ABSTRACT

Title of Document: STUDIES ON UNDERSTANDING INDIVIDUAL WILLINGNESS TO DISCLOSE GENETIC INFORMATION TO PUBLIC AND PRIVATE STAKEHOLDERS

Sathvik Balaram, Tyler Dunn, Michael Harris, Joshua Kohn, Hai Le, Christina Lee, Ori Lieberman, Tiffany Lin, and Aaron Sachs

Directed By: Dr. Ritu Agarwal and Dr. Kislaya Prasad

While technologies for genetic sequencing have increased the promise of personalized medicine, they simultaneously pose threats to personal privacy. The public's desire to protect itself from unauthorized access to information may limit the uses of this valuable resource. To date, there is limited understanding about the public's attitudes toward the regulation and sharing of such information. We sought to understand the drivers of individuals' decisions to disclose genetic information to a third party in a setting where disclosure potentially creates both private and social benefits, but also carries the risk of potential misuse of private information. We conducted two separate but related studies. First, we administered surveys to college students and parents, to determine individual attitudes toward and inter-generational influences on the disclosure decision. Second, we conducted a game-theory based experiment that assessed how participants' decisions to disclose genetic information are influenced by societal and health factors. Key survey findings indicate that concerns about genetic information privacy negatively impact the likelihood of disclosure while the perceived benefits of disclosure and trust in the institution receiving the information have a positive influence. The experiment results also show that the risk of discrimination negatively affects the likelihood of disclosure, while the positive impact that disclosure has on the probability of finding a cure and the presence of a monetary incentive to disclose, increase the likelihood. We also study the determinants of individuals' decision to be informed of findings about their health, and how information about health status is used for financial decisions.

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By

Team MAGIC (Medical and Genetic Information Concerns)

Sathvik Balaram, Tyler Dunn, Michael Harris, Joshua Kohn, Hai Le, Christina Lee, Ori Lieberman, Tiffany Lin, and Aaron Sachs

Directed By: Dr. Ritu Agarwal and Dr. Kislaya Prasad

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Advisory Committee
Dr. Margrét Bjarnadóttir
Dr. Gordon Gao
Ms. Deven McGraw
Dr. Louiqa Raschid

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1. Introduction

1.1 Problem Statement

Recent advancements in genetic research and continuous technological progress have introduced the possibility of digitizing patients' health information and using it to drive better clinical decision-making. We are on the brink of a new era where individual health records can be accessed through electronic databases. Companies have already begun marketing products that are designed to minimize the sharing time and maximize the availability of this information to health care providers while maintaining a high level of security and confidentiality. At the same time, we are also on the verge of gaining access to the vital genetic information that uniquely defines an individual's physiology. Many companies have already expressed interest in sequencing human DNA to scope out genetic markers that may forecast an individual's risk for certain disorders. This powerful approach can be instrumental in transforming the current landscape of health care and crucial in finding new treatments for the myriad diseases currently plaguing our society, ranging from high blood pressure to different types of cancer.

The availability of large databases of genetic information alone may significantly affect the health care industry. The more information regarding genetic-based disorders that researchers have access to, the more likely they will be able to begin creating new treatments and cures. At the same time, if health care providers have direct access to patients' genetic information, then personalized treatments tailored to maximize the health benefits for the patients could be more widely administered. While the emerging field of personalized medicine promises an array of benefits to patients, it will involve several challenges. These include procedures for efficiently and securely storing and sharing personal data, and inducing the public to make these data available to researchers.

Currently, people are hesitant to share their personal genetic information due to concerns about the privacy of this information. This information is highly sensitive and can potentially be used to discriminate against individuals based on their genetic profile or predisposition towards certain diseases. Health care providers and employers are in a special position to abuse such information and selectively prefer certain individuals over others (Wilde, Meiser, Mitchell, & Schofield, 2009). This fear of discrimination is hindering the research on personalized medicine by preventing widespread sharing of personal genetic information. If this continues, then the personalized health care industry will continue to struggle to expand, and the development of new clinical applications will be impeded (Hogarth, Javitt, & Melzer, 2008).

At the same time, there are many reasons for individuals to willingly disclose their personal genetic information. They may be motivated by financial gain - for example, in some cases, groups such as biobanks are willing to pay for someone's genetic information in order to distribute it to researchers. Further, people with increased risk for certain health conditions may want to know about their vulnerability in order to best adjust their lifestyle. Or, an important driver for sharing personal information could simply be the natural tendency for a person to be altruistic. In other words, an individual may donate their genetic information voluntarily because they believe it may be helpful for the general populace, even though they may not receive any personal benefit. In order to understand people's willingness to share their genetic information, we must acknowledge the different factors in play and determine the influential forces behind their decisions and choices. Elucidation of these factors will allow for solutions to be implemented that promote disclosure of genetic information and facilitate further advancements in this field.

1.2 Research Questions

Our research is motivated by the importance of understanding how society can collect, store, and analyze personal genetic information. A careful approach will enable numerous advances in biomedical science and efficiently regulate and advance the field of personalized medicine. The voluntary disclosure of such information is likely to be driven by individual-level factors as well as the nature of institutions that will be responsible for managing the information. First, we pose the question: what are the factors that are significantly associated with an individual's willingness to disclose personal genetic information to different institutions for the purpose of research? We hypothesize that individual perceptions of the risks and benefits of disclosure will affect their willingness to disclose. Risks include the potential for the information to be compromised because of improper security, leading to possible employment and health insurance discrimination. Benefits are represented by the value of medical discoveries for self, family, the broader society, or financial incentives. Individuals may also be systematically different in innate characteristics such as risk propensity, trust propensity, altruistic tendency, the extent to which they exhibit rational ignorance, and their perception of specific institutions such as the government, insurance companies, and health care professionals. We theorize that all these factors likely influence one's willingness to disclose personal genetic information.

A second research question we pose attempts to investigate the evolution of attitudes towards information privacy across two generations. We hypothesize that there are likely to be inter-generational differences in willingness to share personal genetic information and that there are systematic differences in the factors related with willingness to disclose across generations. We further expect that attitudes of parents will likely influence their children's disclosure decisions (Bandura & McClelland, 1977). It may be the case that generational differences are not a result of age but rather a result of socialization with technologies, as demonstrated in the Millennial generation's use of social media.

Our last research question examines the role of incentives in motivating genetic information disclosure by altering the circumstances within which disclosure occurs. Here we explore the effects of market mechanisms (purchase of information) versus disclosure driven by pro-social motivations, by explicitly manipulating risks and benefits. We hypothesize that financial incentives will negatively alter how people perceive the act of donating their personal information and this may limit the amount of disclosure that occurs due to motivational crowding.

To address these questions, we performed two research studies. In the first study, we conducted two cross-sectional surveys to distinguish attitudes toward genetic information sharing between the student and parent generations. The conceptual model underlying the study had studied subject willingness to disclose their personal genetic information to three stakeholders and their desire to be informed of being at risk of genetic disease as the focal outcomes. Key predictors of these outcomes included demographic variables, generalized traits, genetic information sharing beliefs, health status variables, and trust in institutions.

The second stage of our research involved an experiment with subjects from the college student population. Participants engaged in a multi-treatment experiment that presented hypothetical scenarios in which they could donate their personal genetic information for research purposes. Decisions made by the participants, along with scenario specific parameters, affected their income for the round. The experiment was intended to simulate real-world situations where people are presented with the option to donate their genetic information.

Findings from this study shed light on the complex decision of genetic information disclosure and its determinants. Our results may be instrumental in the design of institutions and policies that will facilitate the manner in which genetic information is obtained, used, and protected by determining what factors influence an individual to disclose their genetic information.

2. Overview of Thesis

In order to address the issues of genetic information sharing and its subsequent effects on the health care industry, two separate studies were conducted. The first study was a survey analysis regarding health care concerns and willingness to disclose personal information measured across both a student and a parent generation. A portion of the student population at The University of Maryland – College Park was asked to complete the survey. Upon completion of the survey, students were given the opportunity to ask their parents to complete a similar survey. Both surveys contained the same materials, but the student version added an additional section about parental influence. This information allowed us to compare and contrast the opinions of the two different generations.

The survey asked questions regarding privacy, trust in people and institutions, issue involvement, perceived risks and benefits, and social stigma. The dependent variable for this study was how willing respondents were to donate their genetic information to a variety of different stakeholders. Responses were amalgamated into different constructs to represent all of the factors that would influence a decision to donate and the dependent variables were regressed against all of the independent constructs.

The second study was an experiment for college-aged students that explored how willing the participants were to disclose genetic information when presented with varying risks and rewards. A portion of the student population at The University of Maryland – College Park was asked to participate in the experiment.

The experiment was designed with actions and decisions that may occur in one’s lifetime that represent actual issues with donating genetic information. The simulation gave participants a chance of having a hypothetical genetic disease as well as chances they would be discriminated against, become sick, and the chance that a cure would be found for the disease. Participants were then given three decisions: whether or not to donate their genetic information, whether or not they would like to be informed of the results of their genetic test, and whether they would like to make a long-term monetary investment in themselves. Participants were given an income that represents a salary and how much this income increased or decreased depended on their decisions and the parameters of the simulation. By regressing each of their decisions against the simulation parameters, the importance of each parameter in the decisions could be determined, helping to identify what monetary and risk factors influence the decisions made in donating genetic information.

3. Literature Review

In this section, we discuss important findings in prior work related to our research questions. Our research topics encapsulate a number of different disciplines. Therefore, we reviewed relevant work in fields such as health informatics, psychology, sociology, economics, business, and information technology, among other disciplines. We first explore the current legal environment pertaining to genetic information sharing and its evolution alongside the advancement of medical science. Next, we discuss studies that investigate intergenerational differences and how a child's attitudes and ideals are shaped by his or her parents. Furthermore, we consider how factors such as income, race, health, risk perception, and issue involvement influence decision-making processes. Finally, we explore previous research pertaining to how altruism, incentives, and trust influence social behaviors. The literature discussed in this section provides the conceptual and empirical background for the design of the two studies.

3.1 The Legal Environment for Genetic Information

Little legal protection from genetic discrimination existed before the Genetic Information Nondiscrimination Act that was passed in 2008. The first law to prevent genetic discrimination was the Civil Rights Act of 1964 (Gurd, 1992). While originally not designed for this purpose, Title VII of this Act can be used to prevent genetic discrimination against racial or ethnic minorities. However, the anti-discriminatory power of this 1964 Act on genetic discrimination is limited because it was enacted to combat racial and ethnic discrimination; thus, the need to demonstrate a strong connection between race and genetics. However, it must be noted that this has never been successfully applied to a court case (Gostin, 1991).

Next, the Americans with Disabilities Act of 1990 became a source of protection from genetic discrimination. While this act provided protection from discrimination for people with symptoms of a genetic disease, it has some limitations. One problem is that the law does not prevent discrimination against asymptomatic individuals. This makes it possible for an employer to decide not to hire an individual because of the potential for future medical costs. Another weakness is that the law does not forbid employers from requiring genetic testing after an employment offer (Gostin, 1991). This allows companies to discriminate based on genetic conditions in pay and job placement. For example, individuals with genetic conditions may not be offered higher pay in order to offset the future costs stemming from their illnesses.

The Health Insurance Portability and Accountability Act of 1996 was the next major legislation that was passed to protect people from genetic discrimination. This law restricts what large group health insurers are able to do with partial medical information (including genetic information). The law, in theory, prevents group insurers from using medical information to change rates and benefits, but it does not successfully protect consumers due to two main flaws: (1) The act does not prevent the insurer from using medical information to change the rates and benefits of the entire group and, (2) it does not apply to individual or small group insurance (Hudson, Holohan, & Collins, 2008).

The Genetic Nondiscrimination Act of 2008 (GINA) was originally conceived to prevent genetic discrimination against patients and employees by both insurance companies and employers. Under this law, health insurers cannot discriminate against asymptomatic people on the basis of genetic information. So even if a health insurer gains access to genetic information they cannot use the information to change premiums or eligibility. Employers are also restricted from discriminating on the basis of genetic information. For instance, employers are prohibited from using any genetic information to influence decisions regarding hiring, firing, and job placement. Along with setting new restrictions on the usage of genetic information, the law also prevents health insurers or employers from requesting genetic information of an individual or their family members (Hudson et al., 2008). This provision is designed to prevent health insurers and employers from having access to genetic information and is necessary because it removes some of the potential for discrimination to occur.

GINA has several limitations that limit its ability to completely prevent genetic discrimination. Violation of the law’s provisions only results in a civil punishment. This could allow companies to fire employees upon accidental discovery of a genetic condition in order to save costs in the long-term, assuming that the costs of treating the disease exceed the costs of the fine. Secondly, the provisions of GINA do not apply to life, disability, or long-term care insurance. Furthermore, GINA does not apply to businesses with fewer than 15 employees. Finally, GINA does not mandate that health insurers cover the tests and treatments needed by a genetic condition (Hudson et al., 2008). Even after the passage of GINA, the most comprehensive anti-discrimination legislation yet, genetic discrimination continues to be a problem (Williams et al., 2010).

Recently, the Patient Protection and Affordable Care Act passed by the Obama administration in 2010 eliminated discrimination based on preexisting conditions including symptomatic genetic conditions (Patient Protection and Affordable Care Act). Although more aggressive than GINA, further comprehensive laws will be necessary to ensure proper handling and protection of patient's medical records and genetic information.

3.2 Inter-generational Differences

To the degree that public attitudes towards social issues change and evolve over time, one of the goals of our research was to investigate how age plays a factor in one's decision to share genetic information. This effect is to be expected, given that parents (and other caregivers) represent the primary influence on the development of social attitudes and behaviors as dictated through social learning theory (Bandura & McClelland, 1977). A number of studies have identified the similarities and differences between the parental generation (ages 40+) and the student generation (ages 18-24). This may be a result of changing privacy beliefs over the years towards government and personal information privacy. Harris Interactive surveys have shown that privacy beliefs have evolved since the 1960s, which may explain attitude differences between generations. For example, earlier surveys about government surveillance indicate that people were generally against any type of wiretapping, which may constitute an invasion of privacy (Harris, 1974). However, more recent studies conducted in 2002 and 2003 found that Americans were for increased surveillance by the government (Taylor, 2002; Taylor, 2003). In addition, Americans claimed that they trusted health providers to handle their personal information in a secure manner (Fricke, 2009). These types of privacy beliefs suggest that privacy is less of a concern to the younger generation. However, these types of beliefs do not always transfer to behavior.

A general consensus exists that risk evaluation is similar between the two generations of interest. Both age groups express similar decision-making processes when presented with situations with varying level of risk. A study found that young adults and the elderly have similar amounts of skepticism and trust in various risk-level situations. Their response times to risky situations were also quite similar between the age groups suggesting that elderly people are just as cognitively capable of making risk-based decisions as young adults (Ashman, Dror, Houlette, & Levy, 2003). A similar follow-up study by Ashman *et al.* confirmed these initial results. Elderly people respond to changing levels of risk similarly to young adults even when exposed to age stereotypes, like being primed with words like "senile" and "confused". However, this study found that elderly people tended to take longer in making these decisions, contradicting results found by Ashman and colleagues (Ashman et al., 2003).

A key difference between the two age groups lies in benefit evaluation. While risk perception may be similar, younger people tend to value benefits and rewards much higher than the older population. A study done on information disclosure by teenagers on the internet found that even small increases in potential benefits could drastically change risk behavior (Youn, 2005). This suggests that the younger population is more vulnerable to the allure of rewards and perhaps more insensitive to risk. We anticipate this type of behavior to be reflected in our survey of young adults.

In addition to differences that may exist between attitudes across generations and distinctions between the parent and child generations, the interplay between a parent's influence on a child and the traits identified above is significant. A number of studies on parent-child relationships have found that the parent plays a big role in shaping the child's ideals, principles, and behavior. One study confirmed that parent's attitudes were an important predictor in their child's orientation of religion, politics, and gender roles

(Glass, Bengtson, & Dunham, 1986). Furthermore, they found that parental influence decreased as the child became older. This suggests that parental influence may diminish near the end of adolescence.

Interestingly, a parent's influence can sometimes be variable. There are several factors that can make a parent more or less influential. One of these factors is the nature of the relationship between the parents. Higher marital quality correlates with stronger transmission of attitudes and behavior from parent to child (Cunningham & Thornton, 2006). Religious orientation and immigrant status also are two major factors that determine attitude transmission. First-generation immigrants and families that associate with a religion have greater transmission of behavior regarding social involvement than those who do not (Merz, Özeke-Kocabas, Oort, & Schuengel, 2009). We expect to see some sort of convergence of attitudes between our two age groups based on factors mentioned above such as the quality of the parent-child relationship and religious affiliation.

Another aspect that needs consideration is how these attitudes are transmitted from parent to child. The family unit has long been considered the primary factor in the socialization of children (Heilbrun Jr, 1965). Attitude transmission can generally be broken down into two models: direct transmission models and indirect transmission models. Direct transmission models are dictated by the social learning theory. Social learning theory asserts that people often rely on the actions of others in order to learn what to do (Bandura & McClelland, 1977). Essentially, a person's behavior is learned through modeling by another source. This source can be parents, peers, or social media. It is important to note that the range of behavior included in social learning theory also encapsulates prosocial behavior; voluntary behavior that is intended to benefit the population as a whole (Eisenberg, 2007). These actions may include volunteering, sharing, and donating. More research is necessary into whether this type of behavior is transmitted from parent to child, and if it is, how the behavior is transmitted.

As stated above, one of the methods of direct transmission of prosocial behavior involves role-modeling. Studies have shown that this is possible through a reward system, where parents commit prosocial acts and reward their children for joining with them. This is true for volunteering with religious organizations (Bekkers, 2007) and donating money to both secular and religious organizations (Willhelm, 2008). These studies have demonstrated that children will likely carry these behaviors on to adulthood because they were immersed in them as a child. There is significant survey evidence that backs this claim. In one study, people were asked whether they make charitable contributions. They were then asked whether they had family members in the past who had made charitable contributions. 74% of people who said they had family members make charitable contributions in the past currently make charitable contributions. This is in contrast to 50% of people without charitable family who currently make charitable contributions (Hodgkinson and Weitzman, 1996). Similar results were seen in a study on blood donation. A moderate relationship was found between 23 parent-child pairs in the charitable behavior of giving blood (Peters, Ünür, Clark, & Schulze, 2004). However, it is unknown how much of this relationship, in all of these studies, is due to similarities in the traits of the parents and children rather than behavior modeling and transmission.

3.3 Gender, Income, Race and Health Care Decisions

Prior research has identified a variety of individual level factors that can affect the healthcare decisions that individuals make. Socioeconomic status, gender and racial background are such factors.

3.3.1 Income

Socioeconomic status as represented by income may exert some influence on the decision to share one's genetic information. Numerous studies indicate that there is high correlation between health status and socioeconomic status. That is, greater wealth translates to better overall health status (Adler & Ostrove, 2006; Regnerus, Smith, & Sikkink, 1998). Furthermore, limitations imposed on low income individuals, such as lack of access to quality regular health care, leads to a greater hospitalization rate (Billings et al., 1993). Indeed, this suggests that lower income families often visit health care facilities and interact with health care professionals under more dire and stressful circumstances. Therefore, this higher frequency of exposure to the health care industry is tempered with lower overall health quality. If true, this may cause those in lower-income demographics to distrust the health care system and health care professionals; thus, leading to less willingness to cooperate with health care organizations and its personnel.

Further, lower socioeconomic status is also indicative lower college attainment rate and diminished college graduation rate (Sewell & Shah, 1967). Indeed, individuals who do not attend college may underestimate the importance of scientific research and, as a consequence, not be involved with the issue of genetic information disclosure at all. Hence, low socioeconomic status may lead to an under-appreciation for the necessity of genetic information in medical research and lower the likelihood of being willing to donate one's genetic information for the progress of science.

3.3.2 Gender

There is a general consensus in the psychology literature that there are significant gender differences in risk aversion and decision making (Eagly, 1995). However, these differences can arise in two different ways: inherent differences between genders and social and contextual influences. It is not yet clear which is predominant over the other, but differences are still present. Furthermore, the level of difference between genders has changed over the years. Early studies before 1980 recorded women as being more cautious, less confident, less aggressive, and having inferior leadership and problem solving skills (Johnson & Powell, 1994). Some of this may be attributed to the gender bias of the time period, yet there is some merit to how social roles can affect decision making in risky situations.

A study done by Powell and Ansic examined this distinction between social context and inherent differences (Powell & Ansic, 1997). Specifically, they analyzed methods used by both genders when faced with financial decision-making. Their subject population consisted of students from a business school to maximize familiarity and experience with financial decisions. Through a computerized simulation, participants were asked to respond to different situations of financial risk. As they had predicted, females tended to be more risk averse than males. This suggests that the behavior stems from inherent differences rather than familiarity with financial situations.

Females also tend to be more conservative in situations dealing with information collection and privacy. Results from a survey of 898 participants found that women and men differ greatly in their attitudes toward information gathered online (Bartel Sheehan, 2000). Women were more concerned with how the practice could negatively affect them while men are more concerned with how they can protect themselves after the fact. This type of behavior appears consistent with women's tendency towards risk aversion. Disclosure of information is seen as a risk and the act is generally avoided. In relation to our study, this tendency might result in a lower willingness to disclose genetic information among women than men.

3.3.3 Race

Willingness to participate in genetic scientific research is associated with one's ethnic background: research has shown racial and ethnic minorities are less willing to participate. A 2003 study found that trust in different components of the U.S. health care system differ by race (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Specifically, non-Hispanic white respondents were more likely than those of another race to trust their physicians, hospitals, and health insurance plans (Boulware et al., 2003). In addition the analysis of the National Health and Nutrition Examination Survey of 1999-2000 determined that females and black participants were least likely to consent to give their blood samples to a national repository for genetic research (Mcquillan, Porter, Agelli, & Kington, 2003).

Racial discrimination toward African Americans has been documented throughout the advancement of medical research. From the infamous U.S. Public Health Service Tuskegee syphilis experiment in 1932 to recent independent studies on perceived racial discrimination in health care studies, it is evident that there are racial disparities in the health care system and these problems stem from the history of discrimination in the industry (Hausmann, Kressin, Hanusa, & Ibrahim, 2010). Evidently, racial background plays an important role in personal information sharing.

3.4 Prosocial Motivation and Incentives

The act of disclosing personal information voluntarily for a social cause is fundamentally a prosocial behavior. One of the main drivers of prosocial behavior is the individual trait of altruism, originally defined by Auguste Comte as “a motivational state with the ultimate goal of increasing another’s welfare” (Batson & Shaw, 1991; Homans, 1958). Social exchange theory, developed in the 1950s by George Homans, suggests that humans make all decisions after determining the costs and benefits of the decision, which would imply that altruism only occurs if there are more incentives to act altruistically than consequences (Homans, 1958). The other theory underlying motivation for altruism is Batson’s empathy-altruism hypothesis, which argues that if one individual feels empathy towards a second, then the first will act altruistically regardless of the costs or benefits of acting in such a manner (Batson & Shaw, 1991). Currently, there is a debate in the academic psychology and sociology communities regarding which theory more accurately describes altruism.

Although altruism is commonly regarded as a key motivation for prosocial behavior, studies have shown that there are other underlying motivations. In a study performed in Switzerland using game theory simulations, the researchers found that participants acted prosocially if they expected reciprocity from the other players (Gintis, Bowles, Boyd, & Fehr, 2003). This may be thought of as a *quid pro quo*: if a player trusts that others will participate then they will participate as well; if there is a lack of trust, then the process breaks down and very few people will participate or cooperate. Another study done in the United States regarding why people donate blood found that social pressure is as strong a motivating factor, if not stronger, than any altruistic feelings in an individual(Condie, Warner, & Gillman, 1976). The same study also found that people who donated blood showed less of a tendency to "free ride" through the system than those people who choose not to donate. This indicates that the "free rider" explanation may be important in how people decided whether or not to participate.

Recent studies investigating cooperation and altruism revealed that spontaneous decisions lead to greater frequency of selfless acts while delayed decisions lead to greater frequency of selfish acts (D.G. Rand, et al., 2012). This would suggest that instinct actually leads to greater altruism. Indeed, the author of this study suggests that the social advantage of cooperation can be the cause for this spontaneous altruism (D.G. Rand et al., 2012).

Oftentimes, organizations in search of donors use monetary or other incentives to attract and convince individuals to donate. However, there has been evidence that shows that incentives can actually backfire in cases where altruistic motivations exist. In 1970, Richard Titmuss introduced a theory of motivational crowding, which suggests that monetary incentives attract fewer individuals overall because some individuals assume that others will donate and that their contribution is no longer needed (Titmuss, 1970). When this happens on a large scale, the end result is everyone thinks someone else will donate and nobody ends up donating at all (Frey & Oberholzer-Gee, 1997). Motivational crowding was originally applied to the concept of blood donation, but the authors showed how the theory also explained why financial incentives actually decreased support among citizens in towns in Switzerland where important buildings with negative consequences (such as power plants or factories) were to be built.

Interestingly, some recent experiments have demonstrated that reward as well as punishment driven by reputation can significantly increase cooperation in economic games (Rand at al., & Nowak, 2009). Furthermore, the cooperation observed when rewards are given actually persists longer than cooperation observed when punishments are served (Rand et al., 2009). Of course, reputation is a major factor that exerts substantial influence on the social interaction and resulting cooperation of the participants (Milinski, Semmann, & Krambeck, 2002). All in all, the current view of prosocial behaviors is still incomplete but it is tempered with fragmented understanding coming from numerous studies analyzing a vast number of theories on altruism and cooperation. We anticipate that our studies will reveal how perceptions of and actual altruistic acts that promote cooperation will factor into the context of genetic information sharing.

3.5 Issue Involvement, Perceived Benefits, Perceived Risks, Risk Aversion

How comfortable do people feel about the sharing and distribution of their personal genetic information? Overall, people are willing to share their personal information given the right set of conditions. In this section, we will explore what these conditions may be.

Privacy concerns have risen to the forefront of the public's recent discourse especially with the expansion of digitized social networks employing specific marketing techniques to mine both the informed and unaware user for personal information (Ashworth & Free, 2006). Research found that people are uncomfortable with the amount of information that for-profit companies are collecting about them (Nowak & Phelps, 1992). Some of this discomfort stems from the covert manner in which this data is collected and some from the nebulous purpose of the collection (Phelps, Nowak, & Ferrell, 2000). People may feel uncomfortable with sharing their private information with these for-profit and commercialized companies, but are they unwilling to disclose their personal genomic information to other organizations as well? Our research seeks to shed further light on this question.

There are many factors that could further discourage individuals from participating in genetic testing. The theory of rational ignorance suggests that, in certain situations, people may wish to remain ignorant – knowledge may offer more drawbacks than benefits (Hite, 1997). For example, if a patient is at risk for a condition such as Huntington's disease, which genetic testing can accurately identify, knowledge of a positive test may weigh heavily on the patient and seriously hinder his or her outlook on life. Without agreeing to genetic testing, widespread sharing of genetic information is unlikely. Even if such information exists, distrust in the security of information storage methods may further impede advances in personalized medicine.

3.5.1 Institutions for Genetic Research: Biobanks

In order to understand the motivations behind the privacy concerns of individuals, examining biobanks and their current practices in handling genetic information is useful. Although generally, consumers are distrustful of the corporate and government collection of genetic information, they are more willing to disclose the same information to biobanks, "the organized collection of biological samples and associated data" (Cambon-Thomsen, 2004). We discuss the public opinions towards biobanks, and issues of concern people have when faced with the choice to share their private information with these research collections.

According to one finding, people's perceived risk and discomfort in disclosing personal genomic information to biobanks decreased to the point of disappearing given a small monetary incentive. Close to 60% of participants would donate to biobanks after a monetary incentive, regardless of their preconceived reservations towards privacy (Kaufman, 2009).

The publics' attitude towards donations to biobanks is positive when individuals are educated and well-informed citizens. In general, education increases an individual's awareness of critical issues in their environment and they may be more engaged with public debates. A Swedish study found that well-informed potential donors were high consenters to entrusting their genetic information for genetic research. Approximately 86% of the Swedish public was willing to donate a tissue sample for research purposes while only 42% of the American general public consented to do the same (Kettis-Lindblad, Ring, Viberth, & Hansson, 2006). Swedish citizens are some of the best-informed in the European Union about biotechnology, and they also have a high willingness to donate – this poses the question of if the American public were to be more informed about biotechnology, would the willingness to disclose for this group rise in numbers? We see that the more involved the individual is with the issue at hand, the more willing he is to donate.

Since biobanks appear to be the most promising institutional arrangement for personal genetic information collection, much discussion has occurred about what kind of rules and regulations must be implemented in order to ensure the safest experience for donors to these biobanks. Of particular interest is the privacy of the donors and the relation between donor and biological material. Should donations be linked to a donor? Should donations be completely independent of the donor? How often does the donor have to approve the use of his or her genetic information? Several schools of thought have arisen to address these general questions.

Legality and the moral imperative of attaining informed consent forces biobanks to contact donors and obtain express permission for each and every test performed with donated material. The basis for this idea comes from the outcome of the Nuremberg trials, with the conviction that "any risk associated with a research protocol must be accepted on a voluntary basis," (Hansson, Dillner, Bartram, Carlson, & Helgesson, 2006). On the other side of the spectrum is the idea of continuous consent. Under this kind of consent, individuals will disclose personal information to biobanks with the agreement that the information may be used for any biomedical research in the future (Elger & Caplan, 2006). Donors in this scenario will not be re-contacted for future use of their material. Though the two ideas discussed here represent the two extremes of consent in biobank research, most biobanks are following paths somewhere between the two.

In addition to the issue of consent, engaging patients more deeply with the processes involved in medical research is important for advancement in the field of medicine and research and development. Patients can be involved in various ways, from being elected members of review boards, to having the option of an opt-out mechanism (Douglas, van El, Radstake, van Teeffelen, & Cornel, 2012).

According to the De Gruyter study of Dried Blood Spot (DBS) Cards, patient involvement should be present throughout the entire research process, from conception to evaluation. This particular study surveyed American parents and found that parents were more willing to have their baby's blood spots collected for research if they were asked for permission, which is an act of participation. Another American study conducted in Michigan concluded that the more specific the description of the object of research that was provided, the more support and participation from individuals was obtained In order for a biobank to be maximally useful, the information it captures must be available for access over a long period of time, potentially over several years and possibly even decades. Results suggest that storage of DBS information over time does not have much support, and storage for over a decade is unsupported, even for research purposes. (Douglas et al., 2012).

Over the years, biobanks have implemented various structural mechanisms to collect, store, and process the reservoir of genomic information. But it appears that people's willing to disclose is not strictly dependent upon the operational structure of a given biobank. It has even been found that people are willing to donate without proper informed consent or even full knowledge of how their information will be used (Hoeyer, Olofsson, Mjorndal, & Lynoe, 2005).

Overall, it is evident that individual disclosure concerns exist. However, they seem to be potentially be overcome when organizations collect the information privately and conscientiously amongst a well-informed public.

3.6 Social Stigma, Number of Diseases, Positive and Negative Health Emotions

Individuals may harbor a variety of beliefs about the consequences of having a genetic condition that are likely to influence how willing they are for the condition to be broadly known. In addition, there are variations in the health status of individuals that could generate specific behaviors in regard to health related decisions. We discuss these influences next.

3.6.1 Social Stigma and Genetic Determinism

Social stigma toward persons with physical, mental, behavioral and genetic deviance from societal norms causes these individuals to struggle with the negative labels given to them (Ablon, 2002). Having such a negative label attached to their identity encourages people to act according to how they are perceived by society.

Stigma not only affects people's personal and professional life, it also impacts their health and medical care decisions. During the final stages of the Human Genome Project, critics brought up the risk of social stigma deterring future participation from gene donors. The fear of stigma if this private information is leaked could prevent people with genetic markers for certain diseases from being willing to participate in genetic research (Sanbar, 2007). This was evident during the initial outbreak years of HIV and AIDS, individuals with HIV were highly stigmatized in society; the government and health care officials framed negative connotations around venereal diseases with the intention of discouraging risky sexual behavior, but these public dialogues also influenced the HIV community to be less willing to disclose their status especially to health care providers (Madru, 2003). Even in the present, the social stigma toward sexually transmitted infection tests discourages college students from seeking testing, due to fear of being perceived as an infected person (Barth, Cook, Downs, Switzer, & Fischhoff, 2002).

