high school graduate some college classes college graduate education beyond college (advanced degree)

I am:

male female

Have you ever participated in a medical research study before?

yes no

Have you already given samples of your DNA for medical research, or would you be willing to do so at this time?

yes no depends

Figure 2: Demographic Information

Please rank these reasons why you might not want to give a DNA sample in the order of their importance to you, 1st being the most important reason, 6th being the least important reason. Use each number only once. If any of these reasons are not important to you, please leave the "rank" space blank.

I am afraid the results might be given to my employer.

I am worried about getting health insurance or being denied health insurance due to the results.

I am worried that the test would hurt (but I would give a DNA sample if it was quick and painless, like a swab inside my cheek.)

I am afraid that my family would learn of the results.

I am worried that law enforcement might keep the results and try to use them in the future.

Other:

Please put these reasons why you might want to give a DNA sample in order of their importance to you, 1st being the most important reason, and 6th being the least important reason. Use each number only once. If any of these reasons are not important to you, please leave the "rank" space blank.

If I had a disease that might benefit from genetic research, in order to help scientists find a cure to help me beat it.

If it would help scientists find cures for diseases for the benefit of the general public, even if it didn't specifically help me or my family.

If I thought the information might help my children.

I am curious about what the results might say about my health.

If I was thinking of having children and wanted to know the chances of having a child with an inherited disease.

Other:

Thank you for taking this survey! Please click on the little arrows (>>) below to record your answers. If you would like to have a chance to win the \$25 gift card, you will be asked to fill in your contact information following the "thank you" screen.

Figure 3: Attitude Questionnaire

9. References

Abiola, Sara (2008), The Genetic Information Nondiscrimination Act of 2008: “First Major Civil Rights Bill of the Century” Bars Misuse of Genetic Test Results, *Journal of Law, Medicine and Ethics*, 856-859.

Austin, Melissa A., Harding, Sarah E., McElroy, Courtney E. (2003), Monitoring ethical, legal, and social issues in developing population genetic databases, *Genetics in Medicine*, vol 5, no 6, p. 451-457.

BBC News (2008), Commitment phobes can blame genes, *BBC News*, <http://news.bbc.co.uk/2/hi/health/7593301.stm>, accessed October 3, 2009.

Balmana, J, Stoffel, E M, Emmons, K M, Garber, J E, Syngal S (2004), Comparison of motivations and concerns for genetic testing in hereditary colorectal and breast cancer syndromes, *J Med Genet*;41 e44 doi: 10.1136/jmg.

Bartlett VL, Johnson RL.(2009), God and genes in the caring professions: Clinician and clergy perceptions of religion and genetics. *Am J Med Genet Part C Semin Med Genet* 151C:41–51.

Baruch, Susannah and Hudson, Kathy (2008), Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World, *The American Journal of Human Genetics* 83, 435–444, DOI 10.1016/j.ajhg.2008.09.003.

Burton, Bob (2002), Proposed genetic database on Tongans opposed, *British Medical Journal* Vol. 324, p. 443.

(Chapel Hill Demographics, Area Guides.Net, based on 2000 Census Data <http://chapelhill.northcarolina.com/demographics.html> , accessed 7/29/09).

Cullen, Rowena and Marshall, Stephen (2006), Genetic research and genetic information: a health information professional’s perspective on the benefits and risks, *Health Information and Libraries Journal*; 23, 275-282.

Cutler, Stephen J. and Hodgson, Lynne G. (2003), To test or not to test: Interest in genetic testing for Alzheimer’s disease among middle-aged adults, *Am J. Alzheimers Dis Other Demen* , Vol.18, No. 1, January/February 2003.

Dalton, Rex (2002), Tribe blasts 'exploitation' of blood samples, *Nature*, Vol. 420, p. 111.

Dao, James (2005), Virginia Governor Orders Review of 150 DNA Cases by Crime Lab, *The New York Times*, as reported by *The National Association of Criminal Defense Lawyers*, May 6, 2005, <http://www.nacdl.org/public.nsf/mediasources/20050509a>, accessed October 2, 2009.

Durham Population Profile, February 2005, City of Durham, North Carolina Official Website, <http://www.durhamnc.gov/departments/planning/pdf/demographics.pdf>, based on 2000 Census Data, accessed 7/27/09.

Eltis, Karen (2007), Genetic Determinism and Discrimination: A Call to Re-Orient Prevailing Human Rights Discourse to Better Comport With the Public Implications of Individual Genetic Testing, *Journal of Law, Medicine and Ethics*, p. 282-294.

Godard, B., Marshall, J., Laberge, C., and Knoppers, B.M. (2004), Strategies for consulting with the community: The cases of four large-scale genetic databases, *Science and Engineering Ethics*, Vol. 10, p. 457-477.

Green, Michael J., and Botkin, Jeffrey R. (2003), "Genetic Exceptionalism" in Medicine: Clarifying the Differences between Genetic and Nongenetic Tests, *Ann Intern Med.*, Vol. 138, No. 7, p. 571-575.

Harris, Gardiner (2009), Pick to Lead Health Agency Draws Praise and Some Concern, *The New York Times*, Money & Policy, July 6, 2009, <http://www.nytimes.com/2009/07/09/health/policy/09nih.html>, Accessed October 4, 2009.