Social stigma arises from group mentality that has been documented since the Middle Ages. This concept is called "quarantine mentality" which occurs when healthy society wishes to distance itself from individuals who are “ill” or abnormal (Markel, 1992). People’s first instinct is to stop the spread of disease or infection and, in the process, neglecting those who need service and medical attention. This mentality persists through modern medicine even when many diseases are not transferable from person to person (Crandall & Moriarty, 2011). As a result, having a disease made public can place a person in a very dire situation. All of the above studies suggest that should there be risk of information leakage, avoiding to disclose of genetic information when having a disease or risk of one could be a serious consideration.

In addition to how stigma surrounding genetic disease is shaped by others, it is important to consider how someone would perceive a genetic disease they suffer themselves. This could have great implications on decisions based around that genetic disease. Genetic determinism, within the context of behavior psychology, is a belief that individual action and behavior is determined solely by genetic makeup. Furthermore, behavior and status cannot be changed by individual influence or control. Initially, there was a strong belief that the media’s portrayal of genetic status being deterministic contributes to this way of thought in the public (Condit et al., 2009) However, there has been much empirical evidence to suggest that the attitude of the general public in Western nations tends to lie towards the middle, acknowledging the influence of both genes and the environment in shaping who they are (Hubbard and Wald, 2003) (Rothman, 1998). Despite this, the belief of genetic determinism to some degree can still have an effect on how people perceive genetic conditions. For example, hypercholesterolemia is a disease caused by a combination of genetic predisposition and diet. A study done by Senior et al. (1999) found that when respondents perceived the disease as more genetic than lifestyle-based, they saw it as more uncontrollable and threatening. Furthermore, in another study conducted by Senior et al. (2000), presenting conditions like arthritis and heart disease with genetics as a possible cause, lead to them being perceived as less preventable. In relation to our study, we may see effects of genetic determinism whenever people self-report themselves or their family as having a history of disease. They may show greater negative health emotions than those who do not. Additionally, this may be another deterrence to donating genetic information.

3.6.2 Positive and Negative Health Emotions

Positive and negative health emotions refer to how a person feels about their own health. In psychology, this experience of emotion towards oneself is known as affect. Positive affect, within the context of our study, is when a person has an optimistic outlook on their health while negative affect or negative emotion means they have a pessimistic outlook on their health. Research has shown that positive affect can have benefits in both a patient's health and the quality of care received. Evidence has shown that positive affect is correlated with lower morbidity and increased longevity in the older population (Pressman & Cohen, 2005). Furthermore, exciting the body with bouts of positive affect triggers physiological arousal in immune and cardiovascular function. Interestingly, this suggests that a person who feels better about their health may be better able to maintain their health. This can have a major effect on perception of risk when donating genetic information. In general, there is a delicate balancing act between risk and benefit in decision-making. Healthier well-being may lean towards a greater risk when deciding to donate information.

Following the previous statement, it seems logical to conclude that having negative health emotions would lead to poorer health and a greater incentive to donate genetic information (or a lesser incentive to donate if negative health emotions translate to belief of conditions which could then have a negative effect through stigma). However, this may not be the case. Negative emotions about health can lead to denial of harmful or life-threatening situations (DeNeve, 1999), thereby reducing the likelihood of donating genetic information.

3.7 Trust in People and Institutions

In a world completely dependent on constant social interactions, trust exists to reduce uncertainty and simplify the social world (Luhmann, Davis, Raffan, & Rooney, 1979). "If, in a given situation, the social actors involved are in a position to assess the consequences of their decisions in very exact and reliable terms, trust will no longer be needed" (Bachmann, 2001). But since this is not the case, trust reduces uncertainty by fostering cooperation, dependability, and confidence between individuals. Paradoxically, the perception of these dependable and positive characteristics must be present in order to promote trustworthiness. Indeed, trustworthiness is often seen as the "perceived goodness or morality" of an individual or institution (Fogg & Tseng, 1999). Therefore, increasing trust between individuals or between individuals and institutions can fundamentally change the interactions between the two parties such that cooperation and willingness to endure risk will occur more frequently.

Allowing trust to flourish, especially towards institutions and companies, depends on several factors that would improve one's perception of their honesty and integrity. The past records, actions, and images of any given institution are important in promoting trust in their target audience and customers (Shneiderman, 2000). This suggests that governmental entities and not-for-profit organizations would invoke more trust than their for-profit counterparts because their past records and actions are often made available to the public. Whereas, for-profit companies such as insurance companies would be less willing to disclose their past records and this may lead to lower trust between them and their constituency.

Further, any given social interaction will be interspersed with both trust and power (Bachmann, 2001). Both are able to reduce uncertainty and simplify the social world. However, if one party possesses more power than the other, it may decrease the proliferation of trust, as trust would no longer be necessary to promote cooperation. Finally, trust may not be possible if the associated risk is “seen as intolerably high, and social actors might not be able to find enough good reasons to base a relationship on the assumption that a potential trustee will behave trustworthily” (Bachmann, 2001). In the context of sharing one’s personal information, if the associated risk of information privacy is too high, the likelihood of information disclosure to institutions perceived as less trustworthy would be lower.

In summary, our consideration of the current literature across numerous disciplines regarding the complex issue of genetic information reveals a host of factors that may potentially be at play. A broad examination of the current legal environment suggests that public policy is still evolving in order to effectively address the increasingly unique problem of genetic information privacy and security. Against the backdrop of the legal environment, individual’s willingness to contribute their genetic information for research is evidently influenced by a multitude of factors. Such factors can be broadly organized into specific categories. These categories include demographics, information privacy, perception of well-being, trust in people and organizations, and altruistic versus incentivized behaviors. A thorough consideration of every variable is necessary to understand people's attitudes towards genetic information sharing.

4. Study 1: Survey

4.1 Theoretical Background

Based on the literature review in Chapter 3, we developed constructs for the factors influencing an individual's willingness to disclose personal genetic information to private and public stakeholders for the purpose of medical and genetic research. A conceptual model of the independent variables predicted to influence willingness to disclose was generated as shown in Figure 8.1.1. Our independent variables include five categories of factors: Demographics, Generalized Traits, Genetic Information Sharing Beliefs, Health Status Variables, and Trust in Institutions. We measured the effect of these independent variables on student willingness to disclose with and without parent predictors and on parents' willingness to disclose. Finally, a binary question measured student and parent desire to be informed of their risk of genetic disease after testing.

Four research questions guided the design of the survey. First, what are the factors that are significantly related to an individual's willingness to disclose genetic information to different stakeholders? Second, are their inter-generational differences in the influential factors across two generations: students and their parents? Third, what is the effect of parent's perceptions and attitudes on their children's decisions? And finally, what factors affect student and parent generations' desire to be informed of the results of a genetic test that revealed the existence of a genetic disease?

4.1.1 Research Methodology

We conducted two cross-sectional surveys of students and parents. With the exception of one section measuring the degree of parental influence through 16 additional questions in the student survey, the student and parent surveys were identical. The surveys were designed using validated scales from prior work to the extent they are available, for all research constructs. We conducted a pilot study prior to the main study. In this section we describe the variables included in the survey, how they were measured, and present results from the pilot.

4.1.2 Dependent Variables

The survey conceptual model can be found in Appendix 8.1.1 and a summary of all research constructs and their descriptions is provided in Appendix 8.1.2.The first dependent variable in this study was measured by a person's willingness to disclose genetic information to different stakeholders. It is the arithmetic average of the responses to three items: the likelihood, probability, and willingness to donate to the specified stakeholder. These items were measured on a 1-7 Likert scale with anchors Unlikely/Not Probable/Unwilling to Likely/Probable/Willing. These stakeholders included government, insurance companies, pharmaceutical companies, and health care professionals. For the second dependent variable, respondents were asked if they would choose to be informed if a hypothetical test revealed they were at risk for a genetic disease**.** This was measured on a binary scale where 0 meant "choose to not be informed" and 1 meant "choose to be informed".

4.1.3 Independent Variables

The independent variables were categorized into five conceptual blocks: demographic variables, generalized traits, genetic information sharing beliefs, health status variables, and trust in institutions. The **demographic variables** include factors shown in prior research to influence health related decisions. We considered gender, income, and ethnicity. The **generalized traits** block included constructs to measure broad propensities and attitudes of individuals that are likely to be relevant to the genetic information disclosure decision. Constructs measured included warm-heartedness and altruism (WHA), trust in people (TIP), and information privacy (IP). The warm-hearted and altruism (WHA) construct measured one's level of concern for the welfare of others. Trust in people (TIP) measured one's trust in new acquaintances and strangers, as well as the contingencies of trusting others. Information privacy (IP) measured one's concern for identify theft as well as their tendency to safeguard their personal health and financial information.

Additionally, respondents were asked questions regarding factors that prior research has suggested would have an effect on one's willingness to share personal genetic information. These **genetic information sharing beliefs** variables included issue involvement (II), genetic information privacy concerns (GIPC), perceived risks (PR), and perceived benefits (PB). Issue involvement tested the subject's interest in relevant issues, genetic information privacy concerns addressed risks involved with the electronic storage of data, and perceived risks and benefits outlined the potential advantages or dangers associated with genetic information sharing. Items for the perceived risks and benefits constructs were developed specifically for this study, drawing on prior literature.

A fourth block of independent variables measured **health status variables**. Positive health and emotions (PHE) and negative health and emotions (NHE) revealed how participants felt about their own mental and physical health. Social stigma (SS) referred to the participants' perception of the social opinions regarding issues related to their health. Number of diseases measured family history of disease.

Finally, **trust in institutions** to which genetic information could be hypothetically donated in the survey included government, health care professionals, insurance companies, and pharmaceutical companies. We measured an individual's trust in each of the four institutions. Trust was measured in two sub-dimensions: perceived benevolence and perceived integrity.

4.2 Survey Methodology

The populations for the survey are two distinct generations: parents, in the age group of 35-70, and college students aged 18-24. We recruited survey samples from students enrolled at the University of Maryland and their parents.

4.2.1 Subject Recruitment and Incentives

Students were recruited to complete the online survey via email using a randomly generated listserv of 5000 undergraduate and 3000 graduate students at the University of Maryland, College Park, which was generated for our research by the university's Office of the Registrar. At the conclusion of the survey, students were offered the opportunity to forward the survey to one of their parents. If the selected parent completed the survey, the student and parent responses were matched with a randomly generated ID that contained no identifiable information; its sole purpose was to allow the two survey responses to be linked.

Students received a $5 Amazon gift card for completing the survey and an additional $5 if their parent completed the survey as well. The distribution of reward was done by the survey company, Qualtrics, that hosted the survey.

4.2.2 Survey Procedures

The student and parent surveys were accessible through an email link sent out to participants via the randomized listserv. The survey was available online for five days of data collection before participation in the study was closed due to the sufficient sample size acquired. Survey completion time was approximately 25 and 30 minutes for student participants and adult participants, respectively.

The participants were first asked to read and accept the consent form and sign the University Honor Code to ensure honesty and accuracy of data. Once confirmed, the survey proceeded to a page with the purpose of the research as well as general directions to guide the participants through the survey. The participants were then asked a number of Likert-scaled questions and binary questions dealing with genetic information and information privacy in addition to demographics questions. The student and parent surveys (Appendix 8.3.1) were identical except that the former contained 15 additional items (questions 150-164) to assess the degree of parental influence. While we composed and validated select survey questions, many of the questions were adapted from the thesis "IT is Risky Business: Three Essays on Ensuring Reliability, Security, and Privacy in Technology-Mediated Settings" (Anderson, 2010).

4.2.3 Risks, Confidentiality, and Benefits

While subjects may have experienced some hesitation about sharing their opinions about potentially sensitive subjects such as genetic information, subjects faced no risks greater than sharing unidentifiable demographic information. Participation in the study was entirely voluntary. Participants' responses were kept confidential in a password-protected section of the Qualtrics software and only the researchers of this study had access to the information. Since no identifiable information was obtained, there was no risk associated with our research. Further, subjects were informed that no direct benefits would result from taking the survey other than improved understanding of attitudes towards genetic information sharing.

4.2.4 Pilot Study

Prior to administering the main survey, we conducted a pilot study to ensure that the survey instrument was reliable and valid, and to address any issues with the procedure. Our pilot survey was administered to a convenience sample of freshman undergraduate students enrolled in the GEMS100 Freshman Honors Colloquium: Introduction to Gemstone. A paper copy of the survey was administered and 10-12 students were seated in a classroom at a time and they were asked to complete the survey.

Respondents were asked to leave comments and feedback regarding the design, wording, and instructions of the survey. We assessed the properties of the scales using factor analysis and reliability analysis (all procedures were performed in SPSS). After administration of the pilot study, it was clear a dependent variable measuring one's decision to be informed of their risk involving the genetic disease was needed. The following question was added after the pilot study:

Unless you specifically choose NOT to be informed, if testing reveals that you are at risk for a genetic disease, you would be informed about it.

○ *I would choose to be informed if I am at risk for a genetic disease*

○ *I would choose NOT to be informed if I am at risk for a genetic disease*

Since the pilot study was not administered through the Qualtrics software, respondents' answers were kept locked in the principal investigator's office.

4.2.5 Main Study

At the conclusion of the pilot, the entire survey was put online with the help of Qualtrics, an online-based survey hosting and survey analysis company. Qualtrics allowed us to create our survey on their website and ensure that respondents had completed all of the items on the survey before continuing. In addition to simply hosting the survey online for ease of access, Qualtrics performed two important functions. First, it allowed students to send a link for the parent survey to a user-specified email address. Thus, students were able to ask their parents to complete the survey, and Qualtrics generated a random ID that linked the student and parent responses without any other identifying information. Second, Qualtrics had begun piloting a new feature that would allow Amazon gift cards of a specified value to be given to survey respondents upon the completion of the survey. This allowed for $5 Amazon gift cards to be distributed without the need for collecting emails from respondents and linking those emails to specific responses.

Due to the fact that Qualtrics was starting their own pilot program of distributing Amazon gift cards, they had not yet implemented measures to prevent the same respondent from completing the survey multiple times. This became an issue with the parent survey responses as discussed in section 4.3.2.

4.3 Analysis and Results

In this section we describe the results of the pilot study, including how the final sample for analysis was constructed. This is followed by a discussion of the procedures used for scale validation. We used multivariate linear and logistic regression for our analyses. Results are presented for these analyses.

4.3.1 Pilot study and initial scale validation

Most constructs on the survey were measured using multi-item scales. After the pilot survey was conducted, we performed a reliability analysis to ensure that the items in a scale were logically assessing the same conceptual construct. We also performed a factor analysis to determine if the scales exhibited convergent and discriminant validity and if any refinement was needed. Items were removed from constructs if they were answered differently than the other questions contained in the construct, ensuring that all of the items in a construct represented the same underlying concept.

In order for the variables to be valid for analysis, the questions included in each construct had to be strongly associated. We did not perform factor analysis on all the constructs due to the small sample size of the pilot. This analysis was only preliminary and was done to ensure the survey was ready for the main study.

While the number of respondents included in the pilot study was not large enough for the results to be significant, the results we observed were consistent with what we expected. These results also helped ensure that the survey was ready for the actual run. An important finding from the pilot was that Willingness to Disclose to Insurance and Willingness to Disclose to Pharmaceuticals factored together. This indicated that respondents felt the same way about donating to insurance companies or pharmaceutical companies, and therefore, we combined these two institutions in our final analysis.

4.3.2 Data Tampering

After receiving our final results, Qualtrics notified our team that there were multiple parent survey results from the same IP addresses. This indicated that there had been instances when participants took the parent survey more than once. In order to remove these invalid responses, we analyzed the IP addresses of all parent survey attempts. When an IP address appeared more than once, we removed all responses associated with it. We then cross referenced the IP addresses from the parent survey with the student survey results to remove the results of the students who also took the parent survey. The removal of these flagged results ensured that all survey results used in our analysis were valid.

4.3.3 Sample Representativeness and Response Bias

We wanted to generalize our results to all undergraduate and graduate college students ages 18-24 and parents of such populations. To establish the representativeness of the sample with respect to the national population, we compared the demographics of the both the student and parent respondents to the University of Maryland, College Park demographics and National Census data. Demographics captured in the survey include sex, age, marital status, race, religion, political beliefs, education level, and income. Other factors in consideration included computer usage, computer skills, and history of chronic and genetic illness in family. However, there was limited data to compare to with the overall University of Maryland demographics.

The pool of respondents included undergraduate college students (ages 18-24) at the University of Maryland, College Park and their parents (ages 35-70) which comprised our adult population. Our student sample was fairly similar to the population of undergraduate students at the University of Maryland. While our sample was 61% Caucasian, the University's population is 57% Caucasian. Our sample is 6% African American compared with 13% for the university population. Finally, the Asian population in our sample was 24% compared with 15% at the University. Our male percentage was 50.1% while the University male population is 52%. Finally all other demographics published by the university were within 1% of our demographic information. Data was only analyzed for released demographic information from the university. This data is shown in Appendix 8.1.5.

The survey student sample was not as similar to national demographic information. Asians were overrepresented (24% sample versus 4.8% national) and underrepresented in Whites (61% versus 72%) and African Americans (6% versus 12.6%) (2010 Census Data). However, the gender breakdown was very similar to the national split (50.1% males in sample versus 49.2% nationally).

Unfortunately, the parent survey was less nationally representative than the student sample was. Asians were overrepresented (33% versus 4.8%) while Whites and African Americans were underrepresented (56% and 3.5% respectively). In addition, the gender breakdown was not congruent. (37.6% males in sample versus 49.2% nationally). This may be due both to the smaller parent sample size and the nature of the survey design where students had to recruit their parents to complete the survey for them.

Out of a potential 8,000 student responses, only 379 unique student responses were received after purifying the data, yielding a response rate of 4.73%. The potential parent sample size was approximately 16,000 parents, however after removing tampered results only 85 records remained, yielding a 0.5% response rate. Neither of these rates is very large, so Wave Analysis was run to detect non-response bias (Rogelberg & Stanton, 2007). Using a 2-sample T test to detect if surveys completed earlier had statistically different results from surveys completed later, we found that there was no statistically significant difference for any dependent variable for either parents or students.

4.3.4 Scale Validation

After cleaning the data for the main study as described previously, we ran the same reliability and validation tests and obtained similar findings. As was seen in the pilot, the factor analysis showed that insurance and pharmaceutical industries grouped into one dependent variable, so we settled on three final willingness to disclose variables: government (WDG), health professionals (WDHP), and insurance and pharmaceuticals (WDIP). Summary statistics for the variables can be found in Appendix 8.1.3 – 8.1.4. Reliability analyses and correlation tables can be found in appendices 8.1.7 – 8.1.11. Items that did not correlate well with the constructs were not used in the final analysis

4.3.5 Results

We used regression analysis to answer the research questions. Three regression models were used to analyze the impact of a variety of factors on the willingness of students, parents, and students with parent predictors to disclose their genetic information to the government, health care providers, and the insurance and pharmaceutical industry. In this section we present the results of the student regression first, followed by the parent regression, and we conclude with a regression of student results with parent predictors.

4.3.5.1 Student Sample Results for Willingness to Disclose

Results for willingness to disclose for the student sample can be found in Appendix 8.1.12. Increases in income were inversely related with disclosing to the government. African Americans were less likely disclose to all three institutions: the government, health professionals, and insurance and pharmaceutical industries. Warm-hearted altruism was positively associated with disclosing to health professionals but negatively associated with disclosing to insurance and pharmaceutical industries. Issue involvement was positively associated with disclosure to the government. Genetic privacy concerns were strongly significantly negatively associated with all three dependent variables but perceived benefits were positively associated with all three. Perceived risk was significantly negatively associated only with insurance and pharmaceuticals. Social stigma was negatively associated with government and significantly negatively associated with health professionals. Positive health and emotions were positively associated with willingness to disclose to insurance and pharmaceuticals. Trust in each institution was strongly positively related to willingness to disclose to the same institution.

4.3.5.2 Parent Sample Results for Willingness to Disclose

Information Privacy was negatively associated with willingness to disclose to government and very significantly negatively associated with willingness to disclose to insurance and pharmaceuticals (Appendix 8.1.13). Warm-hearted altruism was strongly significantly positively associated to disclosure to health professionals while issue involvement was negatively associated with insurance and pharmaceuticals. Genetic privacy concerns were negatively associated with health professionals in addition to insurance and pharmaceuticals. Increases in both the number of diseases and positive health and emotions increased the likelihood of willingness to donate to health professionals. Negative health and emotions were positively associated with insurance and pharmaceuticals. Further, trust in government and trust in health professionals were strongly positively associated with willingness to disclose to the corresponding institutions.

4.3.5.3 Results for Parental Variables on Student Willingness to Disclose

The parental variables that were associated with the student willingness to disclose variable can be found in Appendix 8.1.14. The adjusted r-squared value was 0 for government and negative for insurance and pharmaceutical companies. Because the adjusted r-squared values compensate for the addition of independent variables to the model, the zero and negative values were expected. Parental genetic privacy concern was negatively associated with a student's disclosure to insurance and pharmaceuticals. Parents' perceptions of social stigma associated with genetic disease were negatively associated with student's willingness to disclose to government and insurance and pharmaceuticals. Finally, parent trust in health professionals was very significantly positively associated with student willingness to disclose to the government and health professionals.

4.3.5.4 Student Decision to be Informed Results

The association of different variables with student's decision to be informed can be found in Appendix 8.1.15. Larger scores for information privacy increased the likelihood of choosing to be informed. Social stigma increased the likelihood while the number of diseases in the family decreased the likelihood. Negative health and emotions was negatively associated with the student's decision to be informed (Appendix 8.1.15). It was the only significant relationship in the regression.

4.3.5.5 Parent Decision to be Informed Results

The table that described the associations between parental variables and parental decision to be informed can be found in Appendix 8.1.15. Information privacy was strongly significantly positively associated with parent decision to be informed.

4.4. Discussion of Findings Related to Willingness to Disclose

Our analyses offered answers to the research questions guiding the survey: first, what are the factors that are significantly related to an individual's willingness to disclose genetic information to different stakeholders? Second, are there inter-generational differences in the influential factors across two generations: students and their parents? Third, what is the effect of a parent's perceptions and attitudes on their children's decisions? And finally, what factors affect students' and parents' desire to be informed of the results of a genetic test that reveal the existence of a genetic disease?

We first discuss the regression results for both parent and student willingness to disclose genetic information to the three stakeholders: government, health professionals, and insurance and pharmaceutical companies. The discussion is grouped into the five classes of independent variables: Demographics, Generalized Traits, Genetic Information Privacy Concerns, Health Status Variables, and Trust in Institutions. Interpretation of the student and parent regressions is followed by regression results for parental influence where students' willingness to disclose was regressed on parent predictors. Finally, we discuss the binary logistic regression for student and parent desire to be informed of potential risks identified during genetic testing.

4.4.1 Demographics

Our study included three key demographic variables that have been associated with a range of attitudes and behavior in prior work: gender, income, and race. Men and women have been found to behave differently in a variety of settings; for example, in situations involving financial risk, females are less likely to participate regardless of the circumstances (Powell & Ansic, 1997). Due to the financial risks involved with sharing genetic information, we expected that females would be less willing to share their genetic information than males; however, we found no significant difference (Appendix 8.1.12). One explanation for the lack of significance for gender is that sharing genetic information is not considered a financial risk by individuals simply because the financial costs and benefits are not always clear. For example, some individuals may believe that current law protects them sufficiently from genetic discrimination and that the risk is non-existent. If the decision is not viewed as a financial risk, participants would not be expected to act differently based on their gender. However, this result should be interpreted with caution because it could also reflect a low level of general understanding of the costs and benefits of sharing genetic information. If this is the case, then gender differences could be expected to emerge over time as the public becomes more informed.

Although higher income has been associated with decreased confidence in government (Peters et al., 2004), the influence of income on confidence in non-governmental groups, such as insurance companies, pharmaceutical companies, and the medical community is less clear. We find that among students, higher income has an inverse relationship with willingness to share genetic information with the government. Unexpectedly, there were no significant effects for the parent sample or the other institutions. Non-significance for income of parents could be due to the small sample size or some other unknown reason. The lack of significance for the other institutions was not unexpected, as prior research has not indicated income would affect confidence in these groups. The relationship between income and willingness to contribute to stakeholders other than government merits further investigation.

African American students were unwilling to disclose their genetic information to any of the institutions included in the study. This result, while perhaps surprising in the second decade of the 21st century, is nonetheless consistent by the history of African Americans in the United States where African Americans have experienced centuries of systemic and institutionalized discrimination. Examples of this include incidents such as the Tuskegee experiments purposefully harming African Americans, all the way back to slavery issues (Gamble, 1997). While current levels of institutionalized discrimination are orders of magnitude less than historical levels, the distrust engendered by this mistreatment may still be evident, resulting in a lower willingness to disclose potentially sensitive information.

Due to the potential health benefits of sharing genetic information, this finding is somewhat disturbing. It may take a long time before African Americans trust institutions with their personal genetic information. Therefore, medical advances based on shared genetic number risks may have a reduced impact on the African American community. Since a small amount of African Americans were surveyed, this relationship should be reevaluated with a larger sample size of African Americans in order to strengthen the evidence base.

4.4.2 Generalized Traits

Our study included three generalized traits and attitudes that can potentially influence an individual's willingness to disclose: trust in people, information privacy concerns, and warm-hearted altruism. In general, we expected a positive association between willingness to donate their genetic information and an individual's tendency to being warm-hearted and altruistic. Altruistic individuals are concerned about the welfare of others, without expecting or desiring any sort of pay-off for themselves. By donating their genetic information, people are allowing researchers to gather more information, which could further the social cause of personalized health care.

We found a significant positive relationship between altruism and willingness to disclose for the parent sample only for the stakeholder of insurance and pharmaceutical companies. Surprisingly, when examining the student results, the relationship is negative: altruistic students are significantly less likely to donate their information to insurance and pharmaceutical companies.

This finding may be an outcome of the fact that students scored themselves as being more altruistic than they really are. Many people would like to believe they are altruistic, especially when they are directly asked. Such inaccurate self-ratings would help to make students feel better about themselves regardless of how altruistic they may be. If this occurred consistently throughout the survey, the average score and the distribution of scores for a student's self-reported altruism would be skewed towards being more altruistic. If the true average of students' altruism were lower than the sample average, the association between altruism and willingness to disclose would weaken. This appears to have happened when compared with the parent results, as the coefficient for this variable is much smaller for the students as compared to the parents. Additionally, if the students consistently scored themselves too high, the sample average may influence willingness to disclose in a negative way. For example, people who actually are not altruistic, but respond that they are moderately altruistic will be less likely to donate their genetic information, causing the coefficient for the construct to become negative.

A second explanation for the discrepancy between students and parents is that students may believe that insurance and pharmaceutical companies will not use their information in an appropriate way. If students perceive the companies as using their information in a harmful way, or at least in a way that is beneficial only to the companies, they may not be willing to donate their information. In this light, they may not donate their information in order to prevent another group from misusing it. In this case, students may actually be as altruistic as they report, but simply are shielding the misuse of their information by not donating at all. This could then cause a difference in the association between the students and the parents.

Finally, for both students and parents, results indicate that being warm-hearted or altruistic does not influence willingness to disclose to government or health care professionals. Perhaps these stakeholders are viewed as less threatening to privacy violations than insurance and pharmaceutical companies, thereby rendering the effect of altruism insignificant.

Privacy concern originates from multiple sources and is a function of the experiences an individual has with personal and sensitive information over time. A general concern for information privacy may affect attitudes towards genetic information as well. Drawing on findings in prior literature, initially, we hypothesized that a greater concern for privacy information would be associated with decreased willingness to share genetic information. After all, the most effective method of protecting one’s personal information is simply to not share it. Interestingly, we found no significant association between students’ concern for information privacy and their willingness to share their genetic information to any of the three institutions. Although counter-intuitive, we attribute such lack of association to the students' apathetic attitudes toward personal information as a whole (Malhotra, Kim, & Agarwal, 2004). Since they are the generation that grew up in an environment saturated with technology in which not sharing one's personal information online appears almost unavoidable (shopping online, social networking, online applications, etc.), it is likely that sharing their genetic information would make little difference to this generation of digital natives (Mann, and Hoffman). Further, their concern for information privacy certainly would not increase their willingness to share their information (Kang, 1998). As a result, their concern for information privacy neither increased nor decreased their willingness to share such information.

The results for the parent sample are similar to the student sample with one important exception: parents' concern for information privacy is negatively associated with willingness to share their genetic information with insurance and pharmaceutical companies. It appears that the parental generation has dealt more with the complexity and financially motivated self-interest of insurance and pharmaceutical companies simply by having more interactions with and a longer exposure to these institutions. As a result, the parent population in our sample who are concerned about their information privacy would be less likely to share their genetic information with private, for-profit organizations such as insurance and pharmaceutical companies. Since the other two institutions in our studies are non-profit entities or actively involved in our health care, the concern for information privacy in the parental population is not a significant factor in influencing their willingness to share their genetic information.

Trust, in a general sense, is a tendency to regard others as benevolent and competent. Usually, this is directed into the future where a trustor gives control of a situation to a trustee such that the trustor must rely on the decisions made by the trustee. Based on this idea, it was expected that trust in people would be a strong indicator of how willing someone would be to donate their genetic information. If someone is generally trusting towards individuals, they would continue to be trusting towards institutions and therefore would give control of their genetic information to institutions. Instead, there was no significance found between trust in people and willingness to donate information.

Trust in people did not show significance for any of the institutions when looking at student response, parent response, or student responses with parent predictors. This lack of significance could potentially be a result of the fact that the trustee in this situation is not an individual, but an institution. With the point of view taken above, sharing personal genetic information is not being directed as trust in a single person but an entire group of people that operate under a specific institutional arrangement and set of norms. Trust in people may influence relationships at the inter-personal level, but this lack of significance suggests that the respondents to the survey perceive institutions as a distinct social structure from individuals. Respondents may also believe that because institutions are comprised of large groups of individuals, their information is not as secure since only one individual is required for their information to be misused.

4.4.3 Genetic Information Sharing Beliefs

The third block of hypothesized influences on willingness to disclose, issue involvement, personal genetic privacy concern, and perceived benefits and risks, captured individual attitudes and beliefs about issues that are more proximal to the outcome. Issue involvement indicates how aware or how relevant an issue is to a subject, usually through the individual's previous life experience. The issue involvement construct was composed of three questions involving the relevance of invasion of privacy, potential misuse of electronic health records, and computer security concerns for an individual. We found that the student's perception of issue involvement is a marginally significant influence on willingness to disclose to the government, but not significant for other institutions. Perhaps students perceive government as an institution that is competent in ensuring the security of sensitive information.

For the parent sample, issue involvement did not significantly affect their willingness to disclose to any of the institutions. It may be the case that the issue was not salient to this generation because they had no previous exposure to privacy invasions. However, given the small sample size, this finding should be interpreted with caution

Survey participants were asked to respond to five questions regarding perceived benefits of genetic information sharing. Potential benefits of genetic information sharing addressed in the survey included medical advancement and discoveries, developing research for treatment of diseases, improvements to the current health care system, and the use of genetic markers as a tool in the future of medicine. For students, there was a strong positive relationship between perceived benefits and willingness to disclose genetic information to government, health professionals, and insurance and pharmaceutical companies. This indicates that the more students believe that genetic information will yield social benefits, the more likely they are to share it.

The perceived risk construct included discrimination based on genetic information and how poor health could influence an employer's view of an individual. In general, we would expect people with a high perception of risk to be less likely to entrust their genetic information to the government, health professionals, and pharmaceutical and insurance companies. For students, these perceived risks were significant only for pharmaceutical and insurance companies. This indicates that students who believe that an employer's knowledge of a genetic disorder or poor health would put them at risk are less likely to entrust their genetic information to pharmaceutical and insurance companies. This comes as no surprise because it is common belief that insurance companies may charge higher premiums for customers who are at a higher risk of poor health. On the other hand, the student values were insignificant for the government and health professionals, indicating that perceived risks are not a barrier to the disclosure of genetic information to these institutions. For the parent sample, perceived risks were not significantly associated with the disclosure decision for any of the three institutions.

4.4.4 Health Status Variables

Factors reflecting an individual's health condition and associated beliefs were hypothesized to have an effect on the decision to disclose. We included four variables in this fourth block: perceptions of social stigma arising from a genetic condition, the number of diseases an individual is suffering from, and positive and negative health and emotions. Results from the survey demonstrated that the more students perceived the social stigma of a genetic disease, the less likely they were willing to donate their genetic information to the government. From a historical perspective, government policies regarding healthcare have led to stigmatization of certain populations. For example, the city of Chicago passed a law in 1901 that did not allow disabled or mutilated people to be in public areas. This was only recently repealed in 1974 (Ablon, 2002). On a national level, the AIDS epidemic of the 1980s led the CDC to publicize at-risk populations such as homosexuals and Haitians without concrete evidence regarding the cause of this disease. Subsequently, members of these groups were greatly stigmatized (Madru, 2003). Given their checkered past, awareness of social stigma would indeed decrease willingness to donate information to the government. Interestingly, social stigma did not significantly affect the willingness to donate to health professionals or insurance and pharmaceutical companies. These entities generally hold objective perspectives regarding diseases and have little direct influence on shaping public policy that may promote social stigma. Such views may explain why there is no statistical significance between perception of social stigma and willingness to disclose to health professionals, insurance and pharmaceutical companies.

In contrast to the significant effect for perceived social stigma for students, we do not find a significant effect in the parent population. One explanation for this difference may be that the younger generation is more influenced by what “others think” and may worry less about losing social approval. Older adults may be less susceptible to the need for social approval and therefore, social stigma is not a significant factor in their disclosure decision.

The number of diseases in the family did not affect the students’ willingness to donate to any of the entities. One explanation of this finding is David Elkind’s concept of the personal fable. This phenomenon describes how many adolescents believe that “[they] will not die, that death will happen to others but not to [them]” (Elkind, 1967). This belief is inherently false, but the perception can lead to adolescents to take more risks that they might not have as they grow older. In this case, they are not concerned that there is a family history of disease because they believe that they will not contract the diseases. If they are not worried about disease, they may not feel the same compulsion to donate their genetic information.

An individual with a family history filled with hereditary diseases should be reasonably expected to donate their genetic information more than an individual with a family history with no or few hereditary diseases. Indeed, our survey shows that parents with a high number of diseases in their family are more likely to donate their information to health institutions, though less likely to donate to the government and insurance agencies. As discussed subsequently, our survey discovered that parents place a high degree of trust in health professionals. When an adult knows that they can be potentially afflicted with a genetic disease, it makes sense for them to donate their information to a group that they trust and can help them-- health professionals. Even though we also discover that parents of college students trust the government and generally do not trust insurance agencies, neither of those two institutions is found to be significant for people with a high number of diseases in the family.

Positive health and emotions in the context of our research describes how positively people look at their life and their health in the present moment. That is, someone who is in high-spirits and is healthy will answer questions in this section higher than individuals who are lonely or are sick. Student respondents who felt more positive about their current physical and mental health were more likely to donate their information to the insurance and pharmaceutical industries. One reason for this result is that patients could try to use their positive image to try and negotiate better care or better rates. A 2004 study found a perception among patients who presented an optimistic view of themselves to insurance that they could obtain better medical care. This belief was especially found in ethnic minorities and lower socioeconomic positions (Malat, van Ryn, & Purcell, 2006). This idea could convince students to donate their material because if they present a good image to the insurance company and back it up with genetic material, they could potentially receive a monetary gain or better care because the company views them as less risky. Presenting themselves in this manner to their doctors or the government yields no advantage to the students, which could be why they do not play a significant role in the model.

We also found that parents of college students who view their health better are more likely to donate to health professionals but not to insurance and pharmaceutical companies like their children. When an adult feels that they are healthy, they may feel more magnanimous and believe that donating their genetic information will have a positive impact on research. This mindset is unique to the parents and does not reflect in the regressions for the students.

Negative health and emotions in our research describes how negatively people look at their life and health in the present moment. Someone who is worried about their health or someone who is sick will score high on this variable. Interestingly, we find that people negative health and emotions is positively associated with donating to health professionals. A student’s negative perception of their mental and physical health had no significant impact on donating to any of the organizations. One rationale is that the negative self-image is something that is too day-to-day to want to report to any of these entities. Respondents presenting a negative image could put themselves in a worse situation, so there is no incentive to donate to insurance like there is with positive self-image. There is no disincentive to donate, however, because the next day they could feel more positive about their situation.

On the other hand, parents of college students who are sad and despondent about their health may believe that sharing genetic information with health professionals would increase the likelihood of better treatment, and the alleviation of their poor health condition. In other words, when people are sick, they may believe their doctor may help them. Likewise, to the degree that insurance and pharmaceutical companies can be instrumental in finding cures for ailments, negative health and emotions increases individuals' willingness to provide information that may contribute to the cure. Since this despondency can be expected to increase with age, it makes sense that negative health and emotions is significant only for parents and not with their children in the context of health professionals and the insurance/pharmaceutical industries.

4.4.5 Trust in Institutions

The final block in our conceptual model include a single variable that we believed*, a priori*, to be the single most potent influence on willingness to disclose highly sensitive personal information. The measurement of this construct tapped into individuals' perceptions that the target institution would act in their best interest, would be willing to help the individual, was interested in the individual's well-being, was truthful, would keep its commitments, and was sincere and genuine. For both samples we found highly significant effects of trust in government and health professionals on willingness to share genetic information. These results are consistent with a large body of prior research noting that a willingness to expose oneself to the risk of opportunistic behavior by another party is highly dependent on how much trust exists between parties

(Lars et. al). Institutions can garner trust through three mechanisms: community, frequency of use, and authority (Luo, 2002). Both students and parents are likely to have had multiple interactions with the government and with health professionals, and both institutions reflect varying degrees of authority.

Whereas trust in insurance and insurance and pharmaceutical companies is positively associated with willingness to disclose for students, that is not the case for the parent sample. There are two plausible explanations for this result. One is that the small sample size for parents may have reduced our ability to detect a significant effect. Alternatively while parents may trust insurance companies due to authority and frequency of use, they may not be comfortable with what the insurance company could do with their information (Norberg, Horne, & Horne, 2007). For example, people perceive that an insurance company could deny coverage if they are genetically screened for a disease. This is different from government and health professionals because they are limited in how they can negatively affect a person with that information. Thus, trust in this institution does not influence their willingness to share sensitive information. In fact, it may even benefit a person for a health professional or the government to have that genetic information about them.

4.5 Student with Parent Predictors

One of our research questions sought to understand inter-generational transfer of attitudes. To address this, we regressed the child's willingness to disclose to the different institutions on parent's perceptions and attitudes. In the following section, we discuss which parent variables were significant in student willingness to disclose and whether they shared a positive or negative relationship. In addition, we discuss parent variables that were not significant in our study but we expected to be transmitted based on previous literature.

Three attitudes that were transmitted based on parent predictors were warm-hearted altruism, perceived benefits, and trust in institutions. Essentially, if a parent was altruistic, if they perceived benefit in donating their genetic information, or if they trusted health professionals, the student was more likely to donate information. This was only significant in predicting information disclosure to health professionals. The reason why these three variables are only significant for health professionals, as opposed to government or insurance/pharmaceutical companies, is because altruism and perceived benefit may only be relevant to health professionals. It is logical to think that there is no benefit in being altruistic towards the government or insurance companies as there is nothing to gain from donating information to those organizations. Historically, people have been very wary of giving up information to both these institutions (Harris 1974). However, with health professionals, people may see a benefit of being altruistic. Donating information could perhaps lead to a cure or better treatment for the greater population. This explains why the transmission of these variables did not explain student disclosure to government or insurance and pharmaceutical companies.

It makes sense that altruism would be passed from one generation to another. Previous literature has demonstrated that levels of volunteering and donating in children are associated with the same behavior of their parents (Hodgkinson and Weitzman, 1996; Willhelm 2008). However, we also found in our literature review that perceived benefits differ between age groups (Youn, 2005). The method in which the older generation assesses rewards is much different from the younger generation. This contradicts our findings that perceived benefits are transmitted from parent to child. To explain this, we believe that behavior relating to perceived benefits can be transmitted intergenerationally, but these alone do not make up a child's method of benefit perception. Perhaps other social cues and developmental factors play a larger role than parental influence in developing this behavior.

Another factor that we found to be significant for students with a parent predictor is perceived social stigma. Specifically, there is a negative correlation between a student's perception of social stigma should they donate and their eventual decision on whether or not to donate their genetic information. This means that when parents perceive social stigma, their children's views on stigma are negatively correlated with their donation decision. This can be explained through the students' identification as part of a stigmatized group. In this case, the students see their parents' perception of a stigma that negatively affects them, and thus feel like they are affected by the stigma as well. Crocker and Major find that when individuals identify with a stigmatized group, in this case a group with some sort of genetic disease, their perception of a stigma lowers. However, that lowered stigma is accompanied by a decrease in motivation to help out the stigmatizing group, even when they have the ability (Crocker and Major, 622). For the context of this research, the stigmatizing group is any of the three institutions: government, health care, and insurance.

There were also certain parent variables that we expected to be transmitted to students, but were not within our study. One of these variables was perceived risk. Previous literature on the topic finds that both parents and their children perceive risky situations to the same degree adults (Ashman et al., 2003). However, this was not apparent from the results of the survey. It is interesting that perceived benefit was transmitted and perceived risk was not, when the literature says the opposite. Again, this is attributable to the role that parental influence plays in the development of these behaviors. Parental influence may have a larger role in developing a child's altruism and social stigma than it does in risk-benefit evaluation.

4.6 Discussion of Results for Desire to be Informed

An unresolved question related to the ethics of genetic research is whether individuals who are found to be at risk should be informed or not (Knoppers, Joly, Simard, & Durocher, 2006). Individuals may also choose not to be informed in the fear that such knowledge may require radical lifestyle or other changes. Acknowledging the conceptual similarity between the desire to be informed and willingness to disclose personal genetic information for research, we modeled the predictors of this outcome using similar logic, but eliminated variables that were likely to be not important to this decision. We included the demographic variables of income, race, and gender. Among the generalized traits, we only included information privacy. Genetic information sharing beliefs variables were genetic information privacy concerns and electronic genetic information privacy concerns, while the same health status variables were included as in the previous regressions. Finally, we did not include measures for trust in the various institutions as that is not relevant to this particular choice that individuals are making.

Both students and parents who are concerned with information privacy want to be informed. When people are vested in the privacy concerns of their personal genetic information, they are more likely to want to learn about what that information consists of. People wish to take proactive steps to protect their personal health or financial information, and being informed is part of the process. In order to protect a certain set of personal information, people first need to know what this information is. Arthur Miller says, "...the basic attribute of an effective right of privacy is the individual's ability to control the circulation of information relating to him.." (Miller, 1971). In order to have full control of their information, people must fully understand what they are working with.

Social stigma has some impact on the desire individuals have to be informed. This was marginally significant for student, but not significant for parents. For students, there was a marginally positive association between perceptions of social stigma associated with genetic disease and their desire to be informed. This finding is plausible in that individuals with social stigma would probably find it beneficial to know about any potential health issues they might have before others can find out. They can then use the information to prepare themselves for any social consequences relating to their future health status.

The number of diseases in an individual's family has some effect on students' desire to be informed. For students, there is a slight negative association; the more diseases in a student's family, the less desire they have to be informed.

It is not surprising that a young person wishes to remain ignorant of potential health problems that plague their families. Rather than living with the knowledge of a potentially far-off disease, the student can live safely in the dark. This finding echoes the core tenets of the theory of rational ignorance, which suggests that people will choose to remain ignorant of some knowledge that will impart no utility or may involve some sort of drawback (Hite, 1997). In this case, a student could perceive no additional benefit to his or her life if they learn they have the same disease as someone in their family, and may in fact perceive negative outcomes. Specifically, a student may feel that if they knew they had some disease like Alzheimer’s that will not affect them for many years that their quality of life will decrease.

Students with negative health and emotions showed a strong desire not to be informed of being at risk for a hypothetical genetic disease. This means that students who felt negatively about their mental and physical health did not want to know whether they were at risk of a genetic disease. This finding reinforces the theory of rational ignorance, as explained above. Students with negative health and emotions rather live in ignorance of potentially life-threatening conditions because they feel that they have limited control over their present health condition.

5. Study 2: Experiment

5.1 Background

As with all decisions in life, people weigh various factors when deciding whether or not to donate their genetic information to some organization. Potential benefits for doing so would be learning about personal health issues before they become a problem or contributing data for scientific progress towards finding a cure. A potential risk would be some unwanted group, such as the government, an employer, or an insurance company, gaining access to genetic information, which can potentially lead to discrimination. The decision to donate may be driven by intrinsic altruism, aversion to risk, and perception of their health status. These factors and a number of others, to varying degrees, drive an individual's decision to donate their genetic information.

The motivation for the experiment was to understand how factors such as altruism, risk aversion, and perceived risks impacted the decision to donate in a causal way. The experiment presented participants with hypothetical health scenarios and the risks they represent. Although the situations and scenarios were hypothetical, choices were incentivized through monetary payments. Gains and losses in real life had corresponding monetary payments in the experiment. Through the experiment, we expected to understand how variables such as having a genetic disease, existence of a cure, risk of insurance or job discrimination, and financial incentives would influence a person's decision to donate his or her genetic information. In order to find further nuance in the donation decision, participants were also given the option to be informed of the results of their genetic testing and to invest some portion of their income in an asset that pays off if the subject remains free of disease, but not if they become afflicted by the disease. Choosing to be informed directly increased a participant's chance of being discriminated, but also allowed the participant to fully understand their risk level. This decision, then, measured an individual's balance between wanting to understand their risk and minimizing that same risk. If a participant chose to invest their income, they lost some income if they fell sick, but gained some if they did not. Investing, therefore, measured an individual's perception of their risk.

Participants were presented with the opportunity to earn real monetary income based on the decisions they made throughout the experiment. In each round of the experiment, participants earned a fixed amount of income, $8, which could increase or decrease based on a number of factors. Most notably, this number would drop dramatically if the participant fell sick from some hypothetical disease. The first decision a participant made was whether or not to donate their genetic information, and when there is an incentive to donate, their income for the round would increase if they donated. However, subjects who donated risked the chance of discrimination, which could lower their income. Another decision a participant could make was to invest some portion of their income. Participants would lose this investment if they fell sick, but they would win their investment back if they were healthy or a cure were found for the disease. A cure can be found if no participant donates during a round, but the chance of the cure being found increases dramatically with each additional donation.

Since a participant's ultimate goal is to weigh their options and maximize their payout at the end of the experiment, making decisions based on available incentives is an important aspect of the experiment. Each health state had a corresponding monetary consequence, influencing these decisions even further. The overall design of the experiment was to present participants with a series of scenarios that would determine the causal impacts of the various factors previously discussed.

5.1.1 Variable Selection

The purpose of using a game theory based experiment was to closely mimic a person's working life through the money earned, health events, and the decisions that needed to be made. All of the variables used can be found in Appendix 8.2.2, and this section will discuss the meaning of each variable as well as the reasons it was used in the experiment.

The first variable selected was whether or not a participant would be afflicted by a disease. The affliction would be represented by two variables: the first was the affliction risk, which was a probability that the participant would have the disease, and the second was a Boolean value representing whether or not the participant ended up afflicted. The affliction rate was affected by both the treatment and the participant's constant risk level. That is, each participant was either designated as being at "low risk" or "high risk" for being afflicted, and kept that risk level for the entire experiment. However, this risk level designation was nominal only—the experiment was designed in such a way that subjects who were designated "high risk" had the same risk level as those who were "low risk." However, they were led to believe that high-risk subjects were twice as likely to fall sick as low risk subjects. In each treatment, that risk level and some treatment-specific variables determined whether or not that individual was afflicted.

Paired with the affliction variable was a marker status variable. Everyone had a 75% chance of having a genetic marker and a 25% chance of not having the marker. The presence of a marker indicated that it was likely that the participant was afflicted, though the marker could be a false positive. That is, a participant could conceivably have the marker but not be afflicted. This additional piece of information was intended to help people make further informed choices based off of their health status. Since participants did not know that they would always be afflicted, the marker had meaning, whereas if they knew they were always afflicted, it would have none.

The next variable to be included was a monetary incentive for deciding to donate genetic information. Half of the treatments played had a monetary incentive associated with donating information, and half of the treatments had no monetary incentive associated with donating. The purpose of this variable was to determine if there were participants who were altruistic. In general, if a participant donated their information when they were at low risk and there was no opportunity for monetary reward, they were likely to be considered more altruistic than if they withheld their information. This is based on the fact that donating their information increases their personal risk, but there is no benefit to the participant if they donate their information (Batson & Shaw, 1991). There was also the possibility of motivational crowding, where a participant who would normally donate in an altruistic way actually chose not to donate when there was an incentive to donate (Titmuss, 1970).

There were three additional variables added to the experiment in order to reflect the lifespan of a working individual. The final three variables chosen were all selected together due to the interactions they had and the ways they could affect risks and sickness chances. When a person is afflicted with a disease, this disease can often go unnoticed and not have any negative effect on an individual's life. Therefore, the first of the three variables added to the experiment was whether or not a participant would become sick. A person must be afflicted with the disease in order to become sick. However, there will be no negative effects until they become sick. Once the sickness starts, there is some loss of income in order to represent the increased insurance and medical costs in addition to the discomfort associated with the disease. This variable works in the same way as affliction: there was a probability that a person became sick, referenced as sickness chance and an associated Boolean variable that actually controls whether or not a participant was sick.

The next variable was whether or not an individual would be discriminated against due to their disease. An individual who donated information, and then was found to have a marker for the disease, could find that this information fell in the wrong hands, and led to their being discriminated against. This discrimination is not necessarily on a moral basis or due to prejudices, but may simply be due to the facts of the disease. For example, a person with multiple sclerosis cannot perform a construction job. This is not a reflection of their intellectual ability or their personality, but it is still a limitation on what types of jobs are available. As stated before, most people are generally not discriminated against due to their disease unless they are sick, but it is possible to be discriminated against even if they are not sick. For example, people with an Alzheimer's marker can be discriminated against even before they get the disease. Therefore, being sick greatly increases the chance that a person is discriminated against. This variable is also controlled with a probability and an associated Boolean variable: the probability of being discriminated is the discrimination chance. If someone is discriminated against, they have a loss of income in the game that represents the loss of job opportunities or health insurance coverage.

Based on this model, it was possible that participants could be discriminated against without being affected by the disease. Choosing to donate would cause information to become privately known, increasing the chance of an information leak as well as the resulting discrimination. Additionally, choosing to be informed about the marker status would increase the chance of discrimination. These affects were added because it has recently been shown that with a very limited amount of information, genetic information can be traced back to a specific individual. Therefore, simply choosing to donate or being informed would increase the likelihood of discrimination.

The final variable that was added was the presence of a cure for the disease. There are many diseases that no longer have much of a negative impact on society due to the fact that a cure has been found. The discovery of a cure requires voluntary contributions of many individuals' genetic material. In order to incorporate this into the experiment, the chance that a cure was found was made to be a function of how many people have donated their genetic information in the game itself. There was a base probability that a cure would be found for a disease, known as the cure chance. As each participant donated his or her information, the chance that the cure was found was increased by a set amount, the "impact to cure". It was this amount that was varied between the 16 different treatments of the experiment. Participants were told that if they donated their information, the cure chance would be increased by the impact to cure amount. Because simply donating their information was enough to increase the chance of discrimination, those who were not at a high affliction risk but still donated were expected to be more altruistic than those who did not donate their information under the same circumstances. After all of the participants decided whether or not to donate, the cure chance was finalized and whether or not a cure was found was calculated. The difference with this variable was that all participants would have the exact same value for their cure variable; either a cure was found for all participants, or a cure was not found. Finally, if a participant had become sick and a cure was found, they would lose some money, but not as much as if a cure had not been found. This loss of income with a cure represents having to pay for the cure and take any necessary time off of work.

Together, the four disease-dependent variables act to modify each other. In order to have any effects on the treatment, a person must first have a disease, calculated at the beginning of each treatment by the affliction variable. Once a person has a disease the affliction variable cannot be changed. At this point, a person must develop the sickness, again a Boolean variable calculated by the sickness chance variable. If a person is discriminated against they will start to lose some of their income. This discrimination can occur due to having donated their information, choosing to be informed of the results of genetic testing, or both. Finally, if a cure is found, the negative effects of the affliction Boolean variable will be changed and the negative effects of the discrimination Boolean variable will be changed. Despite this, there will be a slight income loss in order to represent paying for the cost of the cure. Overall, there is a complex, combined effect of many variables and decisions in determining the results of each treatment.

To separate the effects of the variables, we created an experiment design that tests individuals' willingness to disclose their information given differing levels of some of the variables listed above. Specifically, four variables were defined to have a high value and a low value, which resulted in sixteen total rounds for the experiment. Depending on the round, there could be a high or low value for each of the following variables: monetary incentive to donate, chance of falling sick if already afflicted, individual impact to the cure chance, and chance of discrimination. Every participant played each of these sixteen possibilities, which were presented in a random order that changed each session.

5.1.2 Augmenting the Emotional Decision

One issue with this experiment was having the participants be emotionally invested in their decisions so that they would not simply try to earn the most money possible. Instead of trying to take money out of the picture, we decided that adding an investment decision along with the donation decision would help us to determine whether they perceived themselves to be at risk.

After deciding whether or not to donate their information and whether or not they wanted to be informed about their health status, participants were brought to a screen that asked them whether they would like to make an investment. If the participant became sick and a cure was not found in that treatment, they would lose their investment and therefore have an income loss. However, if the participant was not sick or a cure was found in the treatment, they would keep their investment and their income would increase. Participants could additionally use information from their donation and informed decisions in order to help them with their investment decision. For example, if a participant has a marker for the disease, they are at higher risk for becoming sick. Therefore, for someone who expected to be healthy, they could increase the amount of money they earn, but they took the risk that there could be a loss of income if they became sick. Finally, they could choose not to make an investment at all, in which case there would be no corresponding increase or decrease of income.

This additional variable, known as the investment variable, helped to describe whether or not participants believed they were at risk. Those who were afraid of falling sick would not invest any money, preventing a loss of additional income. Those who did not feel any risk, or at least a minimal risk, of falling sick would invest money, potentially increasing their income.

Participants were not told the values for any of the probabilities associated with the variables in the experiment. The values for the probabilities also had a slight random influence. For example, there was a baseline 25% chance that a cure would be found, but that number was not made public to the participants. Therefore, for each successive trial, participants would not be able to correlate their monetary payoffs. It was probably sufficient that the values were simply not stated, but this was an extra precautionary measure to help create an emotional decision. One exception to this was that participants were told that donating their information would increase their chance of discrimination by 20% and that choosing to be informed about their health status would increase their chance of discrimination by 20%. The baseline discrimination was always set at 0%, but this value was not explicitly stated. Therefore, if a participant donated their information, their discrimination chance would become 20%, if they chose to be informed, it would increase by an additional 20% to a maximum of 40%. At this point, the discrimination multiplier, one of the high or low independent variables, was multiplied to give the final discrimination chance.

In order to ensure that participants understood the consequences of their decisions, a table was attached to the end of the instructions handout, with which they were provided, that described the monetary consequences of various events in the experiment. This is attached in Appendix 8.3.2.1, but an example is that when there is an incentive to donate, donating information would increase a participant's income by $0.80.

5.2 Experiment Methodology

5.2.1 Subject Recruitment

Our target population was 100 University of Maryland students ages 18-24. In order to select the participants for this portion of the study, we used two listservs to which team MAGIC members were a part of: the University of Maryland Honors Listserv, and the same randomized listserv that was generated for the survey portion of the study. This listserv was a randomized list of 5,000 undergraduate students and 3,000 graduate students from the University of Maryland, College Park. An email was sent to this list stating that we required 100 participants for a hypothetical game theory based simulation. The times and locations of each session were stated in the email. Participants were provided with a link that would allow them to sign up to one of the sessions of the study through the use of Google Forms. Additionally, Dr. Gao, a professor in the School of Business, informed his undergraduate students of the study and participants were recruited from his class. Dr. Gao offered his students extra credit in his class for their participation in the experiment. There were no factors other than student status that could eliminate participants from the study.

5.2.2 Decision Tree for One Round

There are several possible outcomes that can occur when playing each treatment of the experiment. Each treatment starts with every participant having an income of $8.00. Based on the decisions made throughout the treatment, this value can increase or decrease. At the beginning of each treatment, participants are informed about the relative values of several variables. The first variable is the affliction risk, which can be either high or low. The next variable is the chance of falling sick, which represents how likely it is a participant will become sick given that they have the disease. If they do not have the disease, the participant will not become sick. The percent chance that a cure is found is a function of how many participants donate their information during that specific round. The amount that each participant contributes to increasing the chance of a cure can be high or low. Finally, they are told whether they will be paid $0.80 for donating their information.

At the beginning of the session, during the instructions, participants are told how these variables can affect their monetary income. For example, if they fall sick and cure is found, they will not lose as much money as if they fall sick and a cure is not found. They are also told that if they donate their information, there is an increased chance that they could be discriminated due to loss of confidentiality. After making a decision on whether or not to donate their hypothetical genetic information, participants could be taken to the “informed choice” screen. If participants decided to donate their information, they were able to make a decision about whether or not they wanted to be informed about their marker status. They are also told that if they chose to be informed, there was a 20% increased chance of discrimination. If participants decided not to donate their information, they would skip over the decision to be informed.

The final screen that presents a decision asks whether or not they would like to invest their income. They are told that there are three outcomes that can occur from their investment decision. If no investment is made, the investment does not impact the income for the round. If an investment is made and they do not become sick or a cure is found, they will earn $1.20. If an investment was made and they become sick and a cure is not found, they will lose $1.20.

Based on the information provided, participants were able to make three decisions: whether to donate their information, whether they would like to be informed about their results, and whether they would like to make an investment of income knowing that there could be potential loss of income in certain cases. These three variables, regressed against the five high and low variables, allowed us to determine how participants viewed the risks involved with each decision and the potential benefits they could receive.

5.2.3 z-Tree

The experiment was written using a program called z-Tree (Zurich Toolbox for Readymade Economic Experiments), a software package developed at the University of Zurich's Department of Economics and intended to aid in the development of economic experiments (Fischbacher, 2007). z-Tree allows a developer to design an experiment that links many participants, or clients, to a central controlling computer, or host. z-Tree is popular for designing experiments because it has a large number of built-in features necessary for any kind of experiment with subjects: keeping track of money earned, resetting the game for multiple rounds, the inclusion of practice rounds, easy communication between the host and clients, and more. We chose to use z-Tree for the experiment for its flexibility. Since z-Tree handles connecting many participants to each other and keeping track of money, it allowed the developers on the team to spend their time programming the experiment rather than working on the infrastructure that made it run.

A z-Tree program is separated into several distinct parts which can be combined in order to make any kind of economic experiment. First, there is the Globals table. This table keeps track of any variables that should be the same for all participants. For example, since every participant plays the same round at the same time, the round number is stored in the Globals table. Second, there is the Subjects table. This table keeps track of any variables that are unique to each individual participant. For example, in many experiments, participants earn a small amount of money every turn. This amount can be different per participant and should be stored in the Subjects table.

In order to interact with the variables, z-Tree has a customizable screen that the experiment developer creates. Each decision in our experiment is a different version screen in z-Tree. This allows each decision to use and set the variables necessary in the experiment. Screenshots of the z-Tree program are available in Appendix 8.3.2.2.

5.2.4 Risks, Confidentiality, and Benefits

The two risks anticipated in participating in the experiment are fatigue due to the hour long session, and anxiousness or unease due to the treatments presented. The fatigue was somewhat compensated due to the fact that each round only lasted roughly three minutes, allowing for participants to have a short break between each round. In order to keep participants at ease about discussing hypothetical personal health issues, they were told many times at the start of the session that no information of their own would be recorded at any time during the session.

The participants did not provide any personal information during the experiment at all. They were asked to show their student ID's in order to enter the behavioral lab to match with their assignment of session time period. They were also asked to sign their names on the consent form. There are no other uses or needs for participants' personal information before, during, or after the experiment. Demographic information was taken only to ensure a reasonable population set.

The only anticipated benefits of the experiment for the participants were the monetary rewards provided for participation. There were no anticipated benefits for the researchers other than data for research. We hope to be able to use this information to determine what factors influences an individual's willingness to disclose personal health information. This information could then be used to propose legislative measures that would allow the general populace to become more comfortable sharing their personal health information.

5.2.5 Procedures

On the day of the experiment, each of the students was asked to arrive 10 minutes before their assigned session time. The location used was the R.H. Smith Business School Behavioral laboratory, which contains computers for each of the students to use during the experiment. Each student was asked to sit at a computer and fill out the consent form and demographic survey on the desks. These computers were separated by partitions so that participants could not see what others were writing or typing on screen. Each computer already had the program, z-Tree, running without any additional setup. The proctors of the experiment, the students on Team MAGIC, read the instructions, risks, and benefits aloud to the entire group. All of the documents pertaining to the performing the experiment are available in Appendix 8.3.2.

At this point, the session proctors walked all of the participants through a packet of screenshots and explained all of the visual elements of the program. This allowed for all of the participants to step through the entire game before they were asked to do it alone. Instructions were read aloud from a script, attached in the appendix, in order to ensure that all participants received the same information within the session and between sessions.

Once the instructions were completed, participants were instructed to start the two practice simulations, providing them with a chance to understand how each of their decisions affected their net income at the end of the round. Both of these practice rounds were timed and were no different from the 16 main rounds. Data from these rounds were not used in any of the analysis of the experiment and participants were told that these rounds would not count towards determining how much money they would earn for their participation. Participants were allowed to proceed at their own pace through both practice rounds but were required to finish within the time limit, just as in the real rounds in the experiment. Both of these practice rounds had different variable values than the rounds the participants played later in order to prevent participants from simply copying these rounds. However, the main difference was that these rounds did not count towards their reward for participation.

Once the experiment started, each participant had the allotted time of thirty seconds to re-read the instructions, thirty seconds to decide if they would donate their personal health information, thirty seconds to decide to be informed of the results of testing, and thirty seconds to invest. They were free to complete the decisions as quickly or slowly as they pleased within this time limit. These time limits were selected after completing the pilot study. During the pilot study, participants noted that one minute was too much time as it simply dragged out each treatment. Additionally, the majority of the participants made their decision within five to ten seconds, showing that no additional time was required. Finally, it was hypothesized that providing too much time would result in participants attempting to learn the system and earn income rather than making decisions that they perceived ask minimizing risk.

At the end of each round, the program started the next round at the same time for all of the participants so that each of the participants finished the session together. Once the experiment finished, each participant was given the amount of money that they earned in the experiment based on a randomly selected round from the 16 rounds that were played. Participants were clearly told during the instructions that during each round they could earn up to $10.00. However, one of the sixteen rounds would be randomly chosen at the end of the experiment and participants would receive their income only for that round. They were also provided with a $10.00 reward for participation alone. Therefore, based on the decisions that were made during the experiment, participants could earn anywhere between $10.00 and $20.00. Once the participants received the money that they earned in the experiment, they were free to leave.

There were seven different sessions during which the experiment was conducted. Each of the sessions had between ten and sixteen participants, with a maximum occupancy of eighteen participants. During each session, all of the participants played two practice treatments and the full sixteen-treatment experiment. One possible difference between the seven sessions is that the cure percentage had a different maximum value when there were a different number of participants. However this was not a significant impact as the “impact to cure” value was too small to create large changes in the cure chance.

5.2.6 Pilot Sessions

Two pilot sessions of the experiment were run in the week before the final data collection began. The purpose of the pilot sessions was to determine if the instructions were clear, to make sure the software ran as expected, and to allow the researchers to rehearse their roles for the main sessions. These pilot sessions were run following the same procedures as the main sessions outlined in the previous section, except with different subject recruitment and an additional feedback phase at the end of the experiment.