Henderson, Gail, Garrett, Joanne, Bussey-Jones, Jada, Moloney, Mairead Eastin, Blumenthal, Connie, and Corbie-Smith, Giselle (2008), Great expectations: views of genetic research participants regarding current and future genetic studies, *Genetics in Medicine*, Vol. 10, No. 3, p. 193-200.

Hsieh, Alice (2003-2004), A Nation's Genes for a Cure for Cancer: Evolving Ethical, Social, and Legal Issues Regarding Population Genetic Databases, *Colum. J.L. & Soc. Probs.*, Vol. 37, p. 359-412.

Hudson, Kathy L. (2007), Prohibiting Genetic Discrimination, *N Engl J Med* 356;20, 2021, downloaded from www.nejm.org at UNIV OF NC/ACQ SRVCS on August 30, 2009.

Kaufman, David, Murphy, Juli, Scott, Joan and Hudson, Kathy (2008), Subjects matter: a survey of public opinions about a large genetic cohort study, *Genetics in Medicine*:10(11), 831-839.

Kaufman, David, Murphy, Juli, Erby, Lori, Hudson, Kathy, and Scott, Joan (2009), Veterans' attitudes regarding a database for genomic research, *Genetics in Medicine*, Vol. 11, No. 5, May 2009.

King, Nancy M.P. (2007), The Ethics of Genetic Testing: Is More Always Better?, *NC Med J.*, Vol. 68, No. 2, 112-114.

Laskey, Sara, Williams, Joseph, Pierre-Louis, Jacqui, O'Riordan, MaryAnn, Matthews, Anne, and Robin, Nathaniel (2003), Attitudes of African American premedical students toward genetic testing and screening, *Genetics in Medicine*; Vol.5, No. 1, 49-54.

Lunshof, Jeantine E., Chadwick, Ruth, Vorhaus, Daniel B., and Church, George M. (2008), From Genetic Privacy to Open Consent, *Nature Reviews/ Genetics*, Vol. 9, p. 406-411.

Macur, Juliet (2008), New genetic test asks which sport a child was born to play, *The New York Times*, <http://www.nytimes.com/2008/11/29/sports/29iht-30genetics.18246214.html>, accessed October 3, 2009.

Matsui, K, Kita, Y, Ueshima, H, Informed consent, participation in, and withdrawal from a population based cohort study involving genetic analysis (2005), *J Med Ethics*; 31: 385-392.

McGregor, Joan (2007), Population Genomics and Research Ethics with Socially Identifiable Groups, *Journal of Law, Medicine and Ethics*, p. 356-370.

McQuillan, Geraldine M., Porter, Kathryn S., Agelli, Maria, and Kington, Raynard (2003), Consent for genetic research in a general population: the NHANES experience, *Genetics in Medicine*, Vol. 5, No. 1, p. 35- 42.

Merz, Jon F., McGee, Glenn E., Sankar, Pamela (2004), Iceland Inc.: On the ethics of commercial population genomics, *Social Science & Medicine*; 58, 1201-1209.

Nakashima, Ellen (2008), From DNA of Family, a Tool to Make Arrests, *The Washington Post*, <http://www.washingtonpost.com/wp-dyn/content/article/2008/04/20/AR2008042002388.html>, accessed October 3, 2009.

National Conference of State Legislatures, *Genetics and Health Insurance State Anti-Discrimination Laws*, last updated January 2008, <http://www.ncsl.org/default.aspx?tabid=14374>, accessed September 9, 2009.

Personal Genome Project, <http://www.personalgenomes.org>, accessed October 20, 2009.

Pulley, Jill M., Brace, Margaret M., Bernard, Gordon R., Masys, Dan R. (2008) , Attitudes and perceptions of patients towards methods of establishing a DNA biobank, *Cell Tissue Banking*, 9:55-65, DOI 10.1007/s10561-007-9051-2

Sanner, Jennifer E., Frazier, Lorraine (2007), Factors that Influence Characteristics of Genetic Biobanks, *Journal of Nursing Scholarship*, 2007; 39:1, 25-29.

Singer, Eleanor, Antonucci, Toni, and Van Hoewyk, John (2004), Racial and Ethnic Variations in Knowledge and Attitudes about Genetic Testing, *Genetic Testing*, Vol.8, No. 1, p. 31-43.

Smith DH. (2009), Christianity, health, and genetics. *Am J Med Genet*, Part C ,Semin Med Genet 151C, p.77–80.

Surgeon General's Family Health Initiative, *U.S. Department of Health and Human Services*, <http://www.hhs.gov/familyhistory/>, accessed September 9, 2009.

Suter, Sonia M (1993), Whose genes are these anyway? Familial conflicts over access to genetic information, *Michigan Law Review*, 91.n7, 1854-1908.

Tyshenko, Michael G., and Leiss, William (2005), Current trends in publicly available genetic databases, *Health Informatics Journal*, vol. 11(4): 295-308.

Vorhaus, Daniel and Moore, Lawrence (2009), Guest Post by Daniel Vorhaus and Lawrence Moore, what happens when a personal genomic company goes bankrupt?, *Genetic Future; how genes affect your future and the future of society*, http://scienceblogs.com/geneticfuture/2009/09/guest_post_daniel_vorhaus_and.php, accessed October 2, 2009.

Wong, M.L., Chia, K.S., Yam WM, Teodoro, GR, Lau, KW (2004), Willingness to donate blood samples for genetic research: a survey from a community in Singapore, *Clin Genet* 2004: 65: 45-51.