Subjects for the pilot study consisted of friends of researchers, and were given pizza for their participation instead of money. Upon completion of the pilot study, the subjects answered questions by the researchers in order for the researchers to gain a clear understanding of how the subjects felt during the experiment. The question and answer afterwards proved to be very valuable for modifying the instructions and software for the main sessions. Some of the changes based on this questioning were:

- Instead of displaying the instructions at the beginning of all sixteen rounds and both practice rounds, only display during the practice rounds and the first real round.
- Make the wait screen more descriptive when other players are finishing the round.
- Combining several summary screens into one screen at the end of each round.

Additionally, the pilot study showed that z-Tree had an unexpected amount of lag between each screen displayed to the participants, which was frustrating to them. This problem was also ironed out before the main sessions began.

5.3 Experiment Results

5.3.1 Experiment Demographics

The experiment in total had 94 respondents that completed the demographics survey. There was one participant who did not turn in their demographics survey and so their information was not used in any of the analysis of the results. In Appendix 8.2.4 of this document, several pie charts are shown that represent the overall demographics distribution of our experiment participants. There was an almost even split along gender lines with 49% male and 51% female participants. There was a large distribution of races with roughly 30% Asian, 15% African American, 2% Latino, and 53% Caucasian. The religious views of the participants showed that the majority were Christian, Jewish, or unaffiliated with small representations of other religions. The majority of the participants were Democratic with the remainder being split between Republican and independents. More than half of the participants had a family income level of greater than $100,000 and more than three quarters of the participants had a family income level of greater than $50,000. Finally, 85% of the participants were undergraduate students with the remainder were undergraduates having an associate's degree before coming to the university. There was one participant who stated that they had a doctorate degree, but this is likely to be a false report by the participant.

The experiment sample was fairly similar to the university's demographics. Males were underrepresented slightly (49% sample versus 52% university), whites were underrepresented slightly (53% versus 57%), African Americans were overrepresented slightly (15% versus 13%), and Asians were overrepresented substantially (30% versus

15%). Data was only compared to released demographic information from the university. This data is shown in Appendix 8.2.4.

The experiment sample deviated more from national percentages. Males were marginally underrepresented (49% sample versus 49.2% nationally), whites were underrepresented substantially (53% versus 72%), African Americans were slightly overrepresented (15% versus 12.6%), and Asians were significantly overrepresented (30% versus 4.8%) (2010 Census Data).

5.3.2 Experiment Correlation Tables

Each of the independent variables was correlated with the decisions made during the experiment. These correlations help to establish the existence of relationships between the dependent and independent variables in the study. From the tables available in Appendix 8.2.5, the impact to cure, incentive, impact to discrimination, and religion unaffiliated are all significantly correlated with the donation decision and the informed decision. None of the other variables included in the correlation are significant with any of the decisions made during the experiment.

5.3.3 Game Analysis

In order to analyze the results of the experiment, random effect logistic regressions were run for each of the dependent variables: the decision to donate, the decision to be informed, and the decision to invest. This model was chosen because each dependent variable was binary and there were repeated observations for the same subject, so the data were not all independent as is the assumption for a simple logistic regression. Fixed effects models were also run (without the demographic variables); however, the results are almost identical so we focus our analysis on the random effects model. These results can be seen in Appendix 8.2.8.

The decision to invest was split into two regressions due to the fact that participants had differing amounts of information when making the investment decision. Some players had chosen to be informed, which could only happen for individuals who had chosen to donate that round, and therefore knew their marker status. Meanwhile, other participants chose not to be informed and did not know their marker status or did not make a decision during the time allotted. Therefore, two investment regressions were created, one for investment decision when the marker status was known and another for the investment decision when the marker status was unknown. The table that contains the regression coefficients for all four of the experiment regressions can be found in Appendix 8.2.7 at the end of this document. In this table, the stars after the regression coefficients represent the significance of each of the variables. One star is a significance level of 90%, two stars is a significance level of 95%, and three stars is a significance level of 99%.

Since some of the subjects received extra credit for participating in the experiment, we had to determine if this discrepancy provided any statistical difference to the subjects’ responses. We ran two sample t-tests for each of the four regressions: one test for students receiving extra credit and one test for everyone else. No significant differences were found between the two samples, indicating that receiving extra credit did not have the additional affect on changing the participants’ decisions.

When looking at the regression results, only two of the demographic variables were significant across the four regressions, and even then, they were only marginally significant. The unaffiliated religion demographic had a negative association for the donate decision and the decision to be informed, indicating that on average, people who report their religion as unaffiliated are less likely to donate their information and are less likely to choose to be informed of their results of genetic testing. The total family income demographic had a negative association for the investment decision when the marker status was unknown, indicating that on average, the higher the participant's family income, the less likely they are to invest when they don't know their marker status.

Each of the treatment variables was significant for at least one of the regressions. The impact to cure had a strong positive association for the donation decision, the investment decision when the marker status was known, and the investment decision when the marker status was unknown, indicating that on average, as an individual's potential impact towards finding a cure increases, people will donate and invest more regardless of marker status. The sickness chance had a negative association for the investment decision when the marker status was known and a strong negative association for the investment decision when the marker status was unknown, indicating that on average, when the chance of a participant falling sick increases, the less likely they are to donate or to invest regardless of marker status. The incentive had a strong positive association for both the donation decision and the investment decision when the marker status was unknown, indicating that on average, when there was an incentive to donate, people tended to donate more and invest even without knowing their marker status. The impact to discrimination had a strong negative association for each of the donation decision, the decision to be informed, and the investment decision when the marker status was unknown, indicating that on average, when the chance of discrimination increased, people were less likely to donate or to invest. The “marker present” marker status had a strong negative association for the investment decision, indicating that on average, when people knew their marker status (regardless of whether they had the marker or not), they were less likely to invest.

5.4 Experiment Discussion

5.4.1 Demographics

5.4.1.1 Unaffiliated Religion

The variable that represents participants who are not religiously affiliated is significant for two of the decisions that participants make: whether to donate their information and whether to be informed about their marker status once they have chosen to donate. In both cases, the regressions have negative coefficients. That is, people who are religiously unaffiliated are less likely to donate, but if they do, they are less likely to choose to be informed of their marker status. In this study, religiously unaffiliated means atheist, agnostic, or unaffiliated religion, based on the available choices in the demographic survey.

A person’s decision on whether or not to donate has a lot to do with their overall generosity. In treatments where specific variables have been found to decrease donation rates, personality traits like generosity or altruism play a large part in determining whether a person donates. In general, studies have found that people who do not affiliate with a specific religion are less generous. They are less likely to donate money to the poor (Regnerus et al., 1998), are less generous towards anonymous strangers (Norenzayan & Shariff, 2008), and show less empathy and altruism towards others (Smith, 2003). Since the act of donating in this experiment necessarily increases an individual’s risk to being discriminated, but increases the chance of a cure being found, we can assume that those who choose to donate even in harsh treatments are doing so through generosity towards the other participants in the session. The correlation found makes sense then, since religiously unaffiliated people, who are often less generous than the rest of the population by elimination, choose to donate less often.

Based on the literature we read, we were not expecting the unaffiliated religion variable to have an association with the decision to be informed. Indeed, we have no explanation for why this association occurs, either supported by literature or by reasoning through it.

5.4.1.2 Family Income

We found that in general, students from families with higher incomes are less likely to invest their income when they do not know their marker status for the disease. In our experiment a participant who does not know their marker status when investing has either not donated their information or decided to not be informed of their marker status. This unwillingness is likely a reflection of the financial literacy the participant has developed from being in a household with financially successful parents. Children often model their financial patterns based on what they observe in their family (Clarke, Heaton, Israelsen, & Eggett, 2005); this certainly applies to investment practices. When a participant in our study was presented with a scenario where they did not know their marker status, and by extension, their chance of being sick, they tended to invest more conservatively, i.e., not invest their income. Additionally a student will more successfully implement sound financial decisions the more they are exposed to those decisions at home (Clarke et al., 2005). We can conclude that higher income at home leads to an increase in financial literacy of college students, which translates to this negative correlation we observed when choosing to invert without knowing the marker status.

5.4.2 Treatment Variables

5.4.2.1 Impact to Cure

The value of the impact to cure was a very significant positive factor in determining whether a person was willing to donate. This makes sense because the more likely it is that a cure is found, the more advantageous it is for the individual to donate. The participants make the decision to donate before they know if they have the disease. Therefore, if they end up having the disease they have a higher chance of survival due to the higher cure chance. If they did not have the disease, they hedged their risk. The associated increase in cure chance also increased the likelihood that the participants will invest regardless of whether or not they know their marker status. This is because they will make money if they were not sick or if they were sick but the cure is found. Not surprisingly, the impact of the donation does not influence the decision to be informed about the disease status since that decision occurs after the donation decision and the effects of knowing marker status do not impact the likelihood that a cure is found.

5.4.2.2 Sickness Chance

The sickness chance itself for the participant surprisingly did not have any impact on the willingness to donate, but was significant in the investment decision. It was also insignificant in the decision to be informed. When making the decision to donate genetic information, participants must weigh the risks and benefits of their decision. For example, donating could result in an increased income, but at the same time, it increases the risk for discrimination.

Initially, it was expected that an increased sickness chance would cause participants to be more likely to donate. This is due to the fact that by donating, the cure chance increases and finding a cure would negate any negative sickness impacts. However, by donating, participants increase their chance of discrimination by 20%. This changes the decision because they increase their risk of a negative effect by a known amount, whereas the cure chance is dependent on all of the other participants. Additionally, the perception of the sickness chance changes drastically if players believe themselves to be at low risk of affliction. In this case, players believe that they won't be afflicted and therefore they cannot become sick. Therefore, the impact to cure that their donation decision has is not important for eliminating potential risk. Due to all of the different effects of the donation decision, the sickness chance did not have a significant impact to the decision.

The sickness chance did not have a significant impact on the decision to be informed. This is a result of the interactions between the variables: the decision to be informed allows for the marker status to be known and changes the discrimination chance. The difference between a high and low sickness chance has no impact on the decision to be informed or any of its results.

The sickness chance had a significant influence on the investment decision when the marker status was known and when the marker status was not known. The investment decision effectively is an assessment of each participant's risk level. The variables that influence the investment decision are the sickness chance and the cure chance. Therefore if participants have a high sickness chance, they would not want to make an investment, eliminating the risk of losing money. Alternatively, if there is a low sickness chance, participants would not perceive as much risk in making an investment and would try to maximize their income.

5.4.2.3 Incentive

Giving participants additional profit just for donating their information is significantly correlated with two decisions: whether to donate and whether to invest when their marker status is unknown. The profit incentive is strongly positively correlated in both cases. This correlation means that when there is an incentive, people are more likely to donate and choose to invest their income when they do not know their marker status. The first regression is self-explanatory: when people are given money for donating, they will donate more often than when they are not given money to donate. In treatments where a participant may usually not feel the need to donate, the promise of an additional $0.80 is enough to change their minds.

It is initially more difficult to comprehend why a participant would associate an incentive for donating with investing their income when their marker status is unknown. Interestingly, this phenomenon can be explained by the attempt to maximize profits. When a participant sees that the incentive variable is high and they choose to donate, they have taken the first step towards reaching the maximum income in a treatment: $20. In order to get this maximum payoff, they also have to invest their income, not get sick, and not be discriminated against. After making a decision to donate, participants are given the choice of whether or not they want to be informed about their marker status. This decision cannot increase their profits itself or through any of its effects, causing the incentive to not be significantly correlated. Additionally, this effect can be a reaction to a perceived reduction of risk involved in the investment. When there is an incentive to donate, the participant may assume that many of the other participants will donate in order to get the incentive, increasing the chance of a cure being found. This cure will guarantee that an investment will pay off, encouraging the participant to invest in the first place.

The incentive does not influence the decision to invest because the incentive has already played its role in the treatment. Therefore, when a participant makes their investment decision when they know their marker status, the decision is independent of the incentive. However, this changes when the participant does not know their maker status. In this scenario, the majority of the risk regarding their investment decision is hidden due to the fact that they don't know their marker status. As previously stated, participants know that they can only earn the maximum $20 if they choose to donate and choose to invest while not becoming sick or being discriminated. Therefore, when the risk of losing their investment is partially hidden, participants will invest, hoping that they will earn the maximum income despite the presence of any risks. The key difference between the two types of investment decision is the knowledge of the marker status. When the marker status is known, there is more knowledge about the risks involved and participants decide more conservatively. When they do not know their marker status, the decision simply becomes a chance to maximize profits.

5.4.2.4 Discrimination Impact

The variable that represents the discrimination impact is strongly significant in three of the four regressions: the donation regression, informed regression, and the investment regression when no marker status was available. The only regression where there was no significance was the investment regression when the marker status was available. In each of the regressions where this variable was significant, the coefficient of the variable was negative, meaning that if the discrimination impact value increased, the likelihood that the player would donate their information, choose to be informed, or make an investment decreased. Additionally, each of the coefficients had a moderate magnitude.

These trends can be explained by examining the risks that are involved with each of the decisions in the game. When choosing to donate their information, the participants were told that there would be an increased chance of discrimination if they donated their information. Therefore, in order to prevent increasing the risk of being discriminated against and thereby increasing the chance of a loss of income, participants would choose to not donate their information. The decision to be informed increases the chance of discrimination the same amount as the decision to donate their information. By the same thought process, if a participant decides to be informed about their health status, they increase the risk that they will have a loss of income. As a result, participants will eliminate this risk by choosing to not be informed about their health status when there is an increased chance of discrimination.

The effect the discrimination impact has on the investment decision can be explained by realizing that participants are trying to maximize their profit in each round. Technically, only the affliction variable and the cure variable affect the investment decision. However, when a participant does not know their marker status, they have less total information about the scenario. In this case, participants could perceive that there is a high risk of having the disease because their marker status is unknown. However, they are told that there is a high overall discrimination impact, making their chance of discrimination more likely than if the discrimination impact were low. In order to prevent any further loss of income that may occur due to their health status and whether or not they were discriminated against, participants would not make an investment.

The investment decision changes entirely with respect to the discrimination impact variable when the participant's marker status is known. As stated previously, discrimination does not actually play a role in the calculation of investment success. Therefore it would be expected that the discrimination impact would not have a significant effect on whether or not an investment is made. This is seen when the marker status is known; in this scenario, participants know how likely they are to be afflicted by the disease. If they do have the marker, they will not invest regardless of the discrimination impact, but if they do not have the marker, they likely will invest in order to maximize the income for the treatment.

5.4.2.5 Has Marker

The variable that represents whether or not a participant has a marker for the disease is strongly significant only in the investment regression when the participant knows their marker status. The donation decision and the decision to be informed are not significant because the knowledge of the marker status does not occur until after these decisions are made. When a participant has the marker for the disease, they know that they are at high risk for being afflicted by the disease, thereby causing them not to make an investment. Alternatively, when a participant does not have the marker for the disease, they know with 100% certainty that they will not be afflicted by the disease, thereby ensuring that they will see a return on their investment. This is supported by the significant result in this regression. Finally, when the maker status is unknown, participants do not have any additional information about their risk of affliction. At this point, participants would choose to make an investment purely based on their ability to maximize their income. Therefore it is expected that this variable would not be significant in this regression.

6. Conclusion

6.1 Summary of Study Findings

6.1.1 The Survey

At the conclusion of the survey, we gained some insights into the complexity of the genetic information disclosure choice. Our findings show that many different personal traits and situational events influence someone's decision on whether or not to disclose personal genetic information. The first study in our research project asked survey respondents about different personal traits regarding demographics, generalized traits, genetic information sharing beliefs, health status variables, and trust in institutions. Each of these traits and the constructs of which they are composed were treated as an independent variable and regressed against willingness to disclose information. The dependent variables in the first study were the willingness to disclose information to three different institutions: government, health professionals, and insurance or pharmaceutical companies. Respondents were asked how willing they would be to donate their genetic information to these three institutions. The final dependent variable was a respondent's willingness to be informed about their health status, asking if the respondent would like to know the results of a genetic test if they donated their information.

There were four groupings of regressions created for the survey. The first three groupings regressed each of the independent variables against the willingness to disclose to three institutions. These first three groupings were student responses, parent responses, and student responses with parent predictors only. The final regression group regressed each of the independent variables against a student or a parent's choice of being informed about their health status.

Our survey results are applicable to students ages 18-24 and parents of such populations. Students had significant positive associations between issue involvement, perceived benefits, and trust in government and their willingness to disclose their genetic information to the government. They had significant negative associations with their income, race (African-American), personal genetic privacy concerns, and social stigma with their willingness to disclose their genetic information to the government. Students had significant positive associations with perceived benefits and trust in health professionals with their willingness to disclose their genetic information to health professionals. They had significant negative associations with their race and personal genetic privacy concerns with their willingness to disclose their genetic information with health professionals. Students had significant positive associations with perceived benefits, positive health and emotions, and trust in insurance and pharmaceutical companies with their willingness to disclose their genetic information to insurance and pharmaceutical companies. They had significant negative associations with their race, warm-hearted altruism, personal genetic privacy concerns, and perceived risks with their willingness to disclose their genetic information to insurance and pharmaceutical companies.

Parents had a significant positive association with their trust in the government and their willingness to disclose their genetic information to the government. They had no significant negative associations with their willingness to disclose their genetic information to the government. Parents had significant positive associations with number of diseases, positive health and emotion, negative health and emotion, and trust in health professionals and their willingness to disclose their genetic information to health professionals. They had a significant negative association with personal genetic privacy concern with their willingness to disclose their genetic information to health professionals. Parents had significant positive associations with warm-hearted altruism and negative health and emotions with their willingness to disclose their genetic information with insurance and pharmaceutical companies. They had negative associations with information privacy and personal genetic privacy concern with their willingness to disclose their genetic information to insurance and pharmaceutical companies.

Students with parent predictors had no significant positive associations with their willingness to disclose their genetic information with the government. They had a significant negative association with social stigma with their willingness to disclose their genetic information to the government. Students with parent predictors had a significant positive association with trust in health professionals with their willingness to disclose their genetic information to health professionals. They had no significant negative associations with their willingness to disclose their genetic information with health professionals. Students with parent predictors had no positive associations with their willingness to disclose their genetic information with insurance and pharmaceutical companies. They had significant negative associations for personal genetic privacy concerns and social stigma with their willingness to disclose their genetic information with insurance and pharmaceutical companies.

It was possible to interpret our survey results through a number of theoretical lenses. The impact of income on disclosure to the government was explained by increased antipathy towards the government as income levels rise (Peters et al., 2004).

The impact of historical institutionalized discrimination against African-American explained the impact of race on disclosure of genetic information. The impact of warm-hearted altruism on disclosure to insurance and pharmaceutical companies was explained by a disbelief that insurance and pharmaceutical companies would be well intentioned with genetic information. The influence of issue involvement on disclosure was explained by the idea that greater understanding of genetic information would decrease fears of the unknown. The relationship between personal genetic privacy concerns and disclosure was explained by fears that the current safeguards were not sufficient to protect the identities of genetic information. The impact of perceived benefits and number of diseases on disclosure was explained by a self-serving reasons for disclosure, such as cures for their own illnesses. Social stigma effects on disclosure can be explained by fears of embarrassment if information leaked to the public. Positive health and emotions might be related to disclosure on the basis of the belief that disclosure could lead to decreased health care costs. The impact of negative health and emotion on disclosure to health professionals was explained by the fact that disclosure could be used to improve health.

6.1.2 The Experiment

The second study sought to determine the situational effects that would influence someone's decision to donate their personal genetic information. A game theory based experiment was developed that allowed participants to earn money based on the decisions they made. There were five independent variables: the likelihood of being afflicted by a disease, the incentive to donate, the likelihood of becoming sick after being afflicted by a disease, the overall impact to discrimination, and the impact to cure. All of the variables except affliction had a high or low value that was dependent on the treatment. In addition to the treatment independent variables, each participant completed a demographic survey. These demographics were used as independent control variables in the regression analysis. The dependent variables that were measured were the decisions made by the participants: whether or not to donate their information, whether they want to be informed about their health status, and whether or not to invest some of their income. Based on these three decisions, there were four logistic regressions performed: decision to donate, decision to be informed, decision to invest with known marker status, decision to be informed with unknown marker status.

After completing the four logistic regressions, each of the four treatment variables that changed was determined to be significant in at least one of the four regressions. Impact to cure was determined to be significant for decision to donate and for the investment with unknown marker status. This shows that when people feel they can make a difference in contributing to a cure, they are more likely to donate. Next, sickness chance was only significant for the investment decisions, showing that people were trying to leverage their risk when making investments. Incentive clearly has a significant effect on the decision to donate as participants would earn money for making a decision when there is no additional risk. This could have major implications for policy actions. The impact to discrimination served only to increase the risk of losing money to discrimination; this effect is shown in that participants are much less likely to donate or be informed, and they appear to try and leverage risk when they have limited information. Finally, when participants are informed about their marker status, they are much less likely to invest their income.

Overall, there are a couple of simple rules to which the average participant appeared to abide. First, try to maximize income when there is no additional risk involved. Second, try to minimize risk by making decisions that do not increase discrimination. Third, when there is inherent risk involved, such as when the discrimination risk and sickness chance are high, make decisions that will minimize risk later in the treatment. All of these basic rules can help to identify suggestions for future health policies.

6.2 Suggestions for Future Health Policy

Our findings offer a number of useful implications that could help inform policy at local, state and national levels. In the experiment, people were shown to be negatively influenced by discrimination risk. Whenever participants were at a high risk for discrimination, they were much less likely to donate their information, much less likely to choose to be informed, and much less likely to invest when their marker status was unknown. As a result, future health policy needs to address the issues involved with discrimination. Currently, health policy addresses who is allowed access to information and when that information is allowed to be shared, but more extensive policy is required in order to make sure that this information is used in the correct way by institutions such as Insurance and Pharmaceutical Companies.

Additionally, the survey results show that Personal Genetic Privacy Concerns negatively influences willingness to disclose for all populations; while this factor does not negatively influence willingness to disclose to all institutions for the two generations, it is nonetheless an important factor to at least one institution for each population. There have recently been several cases of online information privacy violation in many different domains. Additionally, it has been recently shown that de-identified genetic information from databases can be re-identified (Malin 2004). As a result, future legislation needs to address two important issues: one, the alleviation of public concerns through messaging that privacy concerns are being examined in the development of policy, and two, the physical nature by which information is stored. All of these factors suggest that a delocalized database system with several layers of security access may be the best solution. Regardless of the solution that is chosen, both the threat of discrimination and the threat of privacy need to be addressed as major concerns in future systems of genetic-based personalized healthcare.

6.3 Future Work

After spending three years researching and designing our studies, implementing them, and executing the data analysis, we see several aspects of the research that can be improved in the future, as well as robust opportunities for further work. In the experiment, the risk level for each participant could be modified with low and high risk to determine how participants would change their decisions. If the affliction risk were to be changed for each participant, there would be measurably different results. Our experiment found that the risk level for participants was not a significant factor in any of the decisions made. This result is to be expected because all of the participants had the same risk level. In order to more fully understand people's perception of risk, it would be beneficial to test other variations of risk in the experiment.

An improvement on the implementation of the survey would be to develop a method that would increase parent response rates. In our experiment, we had 85 parents respond compared with a student response rate of 379. We incentivized parent responses by rewarding the students for their parent's responses, but this clearly did not have as much of an effect as we had intended. It may have been necessary to shorten the parent survey by eliminating repetitive questions in each construct. This could have caused less confidence for each of the parent construct averages, but it may have increased the response rate. Additionally, a different method of incentive could have been used in order to get parents to respond to the survey. For example, the $5 participation reward could have been increased to $7.50 where $5 went to the parent who responded and $2.50 went to the student linked to that parent response.

A major issue with the survey was that it was possible for the same user to complete the survey more than once. This led to a massive data set for which most of the responses were not meaningful. The issue stems from the fact that Qualtrics did not have a method of restricting participation once the link was emailed to our large listserv. This hopefully will have been fixed before any other surveys are used with Qualtrics again.

6.4 Conclusion

The field of health and medicine has an unprecedented opportunity ahead of it that can significantly improve the development of future treatments through analysis of genetic data. A critical precondition to this is the development of large and representative collections of genetic information. Motivated by the need to understand if and under what conditions individuals would be willing to disclose their personal genetic information, we designed our research to shed some light on these questions. We believe much further work remains to be done in order for society to fully comprehend the policy infrastructure and institutional design that can ensure robust public participation and trust.

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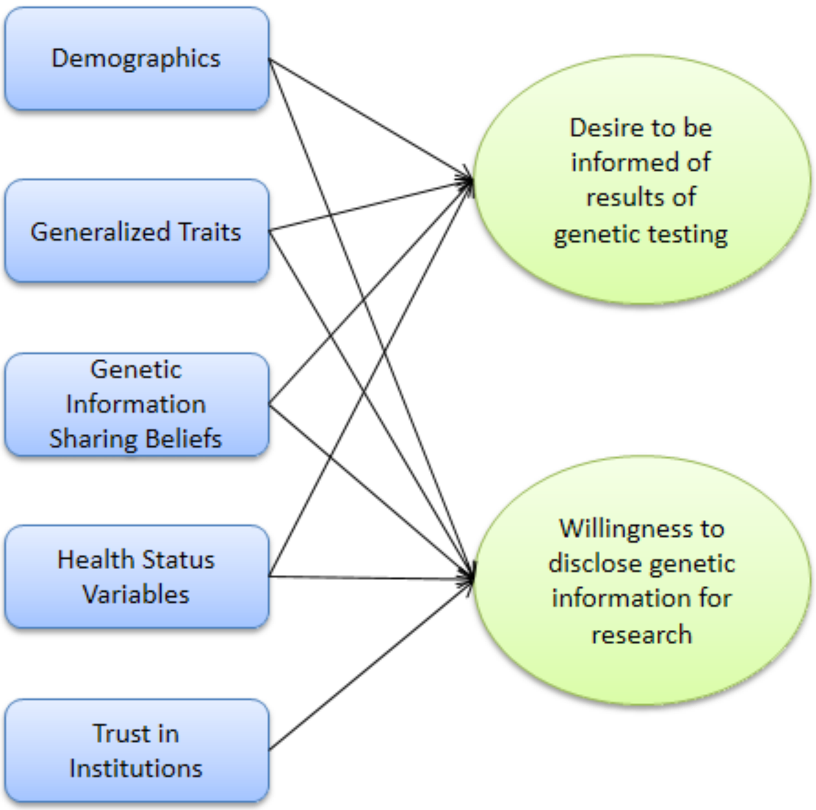
8. Appendices

8.1 Survey Appendices

8.1.1 Survey Conceptual Model



8.1.2 Construct Definitions and Measurement Items

Construct	**Code**	**Description**	#	**Survey Items**
Trust in People	TIP	Trust and reliability in people	7	I usually trust people until they give me a reason not to trust them
			8	I usually give people the benefit of the doubt
			9	My general approach is to trust new acquaintances until they prove I should not trust them
			104	I generally trust strangers
Information Privacy	IP	Information Privacy	102	I am concerned about identity theft
			106	I take proactive steps to protect my personal health or financial information
Warm-Hearted Altruism	WHA	Measure of warm-hearted and altruistic behavior	62	I am an affectionate and tender person
			63	I am generally a sincere and truthful person
			64	If I could help save somebody's life, I would do everything possible
			65	I enjoy doing small favors every day for the people I care about
			66	Helping others is one of the most important aspects of life
			67	I enjoy working for the welfare of others
			68	My family tends to do what we can to help those less fortunate than ourselves
			69	I agree with the old saying, "It is better to give than to receive."
Issue Involvement	II	Prior experience or interest in relevant issues	70	How frequently have you personally been the victim of what you felt was an improper invasion of privacy?
			71	How much have you heard or read during the last year about the use and potential misuse of health information collected electronically?
			110	I often hear about cases in which computer security is a concern.
Genetic Information Privacy Concern	GIPC	Privacy of electronic personal genetic health information	4	Compared with other subjects on my mind, the privacy of my electronic personal genetic health information is very important

			5	I am concerned about threats to the privacy of my electronically stored personal genetic health information today
			6	All things considered, I believe the privacy of my electronic personal genetic health information is seriously threatened
Electronic Genetic Information Privacy Concern	GIPCE	Safety of electronic health records	10	The electronic/digital storage format is a safe environment in which to exchange genetic health information with others
			11	The digital storage format is a reliable environment in which to conduct genetic health related transactions
			12	Organizations handle personal genetic health information submitted by patients in an electronic format in a competent fashion
Perceived Benefits	PB	Medical and health care benefits to genetic information sharing	93	I believe my genetic information can benefit medical advancement in a significant way
			94	Researchers and health officials need access to genetic information to effectively produce treatments
			96	Personalized genetic information will greatly improve the current health care system
			97	Medical discoveries depend greatly on people's willingness to share their genetic information
			100	Predicting serious diseases from genetic information will be an invaluable tool in the future of medicine
Perceived Risks	PR	Employer and insurance discrimination as a results of genetic information sharing	78	My genetic information can be used to discriminate against me
			83	I am afraid that knowledge of my poor health would affect my employer's view of me
Social Stigma	SS	Perception of social opinions regarding issues	118	Social avoidance / pity
			134	Having a genetic disease carries social stigma

		related to health	135	People will see others in a less favorable way if they come to know that he/she has a genetic disease
			136	It is advisable for a person to hide from people with a genetic disease
			137	People tend to like less those with a genetic disease
			138	It is a sign of weakness or inadequacy to have a genetic disease
Positive Health and Emotions	PHE	Positive health status and emotions	38	I am happy about my health right now
			40	I feel ecstatic about life right now
			41	My health state has provoked a profound devotion for life in me
			55	My spirits are high today
Negative Health and Emotions	NHE	Negative health status and emotions	37	Right now I feel sad about something that has happened to my health
			39	I have an intense loathing for my present state of health
			42	Right now other things in my life will have to wait as I focus on my health
			43	My current health state is a real inconvenience
			46	At present I feel extreme dread
			48	I feel everything needs to be approached with caution right now
			49	I am extremely displeased with my present health state
			50	I feel disgust for my current state of health
			52	I feel furious at my present state of health
			54	I feel very deep sorrow because of my health
			56	Health problems are tiresome to me
			57	My present health problems fill me with dread
			58	My state of health has taken me unawares
Trust in Government	TIG	Perceived benevolence and integrity of the government	25	I believe that the government, in general, would act in my best interest
			26	If I required help, the government would do its best to help me

			27	The government, in general, is interested in my well-being, not just their own
			28	The government is truthful in dealings with me
			29	The government would keep commitments
			30	The government is sincere and genuine
			92	I believe that the government is a reliable institution to conduct medical studies that include personal and health information
Trust in Health Professionals	TIHP	Perceived benevolence and integrity of health care professionals	31	I believe that health professionals, in general, would act in my best interest
			32	If I required help, health professionals would do their best to help me
			33	Health professionals, in general, are interested in my well-being, not just their own
			34	Health professionals are truthful in dealings with me
			35	Health professionals would keep commitments
			36	Health professionals are sincere and genuine
			89	I trust my doctor's advice regarding my health
Trust in Insurance and Pharmaceutical Companies	THI	Perceived benevolence and integrity of insurance and pharmaceutical companies	13	I believe that pharmaceutical companies, in general, would act in my best interest
			14	If I required help, a pharmaceutical company would do its best to help me
			15	Pharmaceutical companies, in general, are interested in my well-being, not just their own
			16	Pharmaceutical companies are truthful in dealings with me
			17	Pharmaceutical companies would keep commitments
			18	Pharmaceutical companies are sincere and genuine
			19	I believe that insurance companies, in general, would act in my best interest
			20	If I required help, a insurance company would do its best to help me

			21	Insurance companies, in general, are interested in my well-being, not just their own
			22	Insurance companies are truthful in dealings with me
			23	Insurance companies would keep commitments
			24	Insurance companies are sincere and genuine
			88	I would trust a pharmaceutical company with my medical records
			91	I believe that insurance companies' first priority is their customer's interests and health
Decision to be Informed		Decision to be informed of hypothetical genetic testing	151	Unless you specifically choose NOT to be informed, if testing reveals that you are at risk for a genetic disease, you would be informed about it.

8.1.3 Student Sample Summary Statistics

Descriptive Statistics

Variable	Value	Frequency	Percent	Cumulative Percent
Gender_Male	0	187	49.3	49.3
	1	186	49.1	98.4
	Missing	6	1.6	100
	Total	379	100.0	
Race_Black	0	357	94.2	94.2
	1	22	5.8	100.0
	Total	379	100	

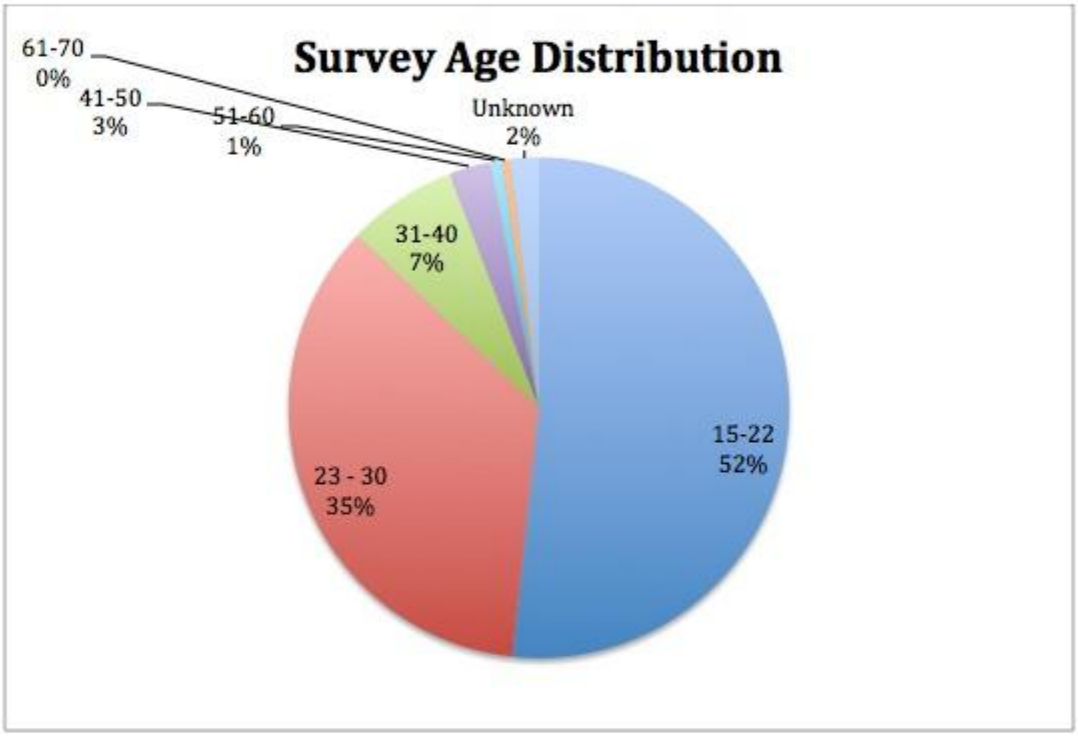
	N	Minimum	Maximum	Mean	Std. Deviation
Age_S	372	15	68	24.33	6.932
Income_S	373	1	10	6.13	2.559
Trust in People, Students	374	1	7	4.2386	1.18130
Info Privacy Student	374	1	7	4.7032	1.30174
Warm Hearted-Altruism Student	374	2	7	5.5314	.96739
Issue Involvement Student	374	1	7	3.6854	1.12303
Personal Genetic Privacy Concern Student	374	1	7	4.0330	1.55232
Perceived Benefits Student	374	1	7	4.7652	1.10041
Perceived Risk Student	374	1	7	4.0227	1.46821
Social Stigma Student	374	1	7	3.7656	1.11861
NumDiseaseFamily_S	379	0	13	1.8997	2.06007
Positive Health and Emotions Student	374	1	5	3.0214	.72735
Negative Health and Emotions Student	374	1	5	1.7104	.78436
Trust in Government, Students	374	1	7	3.7120	1.32575
Trust in Health Professionals, Students	374	1	7	5.2284	1.07689
Trust in Healthcare Industry, Students	374	1	7	3.2995	1.23174
Willingness to Disclose - Government Student	374	1	7	3.9064	1.86956
Willingness to Disclose - Health Professional Student	374	1	7	4.8752	1.71291
Willingness to Disclose - Insurance and Pharmaceutical Student	374	1	7	3.4594	1.60435

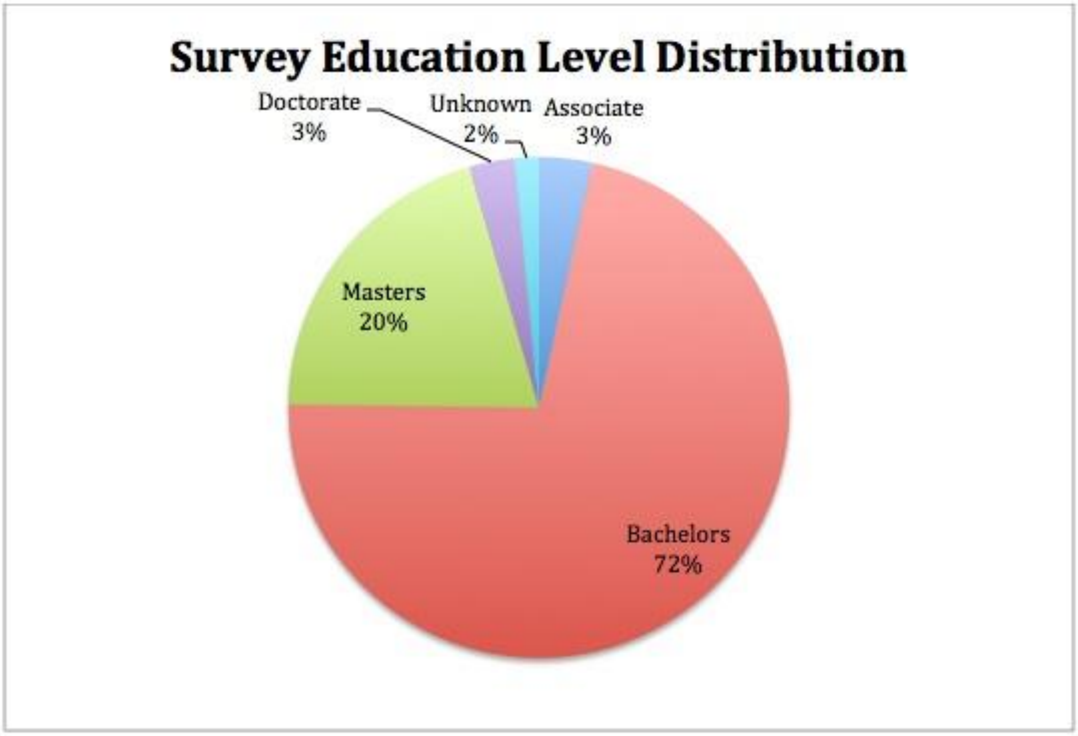
8.1.4 Parent Sample Summary Statistics

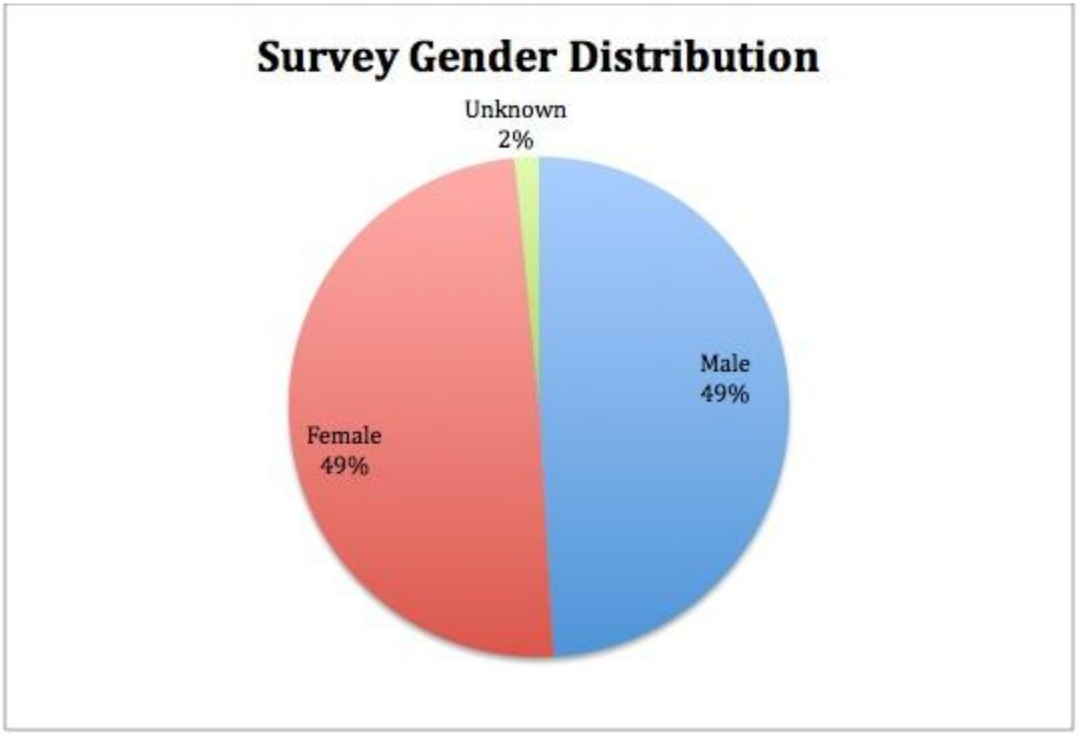
Descriptive Statistics

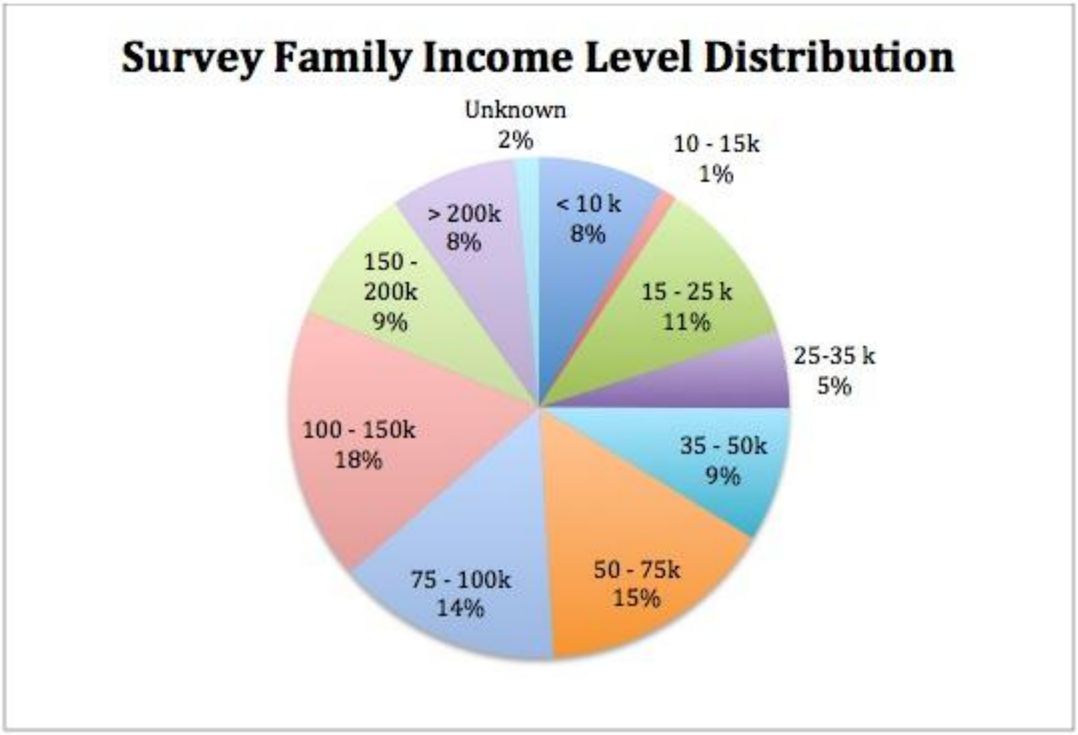
Variable	Value	Frequency	Valid Percent	Cumulative Percent	
Gender_Male	0	53	62.4	62.4	
	1	32	37.6	100.0	
	Total	85	100.0		
Age	1	2	2.4	2.4	
	2	1	1.2	3.5	
	3	2	2.4	5.9	
	4	54	63.5	69.4	
	5	26	30.6	100.0	
	Total	85	100.0		
Race_Black	0	376	99.2	99.2	
	1	3	.8	100.0	
	Total	379	100.0		
	N	Minimum	Maximum	Mean	Std. Dev
Income_P	85	1	10	7.06	2.397
Trust in People, Parents	85	2	7	4.1000	1.11883
Info Privacy Parent	85	3	7	4.9588	1.21795
Warm Hearted-Altruism Parent	85	3	7	5.3868	1.03251
Issue Involvement Parent	85	1	7	3.8196	1.21450
Personal Genetic Privacy Concern Parent	85	1	7	4.5922	1.36991
Perceived Benefits Parents	85	1	7	4.5976	1.19463
Perceived Risk Parents	85	1	7	4.1000	1.49164
Social Stigma Parent	85	1	7	3.7686	1.18022
NumDiseaseFamily_P	85	0	10	.4248	1.28957
Positive Health and Emotions Parent	85	1	5	2.9706	.74543
Negative Health and Emotions Parent	85	1	4	2.0344	.92220
Trust in Government, Parents	85	1	6	3.4908	1.46426
Trust in Health Professionals, Parents	85	1	7	5.0723	1.19190
Trust in Healthcare Industry, Parents	85	1	6	3.0933	1.18738
Willingness to Disclose - Government Parent	85	1	7	3.3255	1.88560
Willingness to Disclose - Health Professional Parent	85	1	7	4.5373	1.85028
Willingness to Disclose - Insurance and Pharmaceutical Parent	85	1	7	2.9412	1.54960

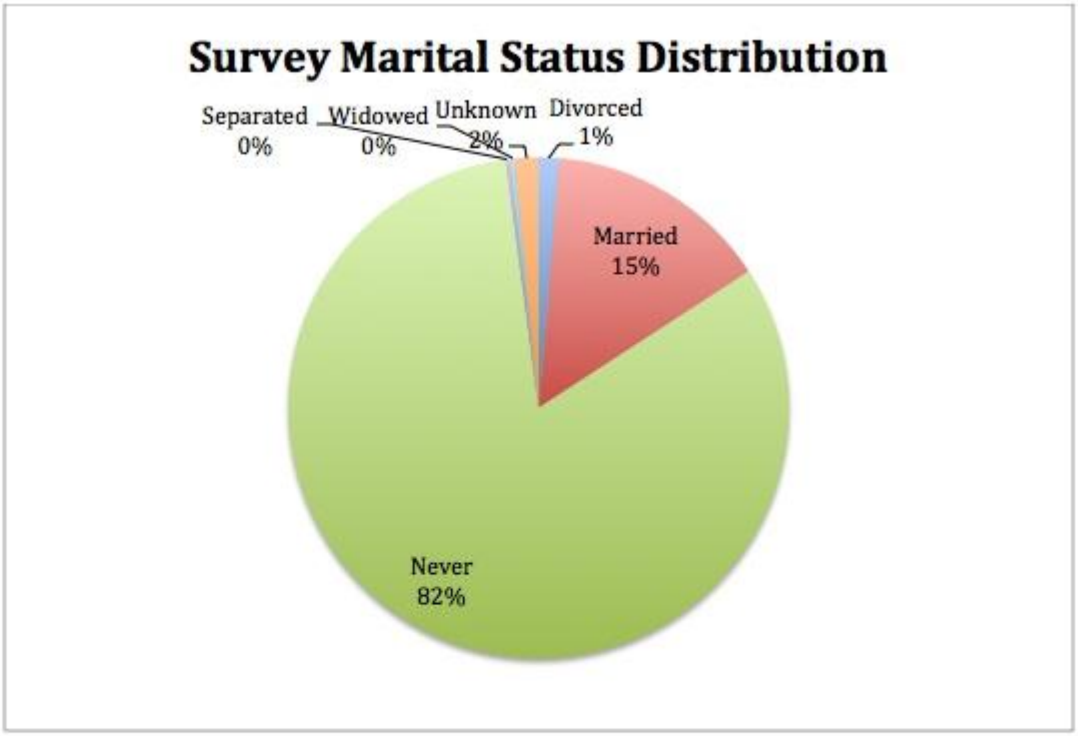
8.1.5 Survey Demographics

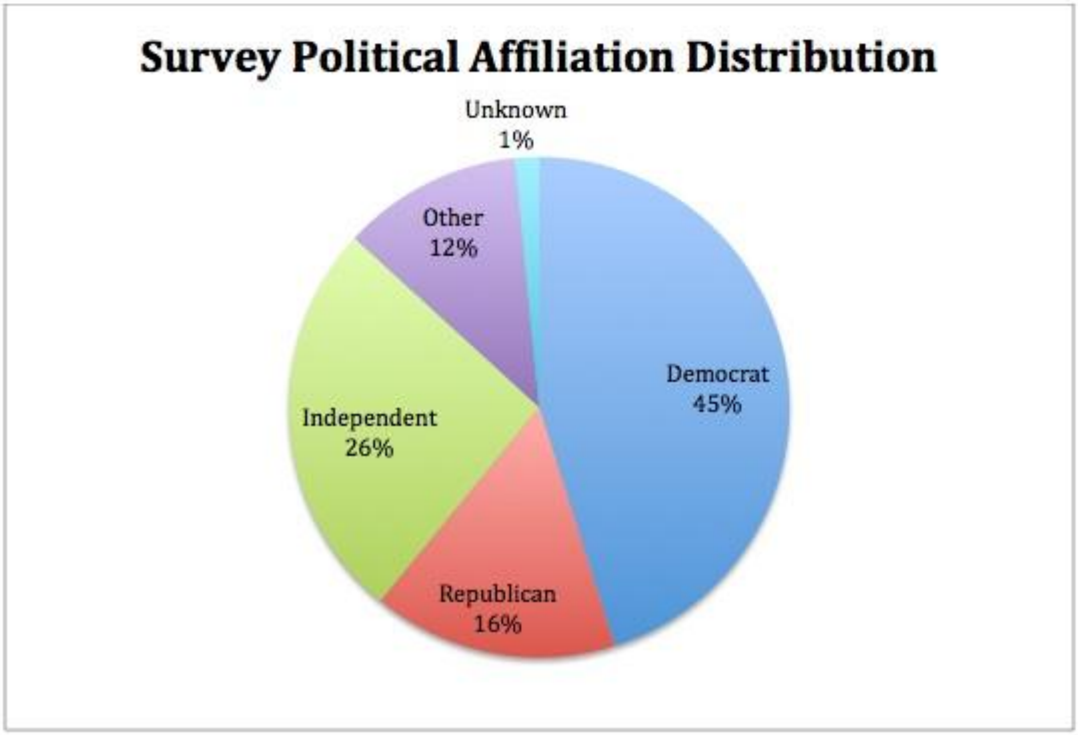


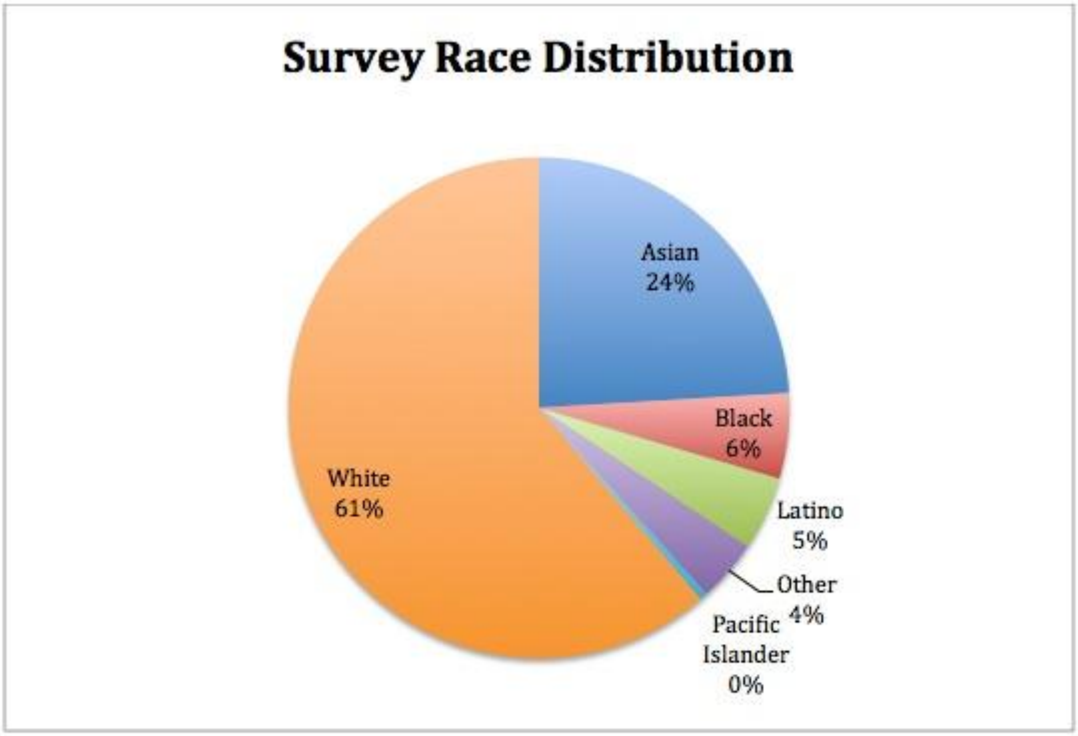


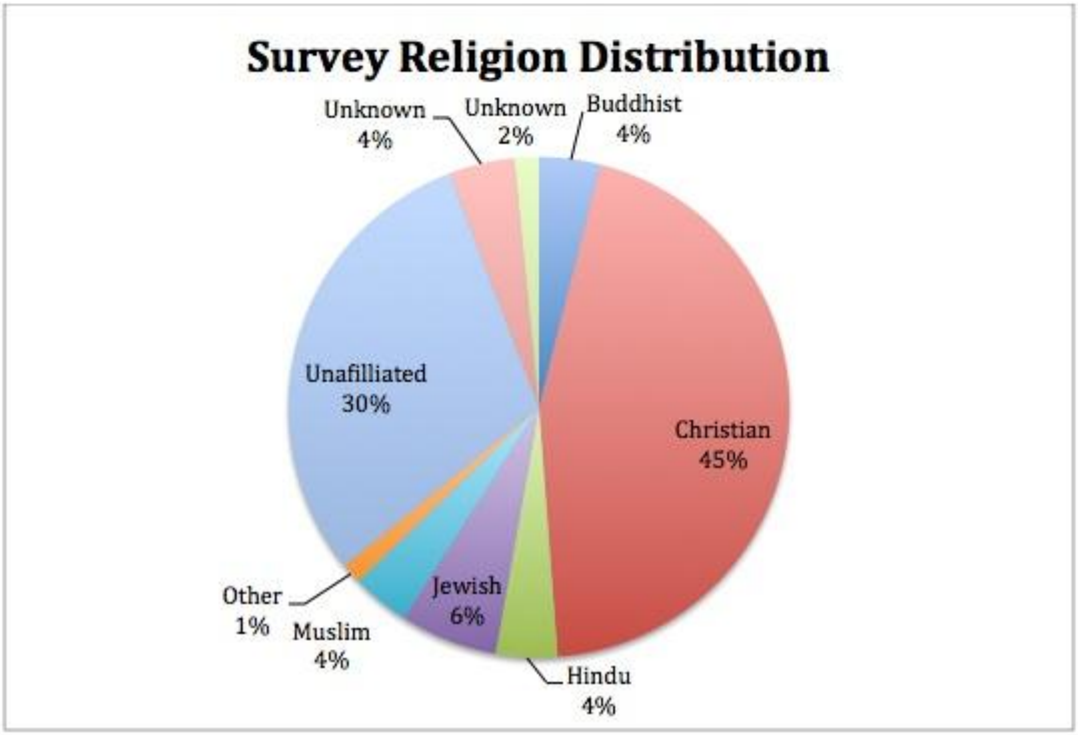

Survey Gender Distribution
Unknown
2%
Male
49%
Female
49%


Survey Family Income Level Distribution
Unknown
2%
10 - 15k
1%
< 10 k
8%
> 200k
8%
150 - 200k
9%
15 - 25 k
11%
25-35 k
5%
100 - 150k
18%
35 - 50k
9%
75 - 100k
14%
50 - 75k
15%


Survey Marital Status Distribution
Separated 0%
Widowed 0%
Unknown 2%
Divorced 1%
Married 15%
Never 82%


Survey Political Affiliation Distribution
Unknown 1%
Other 12%
Democrat 45%
Independent 26%
Republican 16%


Survey Race Distribution
Asian 24%
Black 6%
Latino 5%
Other 4%
Pacific Islander 0%
White 61%


Survey Religion Distribution
Unknown 4%
Unknown 2%
Buddhist 4%
Unafilliated 30%
Christian 45%
Other 1%
Muslim 4%
Jewish 6%
Hindu 4%

8.1.6 Overall Demographics Table

Demographic	Student	Parent	2010 US Census
Gender			
Male	50.1%	37.1%	49.2%
Female	49.9%	62.4%	50.8%
Age			
18-24	63.4%	1.1%	9.1%
25-34	29.6%	2.3%	13.3%
35-44	4.3%	2.4%	13.3%
45-54	1.9%	63.5%	14.6%
55-64	0.3%	30.6%	11.8%
65-74	0.3%	0%	7.0%
Over 75	0%	0%	6.1%
Marital Status			
Married	14.5%	75%	49.8%
Divorced	1.3%	4%	10.6%
Separated	0.3%	0%	2.2%
Widowed	0.3%	1%	6.0%
Never Married	82.1%	5%	31.4%
Race			
White	64.4%	48%	72.4%
Black or African American	5.8%	3%	12.6%
Asian	25.3%	28%	4.8%
Native Hawaiian or Other Pacific Islander	0.5%	1%	0.2%
Spanish/Hispanic, Latino	5%	5%	16.3%
Religion			
Christian	44.9%	37%	76.0%
Jewish	6.3%	12%	1.2%
Muslim	3.7%	4%	0.6%
Buddhist	4%	6%	0.5%
Hindu	4%	3%	0.3%
Unaffiliated	30.1%	20%	15%
Other	1.3%	1%	1.3%
Unknown	4.2%	2%	5.2%
Political Party			
Democrat	45.1%	34.1%	
Republican	15.8%	25.9%	
Independent	25.9%	25.9%	
Other	11.6%	14.1%	
Education			
Some high school, no diploma	0.3%	1.2%	8.5%
High School Graduate	7.2%	8.2%	28.6%

Some college, but no degree	37%	14.1%	21.0%
Associate degree in college	3.5%	7.1%	7.6%
Bachelor’s degree	28.4%	30.6%	17.7%
Master’s degree	20.6%	27.1%	10.5% (all post-graduate)
Professional/Doctorate Degree	2.9%	11.8%	
Income			
Less than $10,000	8.3%	4.7%	7.1%
$10,000 to $14,999	1.1%	1.2%	5.4%
$15,000 to $24,999	11%	2.4%	10.6%
$25,000 to $34,999	5.1%	5.9%	10.4%
$35,000 to $49,999	8.8%	7.1%	13.8%
$50,000 to $74,999	15.5%	16.5%	18.3%
$75,000 to $99,999	14.7%	12.9%	12.4%
$100,000 to $149,999	18%	21.2%	12.7%
$150,999 to $199,999	9.1%	8.2%	4.7%
$200,000 or more	8.3%	20%	4.5%

8.1.7 Student Willingness to Disclose Correlations

Variable	Reliability	Willingness to Disclose – Government	Willingness to Disclose - Health Professional	Willingness to Disclose - Insurance and Pharmacy	Gender Male	Income	Race Black
Willingness to Disclose - Government	0.974	1.000	.590***	.660***	0.065	-0.065	-.148***
Willingness to Disclose - Health Professional	0.974	.590***	1.000	.581***	-0.053	0.045	-.141***
Willingness to Disclose - Insurance and Pharmacy	0.948	.660***	.581***	1.000	0.099*	-0.015	-.105**
Gender Male	1.000	0.065	-0.053	0.099*	1.000	0.044	-0.045
Income	1.000	-0.065	0.045	-0.015	0.044	1.000	-.102**
Race Black	1.000	-.148***	-.141***	-.105**	-0.045	-.102**	1.000
Trust in People	0.817	0.100*	0.061	0.081	-0.031	0.009	-0.067
Information Privacy	0.556	-0.044	0.028	-0.093*	-0.009	0.008	-0.022
Warm Hearted-Altruism	0.898	-0.038	.116**	-.117**	-.196***	0.085	-0.054
Issue Involvement	0.535	-0.027	-0.028	-0.081	0.013	-0.096*	-0.041
Personal Genetic Privacy Concern	0.895	-.216***	-.181***	-.199***	-0.039	-0.077	0.024
Perceived Benefits	0.835	.315***	.329***	.246***	.119**	0.064	-.145***
Perceived Risk	0.491	-0.066	-0.095	-.186***	0.057	-.158***	0.019
Social Stigma	0.766	-.125**	-.161***	-0.057	0.055	-.116**	0.032
Number of Diseases in Family	N/A	0.047	.119**	-0.015	-.115**	0.040	-0.076
Positive Health and Emotions	0.686	0.068	.102**	0.075	-0.013	0.085	0.043
Negative Health and Emotions	0.945	-0.100*	-0.129**	0.035	0.054	-.217***	.104**
Trust in Government	0.939	.407***	0.028	.204***	.125**	-0.042	-0.014
Trust in Health Professionals	0.949	.117**	.356***	0.061	-0.069	0.097*	-0.058
Trust in Healthcare Industry	0.955	0.047	0.028	.337***	.109**	0.060	-0.003

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Trust in People	Information Privacy	Warm Hearted Altruism	Issue Involvement	Personal Genetic Privacy Concern	Perceived Benefits	Perceived Risk
Willingness to Disclose - Government	0.974	.100*	-0.044	-0.038	-0.027	-.216***	.315***	-0.066
Willingness to Disclose - Health Professional	0.974	0.061	0.028	.116**	-0.028	-.181***	.329***	-0.095*
Willingness to Disclose - Insurance and Pharmacy	0.948	0.081	-.093*	-.117**	-0.081	-.199***	.246***	-.186***
Gender Male	1.000	-0.031	-0.009	-.196***	0.013	-0.039	.119**	0.057
Income	1.000	0.009	0.008	0.085	-.096*	-0.077	0.064	-.158***
Race Black	1.000	-0.067	-0.022	-0.054	-0.041	0.024	-.145***	0.019
Trust in People	0.817	1.000	-.159***	.110**	-.128**	-0.085	0.052	-0.072
Information Privacy	0.556	-.159***	1.000	.210***	.406***	.315***	0.067	.199***
Warm Hearted-Altruism	0.898	.110**	.210***	1.000	.106**	0.096*	.119**	0.050
Issue Involvement	0.535	-.128**	.406***	.106**	1.000	.465***	0.016	.341***
Personal Genetic Privacy Concern	0.895	-0.085	.315***	0.096*	.465***	1.000	-.121**	.318***
Perceived Benefits	0.835	0.052	0.067	.119**	0.016	-.121**	1.000	0.043
Perceived Risk	0.491	-0.072	.199***	0.050	.341***	.318***	0.043	1.000
Social Stigma	0.766	-.122**	0.035	-.121**	.135***	.295***	-0.016	.257***
Number of Diseases in Family	N/A	0.073	0.079	0.095*	0.058	-0.096*	0.090*	0.027
Positive Health and Emotions	0.686	.176***	0.032	.300***	-0.009	0.053	0.043	-0.070
Negative Health and Emotions	0.945	-.095*	-0.031	-.252***	.181***	.163***	-.168***	.151***
Trust in Government	0.939	.252***	-0.081	-0.064	-.114**	-.102**	.220***	-0.056
Trust in Health Professionals	0.949	.145***	.106**	.303***	-0.057	-0.087*	.264***	-.106**
Trust in Healthcare Industry	0.955	.133**	-.133***	-0.091*	-.218***	-0.078	0.055	-.238***

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Social Stigma	Number of Diseases in Family	Positive Health and Emotions	Negative Health and Emotions	Trust in Govt	Trust in Health Professional	Trust in Healthcare Industry
Willingness to Disclose - Government	0.974	-.125**	0.047	0.068	-0.100	.407***	.117**	0.047
Willingness to Disclose - Health Professional	0.974	-.161***	.119**	.102**	-.129**	0.028	.356***	0.028
Willingness to Disclose - Insurance and Pharmacy	0.948	-0.057	-0.015	0.075	0.035	.204***	0.061	.337***
Gender Male	1.000	0.055	-.115**	-0.013	0.054	.125**	-0.069	.109**
Income	1.000	-.116**	0.040	0.085*	-.217***	-0.042	0.097*	0.060
Race Black	1.000	0.032	-0.076	0.043	.104**	-0.014	-0.058	-0.003
Trust in People	0.817	-.122**	0.073	.176***	-0.095*	.252***	.145***	.133**
Information Privacy	0.556	0.035	0.079	0.032	-0.031	-0.081	.106**	-.133***
Warm Hearted-Altruism	0.898	-.121**	0.095*	.300***	-.252***	-0.064	.303***	-0.091*
Issue Involvement	0.535	.135***	0.058	-0.009	.181***	-.114**	-0.057	-.218***
Personal Genetic Privacy Concern	0.895	.295***	-0.096*	0.053	.163***	-.102**	-0.087*	-0.078
Perceived Benefits	0.835	-0.016	0.090*	0.043	-.168***	.220***	.264***	0.055
Perceived Risk	0.491	.257***	0.027	-0.070	.151***	-0.056	-.106**	-.238***
Social Stigma	0.766	1.000	-.110**	-0.088*	.156***	0.007	-.163***	-0.016
Number of Diseases in Family	N/A	-.110**	1.000	-0.024	-0.008	-0.070	0.053	-.105**
Positive Health and Emotions	0.686	-0.088*	-0.024	1.000	-.196***	.134***	.156***	0.057
Negative Health and Emotions	0.945	.156***	-0.008	-.196***	1.000	-0.029	-.315***	0.091*
Trust in Government	0.939	0.007	-0.070	.134***	-0.029	1.000	.116**	.380***
Trust in Health Professionals	0.949	-.163***	0.053	.156***	-.315***	.116**	1.000	.122**
Trust in Healthcare Industry	0.955	-0.016	-.105**	0.057	0.091	.380***	.122**	1.000

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

8.1.8 Parent Willingness to Disclose Correlations

Variable	Reliability	Willingness to Disclose - Government	Willingness to Disclose - Health Professional	Willingness to Disclose - Insurance and Pharmacy	Gender Male	Income	Race Black	Trust in People
Willingness to Disclose - Government	0.968	1.000	.562***	.601***	0.012	0.040	-0.011	0.011
Willingness to Disclose - Health Professional	0.962	.562***	1.000	.535***	-0.209*	0.196*	-0.044	0.102
Willingness to Disclose - Insurance and Pharmacy	0.946	.601***	.535***	1.000	-0.125	-0.080	0.111	0.008
Gender_Male	1.000	0.012	-0.209*	-0.125	1.000	0.022	-0.149	0.012
Income	1.000	0.040	0.196*	-0.080	0.022	1.000	-0.058	0.170
Race Black	1.000	-0.011	-0.044	0.111	-0.149	-0.058	1.000	-0.103
Trust in People	0.725	0.011	0.102	0.008	0.012	0.170	-0.103	1.000
Information Privacy	0.365	-.232**	0.048	-.353***	0.077	.288***	-0.020	-0.006
Warm Hearted-Altruism	0.914	-0.030	.332***	0.059	-0.101	0.208*	-0.103	.225**
Issue Involvement	0.502	-0.203	-0.081	-.234**	0.136	0.092	0.046	.220**
Personal Genetic Privacy Concern	0.895	-.226**	-.233**	-.334***	0.185	0.045	0.010	0.014
Perceived Benefits	0.876	0.058	0.157	-0.171	0.128	0.087	-0.075	-0.177
Perceived Risk	0.570	-0.198*	-0.043	-0.196*	0.062	-0.133	-0.056	-0.052
Social Stigma	0.761	-0.176	-0.203*	-0.185*	0.129	-.216**	-0.008	-0.118
Number of Diseases in Family	N/A	-0.102	0.206*	-0.005	-0.120	.224**	0.063	0.213*
Positive Health and Emotions	0.695	-0.007	0.212	-0.032	0.162	.287***	0.094	0.187*
Negative Health and Emotions	0.954	0.029	-0.090	.215**	0.042	-0.205*	0.084	-0.033
Trust in Government	0.943	.554***	0.165	.238**	0.124	-0.209*	0.004	-0.142
Trust in Health Professionals	0.948	.227**	.471***	0.089	-0.156	0.167	-0.112	0.042
Trust in Healthcare Industry	0.940	.251**	0.098	.302***	0.050	-.239**	0.147	-0.140

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Information Privacy	Warm Hearted Altruism	Issue Involvement	Personal Genetic Privacy Concern	Perceived Benefits	Perceived Risks	Social Stigma
Willingness to Disclose - Government	0.968	-.232**	-0.030	-0.203*	-.226**	0.058	-0.198*	-0.176
Willingness to Disclose - Health Professional	0.962	0.048	.332***	-0.081	-.233**	0.157	-0.043	-0.203*
Willingness to Disclose - Insurance and Pharmacy	0.946	-.353***	0.059	-.234**	-.334***	-0.171	-0.196*	-0.185*
Gender_Male	1.000	0.077	-0.101	0.136	0.185*	0.128	0.062	0.129
Income	1.000	.288***	0.208*	0.092	0.045	0.087	-0.133	-.216**
Race Black	1.000	-0.020	-0.103	0.046	0.010	-0.075	-0.056	-0.008
Trust in People	0.725	-0.006	.225**	.220**	0.014	-0.177	-0.052	-0.118
Information Privacy	0.365	1.000	.362***	.295***	0.193*	.265**	0.110	0.000
Warm Hearted-Altruism	0.914	.362***	1.000	0.040	0.060	0.095	-0.069	-0.187*
Issue Involvement	0.502	.295***	0.040	1.000	.332***	0.102	.347***	0.202*
Personal Genetic Privacy Concern	0.895	0.193*	0.060	.332***	1.000	0.113	.290***	.224**
Perceived Benefits	0.876	.265**	0.095	0.102	0.113	1.000	0.165	0.107
Perceived Risk	0.570	0.110	-0.069	.347***	.290***	0.165	1.000	0.177
Social Stigma	0.761	0.000	-0.187*	0.202*	.224**	0.107	0.177	1.000
Number of Diseases in Family	N/A	.256**	.234**	0.139	0.007	-0.038	0.131	-0.172
Positive Health and Emotions	0.695	0.174	0.158	0.155	0.186*	-0.082	-0.111	0.001
Negative Health and Emotions	0.954	-.341***	-.417***	.228**	0.138	-0.011	0.108	.275**
Trust in Government	0.943	-.238**	-0.194	-.250**	-0.151	0.059	-0.145	0.032
Trust in Health Professionals	0.948	.253**	.463***	-0.034	-0.112	.245**	-0.006	0.053
Trust in Healthcare Industry	0.940	-.253**	-0.069	-.216**	-0.021	-0.028	-.227**	0.053

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Number of Diseases in Family	Positive Health and Emotions	Negative Health and Emotions	Trust in Govt	Trust in Health Professionals	Trust in Healthcare Industry
Willingness to Disclose - Government	0.968	-0.102	-0.007	0.029	.554***	.227**	.251**
Willingness to Disclose - Health Professional	0.962	0.206*	0.212*	-0.090	0.165	.471***	0.098
Willingness to Disclose - Insurance and Pharmacy	0.946	-0.005	-0.032	.215**	.238**	0.089	.302***
Gender_Male	1.000	-0.120	0.162	0.042	0.124	-0.156	0.050
Income	1.000	.224**	.287***	-0.205	-0.209*	0.167	-.239**
Race Black	1.000	0.063	0.094	0.084	0.004	-0.112	0.147
Trust in People	0.725	0.213*	0.187*	-0.033	-0.142	0.042	-0.140
Information Privacy	0.365	.256**	0.174	-.341***	-.238**	.253**	-.253**
Warm Hearted-Altruism	0.914	.234**	0.158	-.417***	-0.194*	.463***	-0.069
Issue Involvement	0.502	0.139	0.155	.228**	-.250**	-0.034	-.216**
Personal Genetic Privacy Concern	0.895	0.007	0.186*	0.138	-0.151	-0.112	-0.021
Perceived Benefits	0.876	-0.038	-0.082	-0.011	0.059	.245**	-0.028
Perceived Risk	0.570	0.131	-0.111	0.108	-0.145	-0.006	-.227**
Social Stigma	0.761	-0.172	0.001	.275**	0.032	0.053	0.053
Number of Diseases in Family	N/A	1.000	0.059	-0.101	-.324***	-0.022	-.261**
Positive Health and Emotions	0.695	0.059	1.000	0.022	-0.013	0.088	0.068
Negative Health and Emotions	0.954	-0.101	0.022	1.000	0.108	-.375***	.353***
Trust in Government	0.943	-.324***	-0.013	0.108	1.000	.269**	.554***
Trust in Health Professionals	0.948	-0.022	0.088	-.375***	.269**	1.000	0.213
Trust in Healthcare Industry	0.940	-.261**	0.068	.353***	.554***	0.213*	1.000

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

8.1.9 Student Willingness to Disclose with Parent Predictor Correlations

Variable	Reliability	Willingness to Disclose - Government	Willingness to Disclose - Health Professional	Willingness to Disclose - Insurance and Pharmacy	Gender Male	Income	Race Black	Trust in People
Willingness to Disclose - Government	0.974	1	.590***	.660***	.010	.010	-.033	.124
Willingness to Disclose - Health Professional	0.974	.590***	1	.581***	-.126	.147	-.081	0.201*
Willingness to Disclose - Insurance and Pharmacy	0.948	.660***	.581***	1	.063	.048	-.013	.055
Gender Male	1.000	.010	-.126	.063	1.000	0.022	-0.149	0.012
Income	1.000	.010	.147	.048	0.022	1.000	-0.058	0.170
Race Black	1.000	-.033	-.081	-.013	-0.149	-0.058	1.000	-0.103
Trust in People	0.725	.124	0.201*	.055	0.012	0.170	-0.103	1.000
Information Privacy	0.365	.163	.109	-.025	0.077	.288***	-0.020	-0.006
Warm Hearted-Altruism	0.914	.114	.294***	.000	-0.101	0.208*	-0.103	.225**
Issue Involvement	0.502	-.009	.150	.011	0.136	0.092	0.046	.220**
Personal Genetic Privacy Concern	0.895	-.068	-.016	-.154	0.185	0.045	0.010	0.014
Perceived Benefits	0.876	.131	.222**	.151	0.128	0.087	-0.075	-0.177
Perceived Risk	0.570	.087	.110	.055	0.062	-0.133	-0.056	-0.052
Social Stigma	0.761	-.262**	-.103	-.149	0.129	-.216**	-0.008	-0.118
Number of Diseases in Family	N/A	.068	0.096**	.054	-0.120	.224**	0.063	0.213*
Positive Health and Emotions	0.695	.003	.098	.011	0.162	.287***	0.094	0.187*
Negative Health and Emotions	0.954	-.165	-.121	.100	0.042	-0.205*	0.084	-0.033
Trust in Government	0.943	.070	-.068	.036	0.124	-0.209*	0.004	-0.142
Trust in Health Professionals	0.948	.291***	.484***	.172	-0.156	0.167	-0.112	0.042
Trust in Healthcare Industry	0.940	-.105	-.151	.090	0.050	-.239**	0.147	-0.140

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Information Privacy	Warm Hearted Altruism	Issue Involvement	Personal Genetic Privacy Concern	Perceived Benefits	Perceived Risk	Social Stigma
Willingness to Disclose - Government	0.974	.163	.114	-.009	-.068	.131	.087	-.262**
Willingness to Disclose - Health Professional	0.974	.109	.294***	.150	-.016	.222**	.110	-.103
Willingness to Disclose - Insurance and Pharmacy	0.948	-.025	.000	.011	-.154	.151	.055	-.149
Gender Male	1.000	0.077	-0.101	0.136	0.185*	0.128	0.062	0.129
Income	1.000	.288***	0.208*	0.092	0.045	0.087	-0.133	-.216**
Race Black	1.000	-0.020	-0.103	0.046	0.010	-0.075	-0.056	-0.008
Trust in People	0.725	-0.006	.225**	.220**	0.014	-0.177	-0.052	-0.118
Information Privacy	0.365	1.000	.362***	.295***	0.193*	.265**	0.110	0.000
Warm Hearted-Altruism	0.914	.362***	1.000	0.040	0.060	0.095	-0.069	-0.187*
Issue Involvement	0.502	.295***	0.040	1.000	.332***	0.102	.347***	0.202*
Personal Genetic Privacy Concern	0.895	0.193*	0.060	.332***	1.000	0.113	.290***	.224**
Perceived Benefits	0.876	.265**	0.095	0.102	0.113	1.000	0.165	0.107
Perceived Risk	0.570	0.110	-0.069	.347***	.290***	0.165	1.000	0.177
Social Stigma	0.761	0.000	-0.187*	0.202*	.224**	0.107	0.177	1.000
Number of Diseases in Family	N/A	.256**	.234**	0.139	0.007	-0.038	0.131	-0.172
Positive Health and Emotions	0.695	0.174	0.158	0.155	0.186*	-0.082	-0.111	0.001
Negative Health and Emotions	0.954	-.341***	-.417***	.228**	0.138	-0.011	0.108	.275**
Trust in Government	0.943	-.238**	-0.194	-.250**	-0.151	0.059	-0.145	0.032
Trust in Health Professionals	0.948	.253**	.463***	-0.034	-0.112	.245**	-0.006	0.053
Trust in Healthcare Industry	0.940	-.253**	-0.069	-.216**	-0.021	-0.028	-.227**	0.053

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Number of Diseases in Family	Positive Health and Emotions	Negative Health and Emotions	Trust in Govt	Trust in Health Professionals	Trust in Healthcare Industry
Willingness to Disclose - Government	0.974	.068	.003	-.165	.070	.291***	-.105
Willingness to Disclose - Health Professional	0.974	0.096*	.098	-.121	-.068	.484***	-.151
Willingness to Disclose - Insurance and Pharmacy	0.948	.054	.011	.100	.036	.172	.090
Gender Male	1.000	-0.120	0.162	0.042	0.124	-0.156	0.050
Income	1.000	.224**	.287***	-0.205	-0.209*	0.167	-.239**
Race Black	1.000	0.063	0.094	0.084	0.004	-0.112	0.147
Trust in People	0.725	0.213*	0.187*	-0.033	-0.142	0.042	-0.140
Information Privacy	0.365	.256**	0.174	-.341***	-.238**	.253**	-.253**
Warm Hearted-Altruism	0.914	.234**	0.158	-.417***	-0.194*	.463***	-0.069
Issue Involvement	0.502	0.139	0.155	.228**	-.250**	-0.034	-.216**
Personal Genetic Privacy Concern	0.895	0.007	0.186*	0.138	-0.151	-0.112	-0.021
Perceived Benefits	0.876	-0.038	-0.082	-0.011	0.059	.245**	-0.028
Perceived Risk	0.570	0.131	-0.111	0.108	-0.145	-0.006	-.227**
Social Stigma	0.761	-0.172	0.001	.275**	0.032	0.053	0.053
Number of Diseases in Family	N/A	1.000	0.059	-0.101	-.324***	-0.022	-.261**
Positive Health and Emotions	0.695	0.059	1.000	0.022	-0.013	0.088	0.068
Negative Health and Emotions	0.954	-0.101	0.022	1.000	0.108	-.375***	.353***
Trust in Government	0.943	-.324***	-0.013	0.108	1.000	.269**	.554***
Trust in Health Professionals	0.948	-0.022	0.088	-.375***	.269**	1.000	0.213
Trust in Healthcare Industry	0.940	-.261**	0.068	.353***	.554***	0.213*	1.000

***. Correlation is significant at the 0.01 level (2-tailed).

**. Correlation is significant at the 0.05 level (2-tailed).

*. Correlation is significant at the 0.1 level (2 tailed).

8.1.10 Student Decision to be Informed Correlations

Variable	Reliability	Decision to be Informed	Race Black	Gender Male	Information Privacy	Personal Genetic Privacy Concern	Electronic Genetic Privacy Concern	Social Stigma
Decision to be Informed	1.000	1.000	-0.049	-0.022	0.099*	-0.015	-0.008	0.063
Race Black	1.000	-0.049	1.000	-0.045	-0.022	0.024	-0.028	0.032
Gender Male	1.000	-0.022	-0.045	1.000	-0.009	-0.039	0.045	0.055
Information Privacy	0.556	0.099*	-0.022	-0.009	1.000	.315***	-.222***	0.035
Genetic Information Privacy Concern	0.895	-0.015	0.024	-0.039	.315***	1.000	-.250***	.295***
Electronic Genetic Privacy Concern	0.847	-0.008	-0.028	0.045	-.222***	-.250***	1.000	-0.034
Social Stigma	0.766	0.063	0.032	0.055	0.035	.295***	-0.034	1.000
Number of Diseases in Family	N/A	-0.033	-0.076	-.115**	0.079	-0.096*	-0.019	-.110**
Positive Health and Emotions	0.686	0.051	0.043	-0.013	0.032	0.053	0.066	-0.088*
Negative Health and Emotions	0.945	-.122**	.104**	0.054	-0.031	.163***	-0.005	.156***

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Number of Diseases in Family	Positive Health and Emotions	Negative Health and Emotions
Decision to be Informed	1.000	-0.033	0.051	-.122**
Race Black	1.000	-0.076	0.043	.104**
Gender Male	1.000	-.115**	-0.013	0.054
Information Privacy	0.556	0.079	0.032	-0.031
Genetic Information Privacy Concern	0.895	-0.096*	0.053	.163***
Electronic Genetic Privacy Concern	0.847	-0.019	0.066	-0.005
Social Stigma	0.766	-.110**	-0.088*	.156***
Number of Diseases in Family	N/A	1.000	-0.024	-0.008
Positive Health and Emotions	0.686	-0.024	1.000	-.196***
Negative Health and Emotions	0.945	-0.008	-.196***	1.000

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

8.1.11 Parent Decision to be Informed Correlations

Variable	Reliability	Decision to be Informed	Race Black	Gender Male	Information Privacy	Personal Genetic Privacy Concern	Electronic Genetic Privacy Concern	Social Stigma
Decision to be Informed	1.000	1.000	0.066	0.031	.304***	-0.084	-0.158	-0.052
Race Black	1.000	0.066	1.000	-0.149	-0.020	0.010	-0.078	-0.008
Gender Male	1.000	0.031	-0.149	1.000	0.077	0.185*	0.044	0.129
Information Privacy	0.365	.304***	-0.020	0.077	1.000	0.193*	-0.170	0.000
Genetic Information Privacy Concern	0.895	-0.084	0.010	0.185*	0.193*	1.000	-0.136	.224**
Electronic Genetic Privacy Concern	0.909	-0.158	-0.078	0.044	-0.170	-0.136	1.000	-0.065
Social Stigma	1.000	-0.052	-0.008	0.129	0.000	.224**	-0.065	1.000
Number of Diseases in Family	N/A	0.179	0.063	-0.120	.256**	0.007	-0.202*	-0.172
Positive Health and Emotions	0.695	-0.039	0.094	0.162	0.174	0.186*	-0.133	0.001
Negative Health and Emotions	0.954	-.218**	0.084	0.042	-.341***	0.138	0.091	.275**

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

Variable	Reliability	Number of Diseases in Family	Positive Health and Emotions	Negative Health and Emotions
Decision to be Informed	1.000	0.179	-0.039	-.218**
Race Black	1.000	0.063	0.094	0.084
Gender Male	1.000	-0.120	0.162	0.042
Information Privacy	0.365	.256**	0.174	-.341***
Genetic Information Privacy Concern	0.895	0.007	0.186*	0.138
Electronic Genetic Privacy Concern	0.909	-0.202*	-0.133	0.091
Social Stigma	1.000	-0.172	0.001	.275**
Number of Diseases in Family	N/A	1.000	0.059	-0.101
Positive Health and Emotions	0.695	0.059	1.000	0.022
Negative Health and Emotions	0.954	-0.101	0.022	1.000

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2 tailed).

8.1.12 Student Linear Regression

Demographic Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Gender Male	-.052 (.176)	-0.231 (0.166)	0.044 (.156)
Income	-.073 (.034) **	-0.014 (0.032)	-0.039 (0.030)
Race: Black	-.894 (.366) **	-0.689 (0.347) **	-0.576 (.325) *
Generalized Traits	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Trust in People	-.043 (.077)	-0.039 (0.071)	0.022 (.067)
Information Privacy	-.016 (.074)	0.011 (0.071)	-.011 (.066)
Warm-hearted Altruism	-.134 (.099)	-0.049 (0.095)	-.196 (.088) **
Genetic Information Sharing Beliefs	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Issue Involvement	.174 (.093) *	0.072 (0.088)	.124 (.083)
Personal Genetic Privacy Concern	-.194 (.067) ***	-0.140 (0.063) **	-.163 (.059) ***
Perceived Benefits	.348 (.082) ***	0.371 (0.078)***	.329 (.072) ***
Perceived Risks	-.019 (.064)	-0.044 (0.061)	-.119 (.058) *
Health Status Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Social Stigma	-.151 (.082) *	-0.104 (0.078)	-.007 (.073)
Number of Diseases	.023 (.042)	0.043 (0.040)	-.010 (.038)
Positive Health and Emotions	.110 (.126)	0.180 (0.119)	.230 (.111) **
Negative Health and Emotions	-.125 (.119)	0.085 (0.115)	.125 (.107)
Trust in Institutions	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Student Trust	.493 (.069) ***	0.433 (0.084)***	.366 (.066) ***
Constant	2.568 (.920) ***	1.567 (.908) *	1.794 (.830) **
R^2	0.283	0.232	0.233
Adjusted R^2	0.253	0.2	0.2

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

8.1.13 Parent Linear Regression

Demographic Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Gender Male	-.035 (.391)	-0.391 (0.377)	.044 (.331)
Income	.112 (.085)	0.032 (0.08)	.016 (.073)
Race: Black	.071 (.989)	-0.097 (0.943)	.787 (.847)
Generalized Traits	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Trust in People	.063 (.178)	-0.003 (0.169)	-.053 (.152)
Information Privacy	-.271 (.188)	-0.181 (0.178)	-.303 (.160) *
Warm-hearted Altruism	.132 (.208)	0.249 (0.212)	.431 (.180) **
Genetic Information Sharing Beliefs	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Issue Involvement	.029 (.185)	-0.102 (0.174)	-.121 (.159)
Personal Genetic Privacy Concern	-.124 (.146)	-0.271 (0.141) *	-.315 (.124) **
Perceived Benefits	.147 (.163)	0.227 (0.158)	-.097 (.137)
Perceived Risks	-.071 (.136)	0.078 (0.130)	-.007 (.118)
Health Status Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Social Stigma	-.200 (.166)	-0.265 (0.162)	-.159 (.141)
Number of Diseases	.051 (.093)	0.151 (0.088) *	.039 (.078)
Positive Health and Emotions	-.040 (.268)	0.577 (0.255) **	-.011 (.228)
Negative Health and Emotions	.052 (.240)	0.390 (0.234) *	.505 (.222) **
Trust in Institutions	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Parent Trust	0.720 (.136) ***	0.649 (0.182) ***	.173 (.156)
Constant	1.149 (1.935)	-.785 (1.714)	3.563 (1.573) **
R^2	0.404	0.442	0.364
Adjusted R^2	0.274	0.321	0.225

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

8.1.14 Student Regression with Parent Predictors

Demographic Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Gender Male (P)	-.057 (.485)	-.310 (.393)	.282 (.442)
Income (P)	-.092 (.104)	-.043 (.084)	.032 (.096)
Race: Black (P)	-.728 (1.196)	-1.028 (.965)	-.447 (1.104)
Generalized Traits	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Trust in People (P)	.283 (.223)	.204 (.179)	.107 (.205)
Information Privacy (P)	.288 (.232)	-.147 (.185)	.004 (.212)
Warm-hearted Altruism (P)	-.025 (.264)	.065 (.222)	.077 (.244)
Genetic Information Sharing Beliefs	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Issue Involvement (P)	-.015 (.254)	.133 (.206)	.104 (.237)
Personal Genetic Privacy Concern (P)	-.149 (.185)	-.013 (.151)	-.335 (.167) **
Perceived Benefits (P)	.257 (.207)	.272 (.169)	.256 (.187)
Perceived Risks (P)	.244 (.175)	.139 (.141)	.236 (.164)
Health Status Variables	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Social Stigma (P)	-.530 (.221) **	-.269 (.176)	-.370 (.200) *
Number of Diseases (P)	-.058 (.121)	.156 (.097)	-.035 (.109)
Positive Health and Emotions (P)	.190 (.357)	.139 (.288)	.212 (.323)
Negative Health and Emotions (P)	-.074 (.318)	.187 (.264)	.341 (.309)
Trust in Institutions	**Government**	**Health Professionals**	**Insurance and Pharmaceutical**
Parent Trust	.076 (.175)	.761 (.205) ***	.164 (.212)
Constant	2.390 (2.455)	-1.266 (1.88)	1.146 (2.216)
R^2	0.19	0.396	0.159
Adjusted R^2	0	0.255	-0.039

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

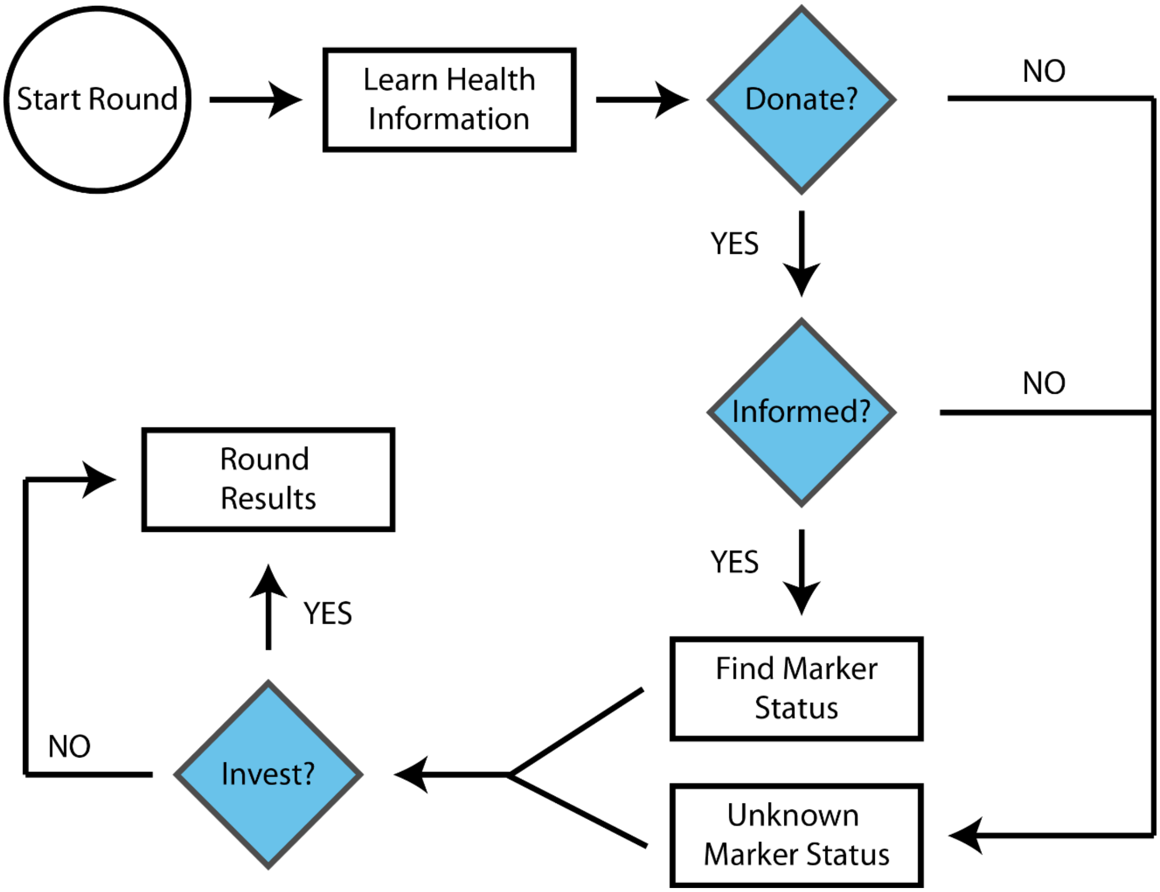
8.1.15 Binary Logistic for Student and Parents

Demographic Variables	**STUDENT**	**PARENT**
Income	-.106 (.088)	.106 (.196)
Race: African American	-.972 (.706)	19.685 (21088.755)
Gender	-.290 (.438)	1.023 (.936)
Generalize Traits	**STUDENT**	**PARENT**
Information Privacy	.398 (.171) **	.997 (.481) **
Genetic Information Sharing Beliefs	**STUDENT**	**PARENT**
Genetic Information Privacy Concerns	-.196 (.151)	-.458 (.481)
Electronic Genetic Information Privacy Concerns	-.012 (.195)	-.428 (.387)
Health Status Variables	**STUDENT**	**PARENT**
Social Stigma	.384 (.224) *	-.083 (.435)
Number of Diseases in Family	-.154 (.089) *	.366 (.350)
Negative Health and Emotions	-.507 (.240) **	-.392 (.495)
Positive Health and Emotions	.290 (.315)	-.056 (.646)
Constant	1.585 (1.880)	2.986 (3.771)

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

8.2 Experiment Appendices

8.2.1 Conceptual Model



8.2.2 Game Construct Definitions

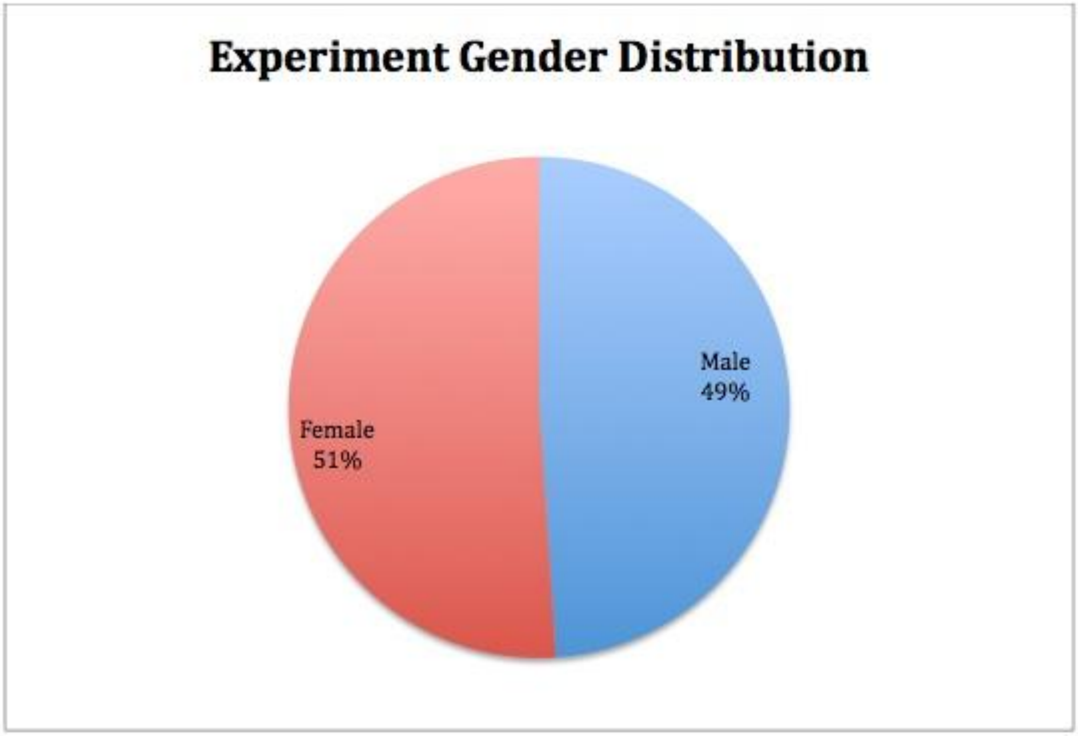
Variable Type	Variable Name	Variable Description
Individual Percentages (Specific to the Treatment)	Affliction Risk	The percentage chance that a participant will become sick during a treatment. This variable was always set to 50%
	Incentive	The amount of money that could be received for donating information, this variable was either \$0.00 or \$0.80
	Sickness Chance	The percentage chance that a participant would become sick if they have the disease. This variable was either 30% or 70%
	Impact to Discrimination	Discrimination chance would be multiplied by this variable, causing a higher or lower chance of discrimination. This variable was either 0.8 or 1.2
	Impact to Cure	The amount that the cure chance would be increased by if a participant chose to donate their information. This variable was either 2% or 3%
Overall Percentages	Discrimination Chance	The total percentage chance that a participant would be discriminated. Different decisions made by the participant would increase the value of this variable. This variable was multiplied by Impact to Discrimination before calculation of the boolean variable
	Cure Chance	The percentage chance that a cure would be found. This variable was identical for all participants in each treatment.
Boolean (Specific to Each Participant)	Affliction	Yes or No, does the participant have the disease?
	Sickness	Yes or No, is the participant currently sick?
	Discrimination	Yes or No, is the participant being discriminated against?
Global (Calculated each treatment)	Cure	Yes or No, has a cure been found for the disease?

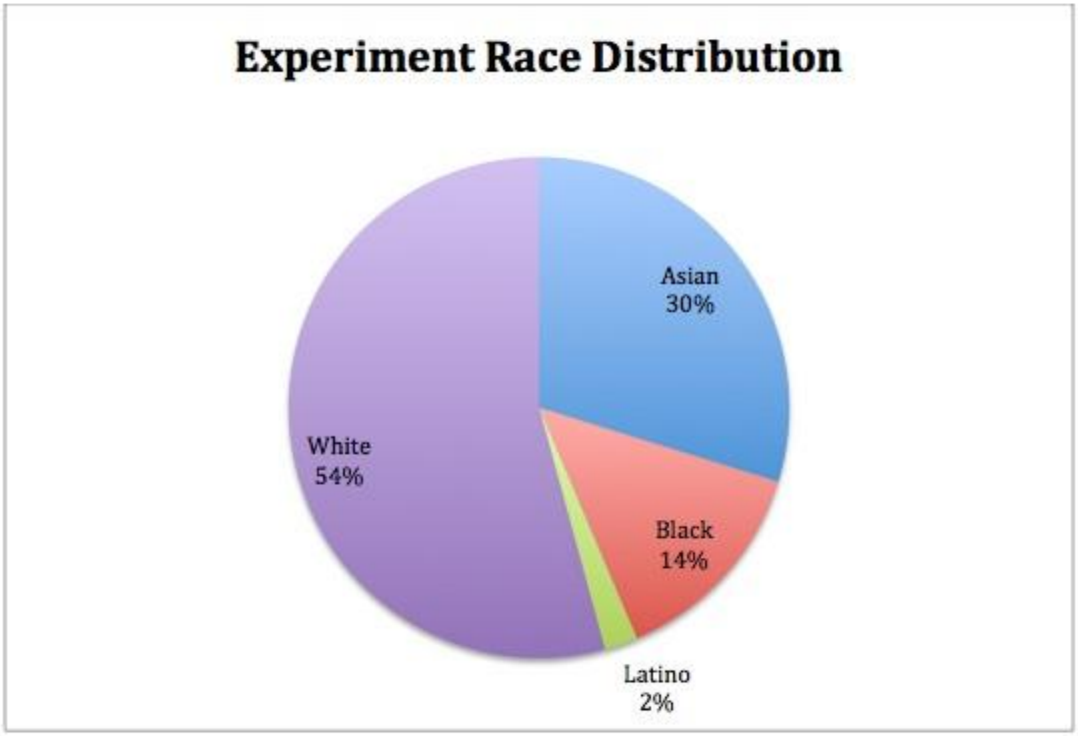
8.2.3 Summary Statistics

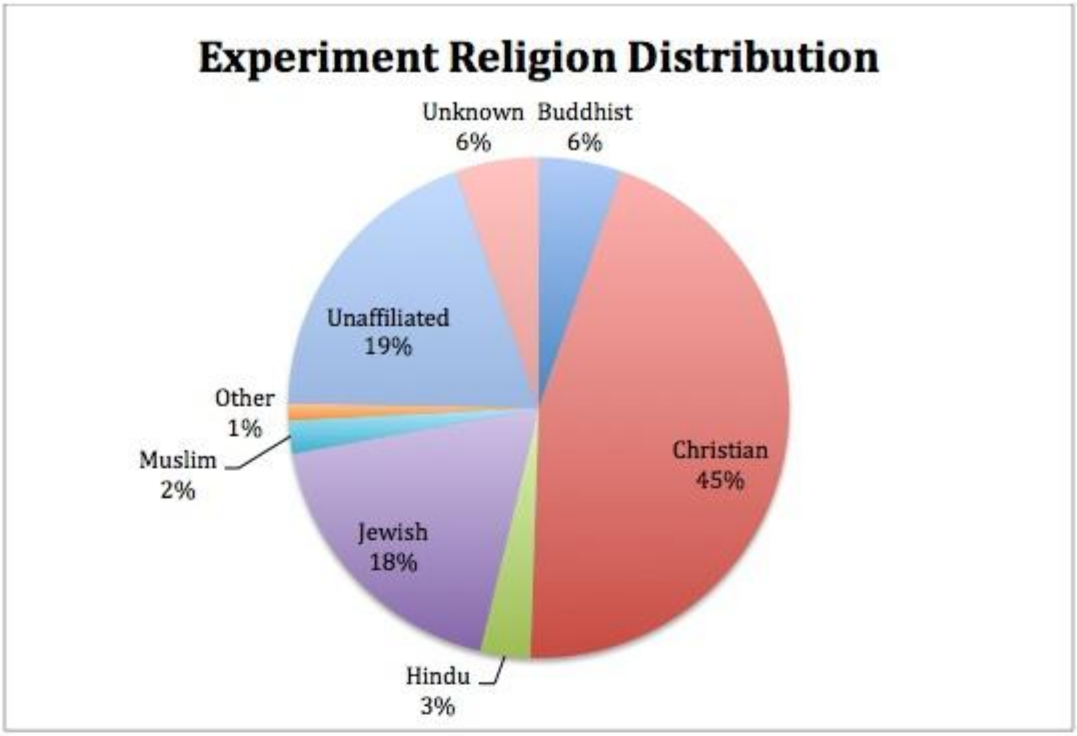
Variable	Value	Frequency	Percent	Cumulative Percent
Donate	0	668	44.4	44.4
	1	838	55.6	100.0
	Total	1506	100.0	
Informed	-1	719	47.7	47.7
	0	323	21.4	69.2
	1	464	30.8	100.0
	Total	1506	100.0	
Invest	0	473	31.4	31.4
	1	1033	68.6	100.0
	Total	1506	100.0	
Marker	0	358	23.8	23.8
	1	1148	76.2	100.0
	Total	1506	100.0	
Sickness Chance	0	745	49.5	49.5
	1	761	50.5	100.0
	Total	1506	100.0	
Gender	0	48	51.1	51.1
	1	46	48.9	100.0
	Total	94	100.0	
Race Black	0	81	86.2%	86.2
	1	13	13.8	100.0
	Total	94	100.0	
Race Asian	0	66	70.2	70.2
	1	28	29.8	100.0
	Total	94	100.0	
Religion Unaffiliated	0	76	80.9	80.9
	1	18	19.1	100.0
	Total	94	100.0	
Political Independent	0	69	73.4	73.4
	1	25	26.6	100.0
	Total	94	100.0	
Income	1	5	5.3	5.3
	2	1	1.1	6.4
	3	2	2.1	8.5
	4	5	5.3	13.8
	5	11	11.7	25.5
	6	10	10.6	36.2
	7	10	10.6	46.8
	8	20	21.3	68.1
	9	16	17.0	85.1
	10	14	14.9	100.0
	Total	94	100.0	
Education	3	3	3.2	3.2

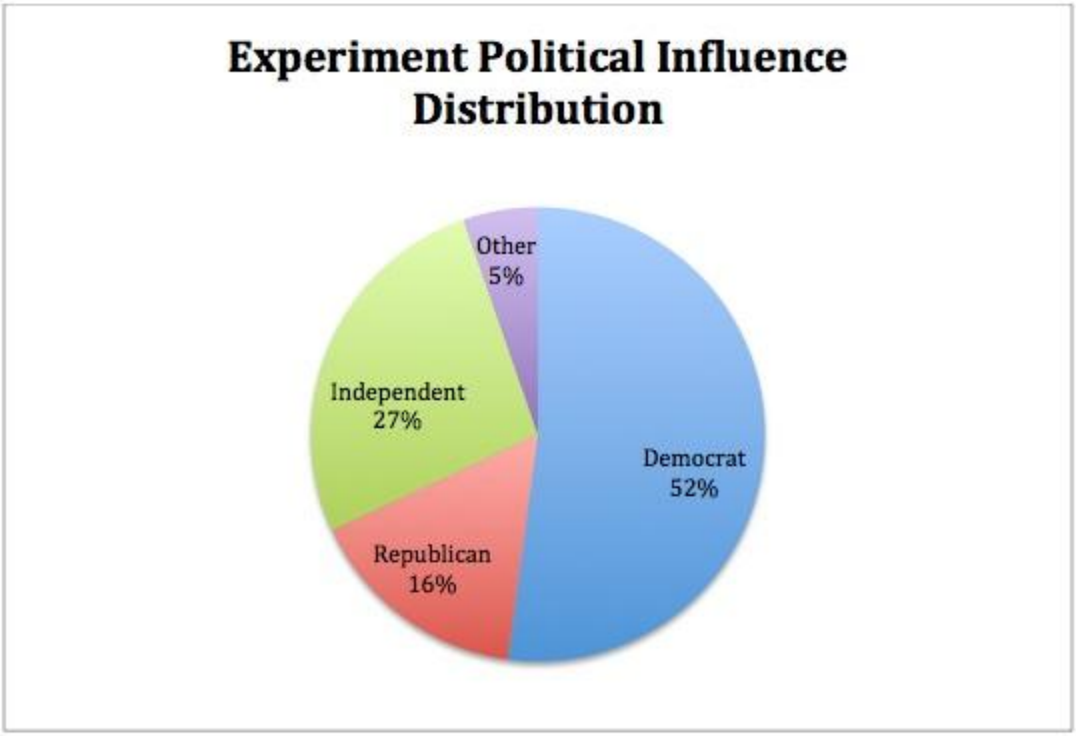
	4	76	80.9	84.0
	5	12	12.8	96.8
	6	2	2.1	98.9
	8	1	1.1	100.0
	Total	94	100.0	

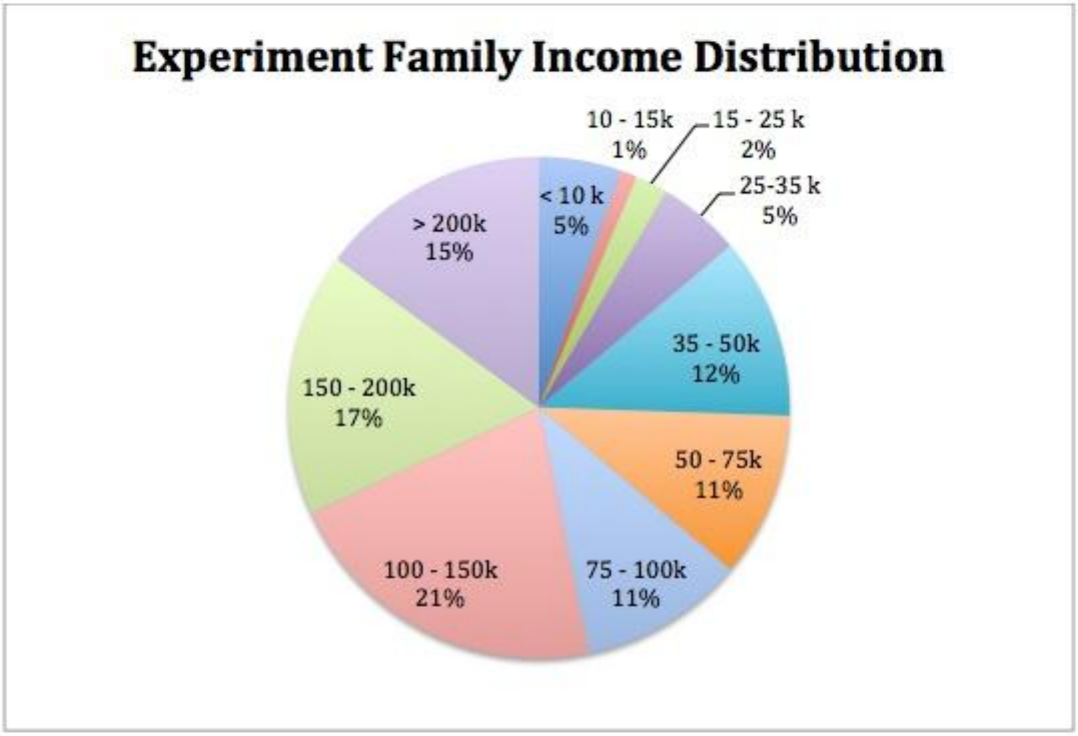
8.2.4 Experiment Demographic Graphs

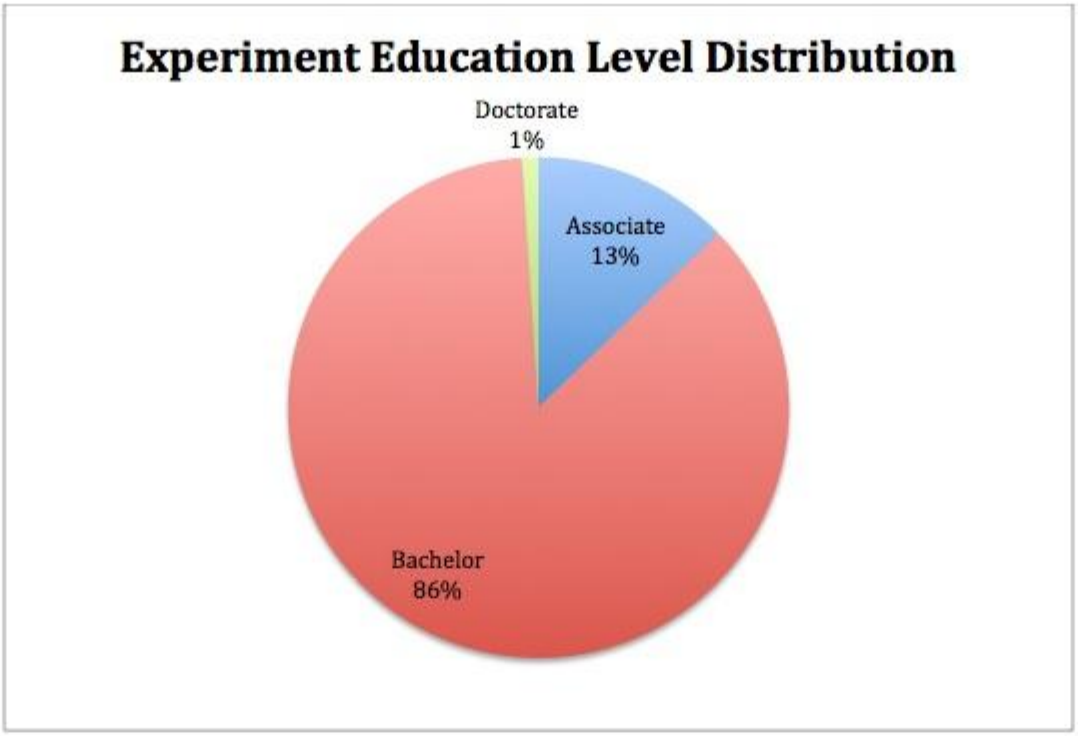





Experiment Religion Distribution
Unknown 6%
Buddhist 6%
Unaffiliated 19%
Other 1%
Muslim 2%
Jewish 18%
Hindu 3%
Christian 45%


Experiment Political Influence Distribution
Other 5%
Independent 27%
Democrat 52%
Republican 16%


Experiment Family Income Distribution
10 - 15k 1%
15 - 25 k 2%
25-35 k 5%
< 10 k 5%
> 200k 15%
35 - 50k 12%
150 - 200k 17%
50 - 75k 11%
100 - 150k 21%
75 - 100k 11%


Experiment Education Level Distribution
Doctorate 1%
Associate 13%
Bachelor 86%

8.2.5 Experiment Correlation Tables

Variable	donate	Informed	Invest With Marker	Invest Without Marker	Impact to Cure	Sickness Chance	Incentive	Impact to Discrimination
donate	1.000	.[a]	.[a]	.202***	.131***	-0.030	.272***	-.211***
Informed	.[a]	1.000	.[a]	.[a]	0.002	0.039	-0.045	-0.068*
Invest With Marker	.[a]	.[a]	1.000	.[a]	0.070	-.111**	-0.012	-0.050
Invest Without Marker	.202***	.[a]	.[a]	1.000	.092***	-.130***	.145***	-.141***
Impact to Cure	.131***	0.002	0.070	.092***	1.000	-0.009	-0.009	0.009
Sickness Chance	-0.030	0.039	-.111**	-.130***	-0.009	1.000	-0.009	0.009
Incentive	.272***	-0.045	-0.012	.145***	-0.009	-0.009	1.000	0.009
Impact to Discrimination	-.211***	-0.068*	-0.050	-.141***	0.009	0.009	0.009	1.000
Affliction Risk	-0.017	0.066*	.098**	.078**	0.000	0.000	0.000	0.000
Marker	0.019	0.027	-.153***	0.017	0.048*	0.007	-0.002	0.005
Gender Male	0.008	-.112***	0.060	0.028	-0.004	-0.004	-0.004	0.004
Race Black	-0.018	-0.047	0.047	0.030	0.000	0.000	0.000	0.000
Race Asian	-0.029	0.011	0.054	-0.052*	-0.003	-0.003	-0.003	0.003
Religion Unaffiliated	-.069***	-.116***	-0.051	0.051	-0.002	-0.002	-0.002	0.002
Political Independent	-0.012	0.013	0.009	0.011	0.004	0.004	0.004	-0.004
Income	0.004	-.084**	-0.037	-.103***	0.002	0.002	0.002	-0.002
Education	-0.026	0.034	0.015	.068**	-0.006	-0.006	-0.006	0.006

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2-tailed).
a. Correlation could not be made because one variable is constant

Variable	Affliction Risk	Marker	Gender Male	Race Black	Race Asian	Religion Unaffiliated
donate	-0.017	0.019	0.008	-0.018	-0.029	-.069***
Informed	0.066*	0.027	-.112***	-0.047	0.011	-.116***
Invest With Marker	.098**	-.153***	0.060	0.047	0.054	-0.051
Invest Without Marker	.078**	0.017	0.028	0.030	-0.052*	0.051
Impact to Cure	0.000	0.048*	-0.004	0.000	-0.003	-0.002
Sickness Chance	0.000	0.007	-0.004	0.000	-0.003	-0.002
Incentive	0.000	-0.002	-0.004	0.000	-0.003	-0.002
Impact to Discrimination	0.000	0.005	0.004	0.000	0.003	0.002
Affliction Risk	1.000	0.000	-0.003	.093***	-.138***	0.000
Marker	0.000	1.000	-0.036	0.001	-0.025	-0.013
Gender Male	-0.003	-0.036	1.000	-0.025	-.169***	0.012
Race Black	.093***	0.001	-0.025	1.000	-.260***	-.194***
Race Asian	-.138***	-0.025	-.169***	-.260***	1.000	.096***
Religion Unaffiliated	0.000	-0.013	0.012	-.194***	.096***	1.000
Political Independent	.074***	0.044*	-0.007	0.039	-.131***	-.112***
Income	-.228***	-.051**	.248***	-0.037	-.282***	0.017
Education	.183***	0.029	.195***	-.069***	.192***	.072***

***. Correlation is significant at the 0.01 level (2-tailed).
**. Correlation is significant at the 0.05 level (2-tailed).
*. Correlation is significant at the 0.1 level (2-tailed).
a. Correlation could not be made because one variable is constant

Variable	Political Independent	Income	Education
donate	-0.012	0.004	-0.026
Informed	0.013	-.084**	0.034
Invest With Marker	0.009	-0.037	0.015
Invest Without Marker	0.011	-.103***	.068**
Impact to Cure	0.004	0.002	-0.006
Sickness Chance	0.004	0.002	-0.006
Incentive	0.004	0.002	-0.006
Impact to Discrimination	-0.004	-0.002	0.006
Affliction Risk	.074***	-.228***	.183***
Marker	0.044*	-.051**	0.029
Gender Male	-0.007	.248***	.195***
Race Black	0.039	-0.037	-.069***
Race Asian	-.131***	-.282***	.192***
Religion Unaffiliated	-.112***	0.017	.072***
Political Independent	1.000	-.122***	-.134***
Income	-.122***	1.000	-.267***
Education	-.134***	-.267***	1.000

***. Correlation is significant at the 0.01 level (2-tailed).

**. Correlation is significant at the 0.05 level (2-tailed).

*. Correlation is significant at the 0.1 level (2-tailed).

a. Correlation could not be made because one variable is constant

8.2.6 Experiment Crosstabulations

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
donateMaxImpact * donate	1506	100.0%	0	.0%	1506	100.0%
donateMaxImpact * informedSelected	787	52.3%	719	47.7%	1506	100.0%
donateMaxImpact * InvestWithMarker	455	30.2%	1051	69.8%	1506	100.0%
donateMaxImpact * InvestWithoutMarker	1029	68.3%	477	31.7%	1506	100.0%
geneExpressionChance * donate	1506	100.0%	0	.0%	1506	100.0%
geneExpressionChance * informedSelected	787	52.3%	719	47.7%	1506	100.0%
geneExpressionChance * InvestWithMarker	455	30.2%	1051	69.8%	1506	100.0%
geneExpressionChance * InvestWithoutMarker	1029	68.3%	477	31.7%	1506	100.0%
profitIncentive * donate	1506	100.0%	0	.0%	1506	100.0%
profitIncentive * informedSelected	787	52.3%	719	47.7%	1506	100.0%
profitIncentive * InvestWithMarker	455	30.2%	1051	69.8%	1506	100.0%
profitIncentive * InvestWithoutMarker	1029	68.3%	477	31.7%	1506	100.0%
discriminationverallMultiplier * donate	1506	100.0%	0	.0%	1506	100.0%
discriminationverallMultiplier * informedSelected	787	52.3%	719	47.7%	1506	100.0%
discriminationverallMultiplier * InvestWithMarker	455	30.2%	1051	69.8%	1506	100.0%
discriminationverallMultiplier * InvestWithoutMarker	1029	68.3%	477	31.7%	1506	100.0%

donateMaxImpact * donate Crosstabulation

	Value	donate		Total
		0	1	
donateMaxImpact	.02	386	374	760
	.03	282	464	746
Total		668	838	1506

donateMaxImpact * informedSelected Crosstabulation

		informedSelected		Total
		.00	1.00	
donateMaxImpact	.02	144	206	350
	.03	179	258	437
Total		323	464	787

donateMaxImpact * InvestWithMarker Crosstabulation

		InvestWithMarker		Total
		.00	1.00	
donateMaxImpact	.02	57	145	202
	.03	56	197	253
Total		113	342	455

donateMaxImpact * InvestWithoutMarker Crosstabulation

		InvestWithoutMarker		Total
		.00	1.00	
donateMaxImpact	.02	204	343	547
	.03	138	344	482
Total		342	687	1029

geneExpressionChance * donate Crosstabulation

		donate		Total
		0	1	
geneExpressionChance	.3	326	434	760
	.7	342	404	746
Total		668	838	1506

geneExpressionChance * informedSelected Crosstabulation

	informedSelected	Total

		.00	1.00	
geneExpressionChance	.3	173	230	403
	.7	150	234	384
Total		323	464	787

geneExpressionChance * InvestWithMarker Crosstabulation

		InvestWithMarker		Total
		.00	1.00	
geneExpressionChance	.3	45	180	225
	.7	68	162	230
Total		113	342	455

geneExpressionChance * InvestWithoutMarker Crosstabulation

		InvestWithoutMarker		Total
		.00	1.00	
geneExpressionChance	.3	143	382	525
	.7	199	305	504
Total		342	687	1029

profitIncentive * donate Crosstabulation

		donate		Total
		0	1	
profitIncentive	0	439	321	760
	10	229	517	746
Total		668	838	1506

profitIncentive * informedSelected Crosstabulation

		informedSelected		Total
		.00	1.00	
profitIncentive	0	118	190	308
	10	205	274	479
Total		323	464	787

profitIncentive * InvestWithMarker Crosstabulation

		InvestWithMarker		Total
		.00	1.00	
profitIncentive	0	45	141	186
	10	68	201	269
Total		113	342	455

profitIncentive * InvestWithoutMarker Crosstabulation

		InvestWithoutMarker		Total
		.00	1.00	
profitIncentive	0	222	341	563
	10	120	346	466
Total		342	687	1029

discriminationverallMultiplier * donate Crosstabulation

		donate		Total
		0	1	
discriminationverallMultiplier	.8	252	494	746
	1.2	416	344	760
Total		668	838	1506

discriminationverallMultiplier * informedSelected Crosstabulation

		informedSelected		Total
		.00	1.00	
discriminationverallMultiplier	.8	172	279	451
	1.2	151	185	336
Total		323	464	787

discriminationverallMultiplier * InvestWithMarker Crosstabulation

		InvestWithMarker		Total
		.00	1.00	
discriminationverallMultiplier	.8	63	210	273
	1.2	50	132	182
Total		113	342	455

discriminationverallMultiplier * InvestWithoutMarker Crosstabulation

		InvestWithoutMarker		Total
		.00	1.00	
discriminationverallMultiplier	.8	120	343	463
	1.2	222	344	566
Total		342	687	1029

8.2.7 Random Effects Logistic Regression

Variables	Donate	Informed	Invest with Marker	Invest
Impact to Cure	66.04 (12.97)***	28.02 (23.85)	64.22 (28.05)**	58.91 (17.77)***
Sickness Chance	-0.258 (0.314)	0.927 (0.585)	-1.653 (0.693)**	-2.037 (0.437)***
Incentive	0.143 (0.0137)***	0.000 (0.026)	0.013 (0.032)	0.105 (0.019)***
Impact to Discrimination	-2.882 (0.334)***	-1.814 (0.640)***	-0.736 (0.718)	-2.455 (0.454)***
Marker			-1.230 (0.369)***	
Affliction Risk	-.0974 (0.208)	0.557 (0.676)	0.548 (0.366)	0.252 (0.348)
Gender_Male	0.0749 (0.213)	-1.083 (0.685)	0.394 (0.384)	0.267 (0.355)
RaceBlack	-0.320 (0.299)	-0.738 (0.948)	0.657 (0.558)	-0.018 (0.489)
RaceAsian	-0.225 (0.244)	-0.134 (0.803)	0.703 (0.484)	-0.626 (0.414)
Religion Unaffiliated	-.490 (.255)*	-1.606 (.852)*	-0.591 (0.525)	0.222 (0.432)
Political Independent	-0.180 (0.229)	-0.251 (0.736)	-0.070 (0.410)	-0.209 (0.382)
Income	-0.030 (0.048)	-0.072 (0.153)	-0.050 (0.088)	-0.148(.082)*
Education	-0.100 (0.181)	0.080 (0.574)	-0.392 (0.333)	0.507 (.349)
Constant	2.035 (1.045)*	2.092 (3.023)	2.725 (1.926)	1.710 (1.810)
Observations	1490	779	456	1034
Number of Subjects	94	92	77	93
Subject FE	no	no	no	no
Period FE	yes	yes	yes	yes

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

8.2.8 Fixed Effects Logistic Model

Variables	Donate	Informed	Invest with Marker	Invest without Marker
Impact to Cure	65.25 (13.51)***	20.91 (25.85)	56.93 (31.94)*	61.15(18.89)***
Sickness Chance	-0.324 (0.314)	.961 (.6222)	-2.020 (.773)***	-1.905(.455)***
Incentive	0.133 (0.0142)***	.005 (.028)	.0145 (.037)	.103(.0201)***
Impact to Discrimination	-2.812 (0.352)***	-1.694 (.695)**	-.263 (.853)	-2.534 (.486)***
Marker			-1.392 (.424)***	
Lagged Sickness	-.064 (0.130)	.088 (.249)	.599 (.312)*	.239 (.180)
Lagged Number of Donations	-0.003 (0.023)	.022 (.045)	.008 (.0559)	-.045 (.0305)

Observations	1352	438	296	833
Number of Subjects	91	55	47	79
Subject FE	yes	yes	yes	yes
Period FE	yes	yes	yes	yes

***. Coefficient is significant at the 0.01 level (2-tailed).
**. Coefficient is significant at the 0.05 level (2-tailed).
*. Coefficient is significant at the 0.1 level (2 tailed).

8.3 Study Documents

8.3.1 Survey Documents

8.3.1.1 Student Survey

INTRODUCTION

Team MAGIC would like to thank you for agreeing to participate in our Gemstone Survey! In this survey, you will be asked how you feel regarding genetic information sharing. You will respond to a series of statements that measure your behavior regarding your personal information and personal demographic information.

The healthcare industry is moving towards personalization of medicine where specific genetic information can be interpreted to assist health care professionals to treat illnesses. Furthermore, other benefits to healthcare by sharing your genetic information include an increase in scientific knowledge and assistance in finding cures. However, sharing genetic information can allow for genetic discrimination, job loss, and insurance discrimination.

SECTION 1 – Individual Characteristics

Please respond to the following questions using the scale provided:

	Questions	Strongly Disagree			Neutral			Strongly Agree
1.	All things considered, I believe my personal privacy is seriously threatened	1	2	3	4	5	6	7
2.	Compared with other subjects on my mind, personal privacy is very important	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
3.	I am concerned about threats to my personal privacy today	1	2	3	4	5	6	7

GENETIC INFORMATION PRIVACY CONCERN

	Questions	Strongly Disagree			Neutral			Strongly Agree
4.	Compared with other subjects on my mind, the privacy of my electronic personal genetic health information is very important	1	2	3	4	5	6	7
5.	I am concerned about threats to the privacy of my electronically stored personal genetic health information today	1	2	3	4	5	6	7
6.	All things considered, I believe the privacy of my electronic personal genetic health information is seriously threatened	1	2	3	4	5	6	7

7.	I usually trust people until they give me a reason not to trust them	1	2	3	4	5	6	7
8.	I usually give people the benefit of the doubt	1	2	3	4	5	6	7
9.	My general approach is to trust new acquaintances until they prove I should not trust them	1	2	3	4	5	6	7

Please rate the extent to which you agree with the following statements:

	Questions	Strongly Disagree			Neutral			Strongly Agree
10.	The electronic/digital storage format is a safe environment in which to exchange genetic health information with others	1	2	3	4	5	6	7
11.	The digital storage format is a reliable environment in which to conduct genetic health related transactions	1	2	3	4	5	6	7
12.	Organizations handle personal genetic health	1	2	3	4	5	6	7

	Questions	Strongly Disagree	Neutral	Strongly Agree
	information submitted by patients in an electronic format in a competent fashion			

TRUST IN INSTITUTIONS

13.	I believe that pharmaceutical companies, in general, would act in my best interest	1	2	3	4	5	6	7
14.	If I required help, a pharmaceutical company would do its best to help me	1	2	3	4	5	6	7
15.	Pharmaceutical companies, in general, are interested in my well-being, not just their own	1	2	3	4	5	6	7

16.	Pharmaceutical companies are truthful in dealings with me	1	2	3	4	5	6	7
17.	Pharmaceutical companies would keep commitments	1	2	3	4	5	6	7
18.	Pharmaceutical companies are sincere and genuine	1	2	3	4	5	6	7

19.	I believe that insurance companies, in general, would act in my best interest	1	2	3	4	5	6	7
20.	If I required help, a insurance company would do its best to help me	1	2	3	4	5	6	7

21.	Insurance companies, in general, are interested in my well-being, not just their own	1	2	3	4	5	6	7

22.	Insurance companies are truthful in dealings with me	1	2	3	4	5	6	7
23.	Insurance companies would keep commitments	1	2	3	4	5	6	7
24.	Insurance companies are sincere and genuine	1	2	3	4	5	6	7

25.	I believe that the government, in general, would act in my best interest	1	2	3	4	5	6	7
26.	If I required help, the government would do its best to help me	1	2	3	4	5	6	7
27.	The government, in general, is interested in my well-being, not just their own	1	2	3	4	5	6	7

28.	The government is truthful in dealings with me	1	2	3	4	5	6	7
29.	The government would keep commitments	1	2	3	4	5	6	7
30.	The government is sincere and genuine	1	2	3	4	5	6	7

31.	I believe that health professionals, in general, would act in my best interest	1	2	3	4	5	6	7
32.	If I required help, health professionals would do their best to help me	1	2	3	4	5	6	7

33.	Health professionals, in general, are interested in my well-being, not just their own	1	2	3	4	5	6	7

34.	Health professionals are truthful in dealings with me	1	2	3	4	5	6	7
35.	Health professionals would keep commitments	1	2	3	4	5	6	7
36.	Health professionals are sincere and genuine	1	2	3	4	5	6	7

The next question is intended to determine how your health is affecting you personally. Read each statement and indicate how each item expresses how you feel using the scale provided; do not dwell on the statement – it is better to respond immediately. There are no right or wrong answers.

	Questions	**Not at all**	**A little**	**Somewhat**	**A lot**	**Intensely**
37.	Right now I feel sad about something that has happened to my health	1	2	3	4	5
38.	I am happy about my health right now	1	2	3	4	5
39.	I have an intense loathing for my present state of health	1	2	3	4	5
40.	I feel ecstatic about life right now	1	2	3	4	5
41.	My health state has provoked a profound devotion for life in me	1	2	3	4	5
42.	Right now other things in my life will have to wait as I focus on my health	1	2	3	4	5
43.	My current health state is a real inconvenience	1	2	3	4	5
44.	At the moment I often think how others will respond to me	1	2	3	4	5
45.	In the future I will make sure I know how to look after myself	1	2	3	4	5
46.	At present I feel extreme dread	1	2	3	4	5
47.	Recent experience has warned me to be more cautious about my health	1	2	3	4	5

	Questions	**Not at all**	**A little**	**Somewhat**	**A lot**	**Intensely**
48.	I feel everything needs to be approached with caution right now	1	2	3	4	5
49.	I am extremely displeased with my present health state	1	2	3	4	5
50.	I feel disgust for my current state of health	1	2	3	4	5
51.	My health has made me think carefully about life	1	2	3	4	5
52.	I feel furious at my present state of health	1	2	3	4	5
53.	I am amazed at my state of health	1	2	3	4	5
54.	I feel very deep sorrow because of my health	1	2	3	4	5
55.	My spirits are high today	1	2	3	4	5
56.	Health problems are tiresome to me	1	2	3	4	5
57.	My present health problems fill me with dread	1	2	3	4	5
58.	My state of health has taken me unawares	1	2	3	4	5

Please respond to the following questions using the scale provided:

	Questions	**Strongly Disagree**			**Neutral**			**Strongly Agree**
59.	Overall, I tend to be a cheerful person.	1	2	3	4	5	6	7
60.	I am not what I would call a warm-hearted person	1	2	3	4	5	6	7
61.	When people hurt me, I usually hold a grudge for a long time	1	2	3	4	5	6	7
62.	I am an affectionate and tender person	1	2	3	4	5	6	7
63.	I am generally a sincere and truthful person	1	2	3	4	5	6	7
64.	If I could help save somebody’s life, I would do everything possible	1	2	3	4	5	6	7
65.	I enjoy doing small favors every day for the people I care about	1	2	3	4	5	6	7

	Questions	**Strongly Disagree**			**Neutral**			**Strongly Agree**
66.	Helping others is one of the most important aspects of life	1	2	3	4	5	6	7
67.	I enjoy working for the welfare of others	1	2	3	4	5	6	7
68.	My family tends to do what we can to help those less fortunate than ourselves	1	2	3	4	5	6	7
69.	I agree with the old saying, "It is better to give than to receive."	1	2	3	4	5	6	7

How frequently have you personally been the victim of what you felt was an improper invasion of privacy?									
70.	*Very Infrequently*	1	2	3	4	5	6	7	*Very frequently*
How much have you heard or read during the last year about the use and potential misuse of health information collected electronically?									
71.	*Not at all*	1	2	3	4	5	6	7	*A great deal*

SECTION 2 – Factors Influence Genetic Information Sharing

Please respond to the following questions using the scale provided:

Rational Ignorance

	Questions	Strongly Disagree			Neutral			Strongly Agree
72.	I would ignore signs that a significant other is cheating on me to maintain a relationship	1	2	3	4	5	6	7
73.	I wait as long as possible to hear test results if I am worried that they could be bad	1	2	3	4	5	6	7
74.	I generally ignore criticism and hope that the problem will go away	1	2	3	4	5	6	7
75.	I would rather someone tell me that I have completed a task well instead of telling me how they truly feel	1	2	3	4	5	6	7
76.	I generally do not look at bills if I am worried about being able to pay them	1	2	3	4	5	6	7
77.	If I knew something bad that affected a friend, I would want them to know	1	2	3	4	5	6	7

Perceived Risks

	Questions	Strongly Disagree			Neutral			Strongly Agree
78.	My genetic information can be used to discriminate against me	1	2	3	4	5	6	7
79.	I generally share sensitive health information with friends	1	2	3	4	5	6	7
80.	I am reluctant to share good news with someone when I know they have recently suffered a setback	1	2	3	4	5	6	7
81.	When given two options, I generally take the less risky path	1	2	3	4	5	6	7
82.	I am comfortable sharing health information with my employer	1	2	3	4	5	6	7
83.	I am afraid that knowledge of my	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
	poor health would affect my employer's view of me							
84.	I believe that insurance companies have the right to deny coverage for people with pre-existing medical conditions	1	2	3	4	5	6	7
85.	I would fear losing my insurance coverage if I were diagnosed with a chronic illness or disease	1	2	3	4	5	6	7
86.	I believe my employer should have access to my genetic information.	1	2	3	4	5	6	7
87.	I would share personal health information with a family member	1	2	3	4	5	6	7
88.	I would trust a pharmaceutical company with my medical records	1	2	3	4	5	6	7
89.	I trust my doctor's advice regarding my health	1	2	3	4	5	6	7
90.	I generally seek second opinions when my doctor gives me a diagnosis or treatment plan	1	2	3	4	5	6	7
91.	I believe that insurance companies' first priority is their customer's interests and health	1	2	3	4	5	6	7
92.	I believe that the government is a reliable institution to conduct medical studies that include personal and health information	1	2	3	4	5	6	7

Perceived Benefits

	Questions	Strongly Disagree			Neutral			Strongly Agree
93.	I believe my genetic information can benefit medical advancement in a significant way	1	2	3	4	5	6	7
94.	Researchers and health officials need access to genetic information to effectively	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
	produce treatments							
95.	Society's contribution to genetic information will benefit me in a significant way	1	2	3	4	5	6	7
96.	Personalized genetic information will greatly improve the current health care system	1	2	3	4	5	6	7
97.	Medical discoveries depend greatly on people's willingness to share their genetic information	1	2	3	4	5	6	7
98.	I would be willing to place myself in some personal jeopardy if it benefits a close family member's health or general wellbeing	1	2	3	4	5	6	7
99.	I would be willing to sacrifice personal gain or put myself at risk to aid a close friend	1	2	3	4	5	6	7
100.	Predicting serious diseases from genetic information will be an invaluable tool in the future of medicine	1	2	3	4	5	6	7

<u>My Attitudes towards Information Privacy</u>

	Questions	Strongly Disagree			Neutral			Strongly Agree
101.	I generally avoid making purchases online	1	2	3	4	5	6	7
102.	I am concerned about identity theft	1	2	3	4	5	6	7
103.	I will freely give away information to telemarketers	1	2	3	4	5	6	7
104.	I generally trust strangers	1	2	3	4	5	6	7
105.	I do not worry about invasion of privacy	1	2	3	4	5	6	7
106.	I take proactive steps to protect their personal health or financial information	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
107.	I bank online	1	2	3	4	5	6	7
108.	I do not think about corporate or governmental tracking of internet traffic	1	2	3	4	5	6	7

Issue Involvement

I often consider myself at risk of genetic discrimination.									
109.	*Not at all*	1	2	3	4	5	6	7	*A great deal*
I often hear about cases in which computer security is a concern.									
110.	*Not at all*	1	2	3	4	5	6	7	*A great deal*
I often consider the benefits of sharing genetic information.									
111.	*Not at all*	1	2	3	4	5	6	7	*A great deal*
I often consider the risks of sharing genetic information.									
112.	*Not at all*	1	2	3	4	5	6	7	*A great deal*
I often consider hereditary conditions at which I am at risk.									
113.	*Not at all*	1	2	3	4	5	6	7	*A great deal*

Genetic Discrimination

If you were tested and found to be at high risk for a genetic disorder with serious complications, indicate the extent to which you would be concerned about each of the following:

In the work place:

	Questions	Strongly Disagree			Neutral			Strongly Agree
114.	Being denied promotion	1	2	3	4	5	6	7
115.	Being forced to retire	1	2	3	4	5	6	7
116.	Being offered fewer opportunities	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
117.	Increased surveillance	1	2	3	4	5	6	7
118.	Social avoidance / pity	1	2	3	4	5	6	7

Financial impacts:

	Questions	Strongly Disagree			Neutral			Strongly Agree
119.	Being denied insurance	1	2	3	4	5	6	7
120.	Increased insurance premiums	1	2	3	4	5	6	7

Healthcare:

	Questions	Strongly Disagree			Neutral			Strongly Agree
121.	Receiving altered medical advice from healthcare professionals	1	2	3	4	5	6	7

Socially with family:

	Questions	Strongly Disagree			Neutral			Strongly Agree
122.	Having family members watch me closely for changes in my health (i.e. symptoms of disease)	1	2	3	4	5	6	7
123.	Having family members distance themselves from me	1	2	3	4	5	6	7
124.	Having family members put pressure on me regarding my decisions about education	1	2	3	4	5	6	7
125.	Having family members put pressure on me regarding my decisions about marriage	1	2	3	4	5	6	7
126.	Having family members put pressure on me regarding my decisions about having children	1	2	3	4	5	6	7

Socially with friends:

	Questions	Strongly Disagree			Neutral			Strongly Agree
127.	Having friends watch me closely for changes in my health (i.e. symptoms of disease)	1	2	3	4	5	6	7
128.	Having friends distance themselves from me	1	2	3	4	5	6	7
129.	Having friends put pressure on	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
	me regarding my decisions about education							
130.	Having friends put pressure on me regarding my decisions about marriage	1	2	3	4	5	6	7
131.	Having friends put pressure on me regarding my decisions about having children	1	2	3	4	5	6	7

Government:

	Questions	Strongly Disagree			Neutral			Strongly Agree
132.	Being denied the privilege of adoption	1	2	3	4	5	6	7
133.	Being prohibited from donating blood	1	2	3	4	5	6	7

Social Stigma

Indicate the extent to which you agree with the following:

	Questions	Strongly Disagree			Neutral			Strongly Agree
134.	Having a genetic disease carries social stigma	1	2	3	4	5	6	7
135.	People will see person in a less favorable way if they come to know that he/she has a genetic disease	1	2	3	4	5	6	7
136.	It is advisable for a person to hide from people with a genetic disease	1	2	3	4	5	6	7
137.	People tend to like less those with a genetic disease	1	2	3	4	5	6	7
138.	It is a sign of weakness of inadequacy to have a genetic disease	1	2	3	4	5	6	7

Willingness to Disclose

Please think of genetic health information as potentially including such information as the results of testing conducted for disease prediction and diagnosis (e.g. Huntington's disease or inherited forms of the breast cancer gene) or results of testing conducted for the purposes of finding interactions between diet and genes to maximize quality of life and avoid disease (e.g. an increased need for vitamin D which could be linked to osteoporosis, cancer and other health conditions).

A pharmaceutical company may be interested in conducting research on patients with specific genetic conditions and may be interested in contacting you for participation in related health studies. Specify the extent to which you would be willing to grant a pharmaceutical company access to your personal *genetic* information for such purposes:

139.	*Unlikely*	1	2	3	4	5	6	7	*Likely*
140.	*Not Probable*	1	2	3	4	5	6	7	*Probably*
141.	*Willing*	1	2	3	4	5	6	7	*Unwilling*

An insurance company may be interested in conducting research on patients with specific genetic conditions and may be interested in contacting you for participation in related health studies. Specify the extent to which you would be willing to grant an insurance company access to your personal *genetic* information for such purposes:

142.	*Unlikely*	1	2	3	4	5	6	7	*Likely*
143.	*Not Probable*	1	2	3	4	5	6	7	*Probably*
144.	*Willing*	1	2	3	4	5	6	7	*Unwilling*

The government may be interested in conducting research on patients with specific genetic conditions and may be interested in contacting you for participation in related health studies. Specify the extent to which you would be willing to grant the government access to your personal *genetic* information for such purposes:

145.	*Unlikely*	1	2	3	4	5	6	7	*Likely*
146.	*Not Probable*	1	2	3	4	5	6	7	*Probably*
147.	*Willing*	1	2	3	4	5	6	7	*Unwilling*

Health Professionals may be interested in conducting research on patients with specific genetic conditions and may be interested in contacting you for participation in related health studies. Specify the extent to which you would be willing to grant health professionals access to your personal *genetic* information for such purposes:

148.	*Unlikely*	1	2	3	4	5	6	7	*Likely*
149.	*Not Probable*	1	2	3	4	5	6	7	*Probably*
150.	*Willing*	1	2	3	4	5	6	7	*Unwilling*

151. Unless you specifically choose NOT to be informed, if testing reveals that you are at risk for a genetic disease, you would be informed about it.

- I would choose to be informed if I am at risk for a genetic disease
- I would choose NOT to be informed if I am at risk for a genetic disease

Parental Influence

	Questions	Strongly Disagree			Neutral			Strongly Agree
152.	I'm glad my parents care so much about me.	1	2	3	4	5	6	7
153.	I get along well with my parents.	1	2	3	4	5	6	7
154.	My parents are proud of me.	1	2	3	4	5	6	7
155.	I am happy when I do well in school because I know it pleases my parents.	1	2	3	4	5	6	7
156.	My parents ask me about homework and projects	1	2	3	4	5	6	7
157.	My parents talk to me about their aspirations	1	2	3	4	5	6	7
158.	I talk to my parents about what I am learning in school	1	2	3	4	5	6	7
159.	I talk to my parents about issues in current events	1	2	3	4	5	6	7
160.	I talk to my parents about my social (personal) life in school	1	2	3	4	5	6	7
161.	My parents call me on my cell phone to find out about my day	1	2	3	4	5	6	7
162.	I call my parents on their cell phones to let them know what's going on	1	2	3	4	5	6	7
163.	My parents show support for the activities I participate in.	1	2	3	4	5	6	7

	Questions	Strongly Disagree			Neutral			Strongly Agree
164.	I tell my parents about where I go	1	2	3	4	5	6	7
165.	My parents have met my friends	1	2	3	4	5	6	7
166.	I get along well with my parents.	1	2	3	4	5	6	7
167.	When my parents ask me to do something, I generally listen to them	1	2	3	4	5	6	7
168.	My parents have a strong influence on my values and beliefs	1	2	3	4	5	6	7

SECTION 3 - Demographics

Finally, we need to collect just a couple pieces of demographic information about you. This information will be combined with others' data and only the researchers will have access to it.

169. What is your gender?
    - ☐ Male
    - ☐ Female

170. What is your age?
    - ☐ 18-24
    - ☐ 25-34
    - ☐ 35-44
    - ☐ 45-54
    - ☐ 55-64
    - ☐ 65-74
    - ☐ over 75

171. What is your marital status
    - ☐ Married (except separated)
    - ☐ Divorced
    - ☐ Separated
    - ☐ Widowed
    - ☐ Never Marries

172. What is your race (select the one race you most consider yourself to be):
    - ☐ 1 White
    - ☐ 2 Black or African American
    - ☐ 3 Asian
    - ☐ 4 Native Hawaiian or Other Pacific Islander
    - ☐ 5 Spanish/Hispanic, Latino
    - ☐ 6 Other, please specify: ___________________________

173. What is your religion (select the one religion you most consider yourself to be):
    - ☐ 1 Christian - Protestant
    - ☐ 2 Christian - Catholic
    - ☐ 3 Christian - Mormon
    - ☐ 4 Christian – Jehovah's Witness
    - ☐ 5 Christian - Orthodox
    - ☐ 6 Christian – Other Christian
    - ☐ 7 Jewish
    - ☐ 8 Muslim
    - ☐ 9 Buddhist
    - ☐ 10 Hindu
    - ☐ 11 Other World Religions
    - ☐ 12 Other Faiths

☐ 13 Unaffiliated – Religious Unaffiliated
☐ 14 Unaffiliated – Secular Unaffiliated
☐ 15 Unaffiliated – Atheist
☐ 16 Unaffiliated – Agnostic
☐ 17 Don’t Know

174. What political party do you best affiliate yourself with?
☐ 1 Democrat
☐ 2 Republican
☐ 3 Independent
☐ 4 Other

175. How would you rate your computer skills?
☐ 1 None
☐ 2 Very little
☐ 3 Average
☐ 4 Quite extensive
☐ 5 Very extensive

176. How often do you use a computer?
☐ Once a month
☐ 2-3 Times a Month
☐ Once a week
☐ 2-3 Times a Week
☐ Daily

177. In general, would you say your health is:
☐ 1 Excellent
☐ 2 Very good
☐ 3 Good
☐ 4 Fair
☐ 5 Poor

178. Do you have a chronic illness? (check all that apply)
☐ No, I don't
☐ Heart Disease/Congestive Heart Failure (CHF)
☐ Diabetes (Sugar)
☐ Asthma
☐ Cancer (any type)
☐ High Blood Pressure/Hypertension
☐ AIDS/HIV
☐ Arthritis
☐ Hypothyroidism
☐ Back problems/surgery
☐ High cholesterol

☐ Depression
☐ Known genetic disorder (any type)
☐ Other, Please Specify: ___________________________

179. Do you have a loved one (e.g. father, mother, sister, close friend) with a chronic illness? (check all that apply)

☐ No, I don't
☐ Heart Disease/Congestive Heart Failure (CHF)
☐ Diabetes (Sugar)
☐ Asthma
☐ Cancer (any type)
☐ High Blood Pressure/Hypertension
☐ AIDS/HIV
☐ Arthritis
☐ Hypothyroidism
☐ Back problems/surgery
☐ High cholesterol
☐ Depression
☐ Known genetic disorder (any type)
☐ Other, Please Specify: _______________________________

180. Which category represents the total combined income of your household during the past 12 months?

☐ Less than $10,000
☐ $10,000 to $14,999
☐ $15,000 to $24,999
☐ $25,000 to $34,999
☐ $35,000 to $49,999
☐ $50,000 to $74,999
☐ $75,000 to $99,999
☐ $100,000 to $149,999
☐ $150,000 to $199,999
☐ $200,000 or more

181. What is the highest level of school you have completed or the highest degree you have received?

☐ 8th grade or less
☐ Some high school, no diploma
☐ High School Graduate or equivalent (For example: GED)
☐ Some college but no degree
☐ Associate degree in college
☐ Bachelors degree (For example: BA, AB, BS)
☐ Master's degree (For example: MA, MS, MEng, MEd, MSW, MBA)
☐ Professional/Doctorate Degree (For example: MD,DDS,JD,PhD,EdD)

Additional Comments/Suggestions:

THANK YOU FOR YOUR ENDURANCE AND PARTICIPATION!

8.3.1.2 Consent Form

Consent Form for Team MAGIC Survey

Project Title	Medical and Genetics Information Concerns
Purpose of the Study	This research is being conducted by **Team MAGIC** at the University of Maryland, College Park. We are inviting you to participate in this research project because you are a member of our target sample. The purpose of this research project is to assess willingness to disclose personal genetic information.
Procedures	The procedures involve completing an online survey that will take about 30 minutes. You will be responding to a number of multiple-choice questions. There are no right or wrong answers. For example: You may be asked to indicate your level of agreement with statements such as: I believe that insurance companies, in general, would act in my best interest.
Potential Risks and Discomforts	There are some risks associated with participating in this research project. You will be responding to survey items about your perceptions of the use of personal genetic information between you and certain institutions. There are no right or wrong answers. However, you may experience embarrassment in responding to some of the questions. You may also experience fatigue during the survey.
Potential Benefits	There are no direct benefits to participation. However, possible benefits include improving the understanding of the motivations behind genetic information disclosure.
Confidentiality	The investigators will do their best to keep your personal information confidential. To help protect your confidentiality, the data collected will be stored on password-protected computers accessible only by members of the research team. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.

Medical Treatment	The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.
Right to Withdraw and Questions	Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator, Ritu Agarwal at 4327 Van Munching Hall, University of Maryland, College Park, MD 20742 ragarwal@rhsmith.umd.edu 301-405-3121
Participant Rights	If you have questions about your rights as a research participant or wish to report a research-related injury, please contact: **University of Maryland College Park** **Institutional Review Board Office** **1204 Marie Mount** **College Park, Maryland, 20742** **E-mail: irb@umd.edu** **Telephone: 301-405-0678** This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

Statement of Consent	*Your signature indicates that you are at least 18 years of age; you have read this consent form; you are who you claim to be; the research has been explained to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.* *If you agree to participate, please sign your name below.*	
Signature and Date	**PARTICIPANT NAME [Please Print]**	
	PARTICIPANT SIGNATURE	
	DATE	

8.3.2 Experiment Documents

8.3.2.1 Instructions

Please fill out the consent form and demographics form. We will come around to collect these when you are all done.

WELCOME

Thank you for participating in today's experiment. I will read through a script to explain to you the nature of today's experiment as well as how to navigate the computer interface with which you will be working. I will be using this script to make sure that all sessions of this experiment receive the same information, but please feel free to ask questions as they arise.

This is an experiment in decision-making. In addition to a $10 participation fee, you will have the opportunity to earn more through the course of the experiment and you will be paid your earnings and the participation fee privately at the conclusion of the experiment. The exact amount you receive will be determined during the experiment and will depend on your decisions. *If you have any questions during the experiment, please raise your hand and wait for an experimenter to come to you. Please do not talk, exclaim, or try to communicate with other participants during the experiment. Also, please turn all cell phones off or on mute for the duration of the experiment.* Participants intentionally violating the rules may be asked to leave the experiment with only the show-up fee.

All monetary amounts you will see in this experiment will be denominated in Real World Monetary Values. At the end of the experiment, your $10 participation fee will be added to a randomly chosen scenario income.

In the game that you are about to play, you will make a *hypothetical* decision about whether to donate your genetic information for research purposes. The information would be stored in a genetic databank that is being managed by a third party. This information would be used to find cures for genetic diseases. However, donation of information also makes you vulnerable because the information could be compromised and your genetic information could be used to discriminate against you.

[INSTRUCTIONS]

You will pay the game for 16 rounds. In each round you will begin by earning some income, but you may lose the income if certain things happen. For example, if you fall sick, you lose money. If your information is compromised and you are discriminated against, you lose some money. You can also make money. If you are suffering from a disease and a cure is found for that disease, you will earn some money. There are other factors that will also affect your income, including your investments. These will be explained in detail later.

At every point in the game you will be given certain information that you may choose to use in your decision-making. You will be informed whether you are at high risk for getting a disease or not; what the chance of being discriminated against is; what is the extent to which your decision to donate your genetic information contributes to a cure. All the information that is relevant to your choice will be displayed on the screen.

Within this context, you potentially have three decisions to make. First, you are asked to decide whether to donate your genetic information or not. If you choose to donate your information, you are further asked if you want to be informed of your health status or not. Regardless of how you answer the first two questions, you are given the opportunity to increase your earnings by choosing between one of two investments. If you choose option A, do not invest, your income will remain the same; if you choose option B, invest, your income will increase by \$1.20 in case you *do not* fall sick or if the cure is found, but will decrease by \$1.20 if you *do* fall sick and the cure is not found.

After you have completed all 16 rounds, the software will randomly pick one of those rounds, and you will be paid based on your earnings for that particular round.

I will now walk you through the game in detail, and will familiarize you with the screens that you will see. Please take out your screenshot packet and look at the donation screen.

[DONATION SCREEN]

This screen in front of you will present you with the two choices – to *Donate* or *Not Donate* your genetic information. There is also some information shown on this screen. I will go through these in turn:

Your starting income is \$8.00. From here you can either earn or lose money

- ◦ You are informed of your risk of having the disease, which can be either high or low. In the case that your risk is high, you are roughly twice as likely to have the disease as a low risk individual. Your risk level will remain constant throughout all of the rounds.

- Chance of Falling Sick represents how likely it is you will become sick, *given that you have the disease*. If you do not have the disease, you will not fall sick.

- If any person falls sick, and a cure is found, they will not lose as much money as if a cure has not been found. The loss in income if you fall sick is \$4.00, and if a cure has been found, your loss of income is \$0.80. These values represent the loss of income due to missing days at work and paying for medication. If a cure is found, you will still have been affected for some period of time, but this impact is not as large.

- The percent chance that a cure will be found depends upon how many people – among those playing the game in this room at the present time – choose to donate their information. If more people donate, it is more likely that a cure will be found. The Impact to Cure number represents how much the chance of a cure being found increases when you donate your information. If nobody donates, the cure probability is 25%; if only one person donates the cure probability is 25% plus this variable; if only two people donate the cure probability is 25% plus twice this variable; and so on until the maximum value is reached.

- Donation of information means that your information can be compromised, as a result of which you could face discrimination (e.g. in employment, or finding health insurance). If you donate, there is an increase of 20% chance of discrimination. If you are informed about your health status there is an additional 20% chance of discrimination. This total value is then scaled to match the scenario's overall chance of discrimination. If you are discriminated you will lose \$0.80. This loss of income represents losing job opportunities.

After you have made a choice, the software will move you to the next screen. If you choose to donate your genetic information, you will be asked whether you want to be informed if have the disease.

[INFORMED CHOICE SCREEN]

Now look at the informed choice screen. On this screen you should see the question asking whether you want to be informed about your health status. If you select yes, you will be told if you have a marker for the given disease or not. If you select no, the marker will be “Unknown”. All of the information from the previous screen is carried over to this screen.

If you have a marker for a disease, you have a possibility of falling sick. However, if you are told you do not have a marker, there is still a chance that you do have the marker and can become sick. This represents the fact that not all tests for genetic disease are truly conclusive. It is possible that you carry a version of the disease that has never been seen before.

[INVESTMENT SCREEN]

Now look at the investment screen. Regardless of how you answer the first two questions, you will be given the opportunity to increase your earnings by choosing between one of two investments.

- If you choose option A, do not invest, your income will remain the same.
- If you choose option B, invest, your income will increase by $1.20 in the case you *do not* fall sick or if the cure is found, but will decrease by $1.20 if you *do* fall sick and the cure is not found.

[OUTCOME SCREEN]

Now look at the outcome screen. After all the choices have been made you will learn the outcome, and the money earned. This depends on the choices you made, as well as chance. A number of screens will inform you of your specific outcome for this round. This information will then be summarized at the end, together with your computed earnings for this round.

- Displayed on the final screen will be your “donation” decision and your “informed” decision.
- If you chose to be informed, your test results for the gene will be shown, otherwise it will display as “Unknown”.
- If relevant, you will be told whether your information was compromised and the loss in income you consequently suffered.
- You will be told whether or not you became sick, and if a cure was found.
- Based on these outcomes, you will be informed of how much money you earned in that round.

At the end of each round, the game will reset, a new round will be presented and you will repeat the process.

Please now click the Z-leaf icon. When you open Z-Leaf you may have to click unblock. You will now begin two practice rounds. Data from the practice rounds will not be used. The 16 rounds that take place after the practice rounds will be used in determining how much you will earn for participating.

Below is a summary of the changes in income that can occur during each scenario.

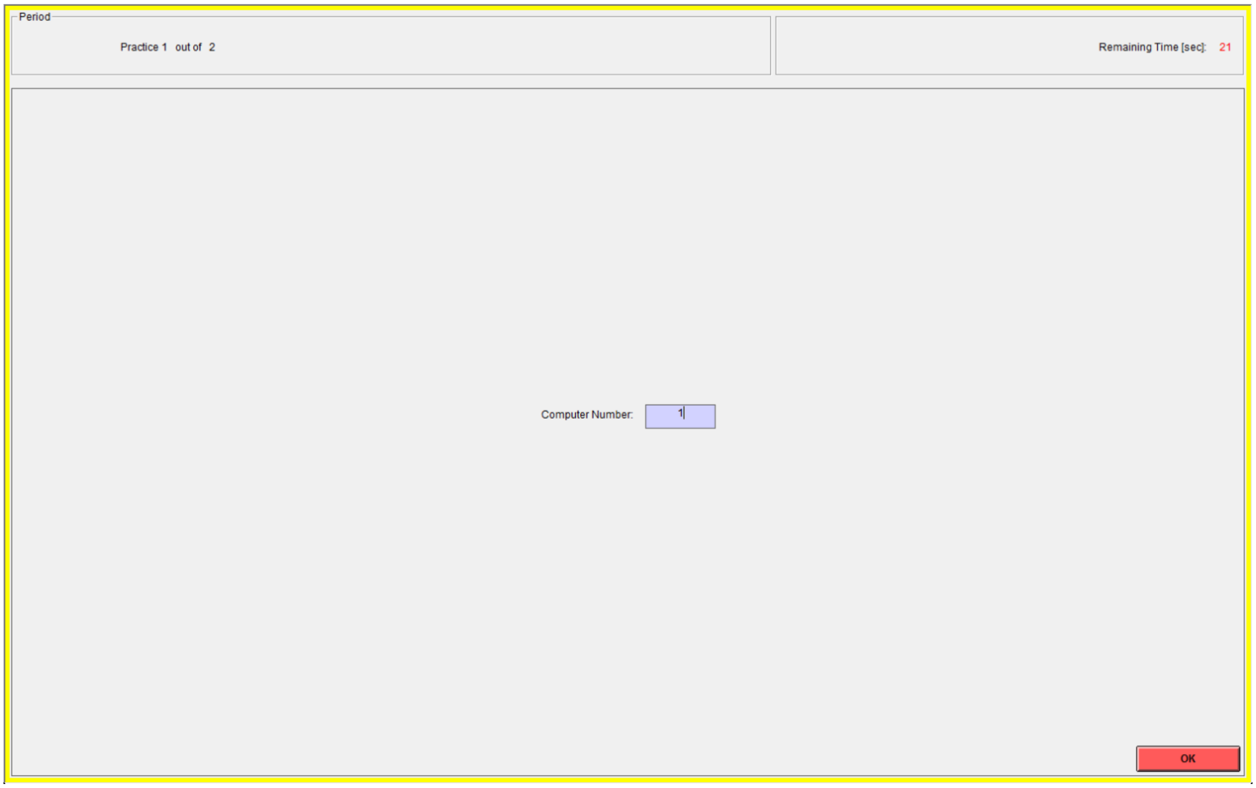
BASE INCOME = $8.00

Event	% Change in Income	$ Change in Income
Investment and NOT Sick	%15	$1.20
Investment and Sick	-%15	-$1.20
Donate and Earn Money	%10	$0.80
Sick and NO Cure	-%50	-$4.00
Sick and Cure	-%10	-$0.80
Discriminated	-%10	-$0.80

Because you earn $10 for participating and the maximum you can earn for in-game decisions is $10, the maximum amount of money you can earn when leaving the session is $20.

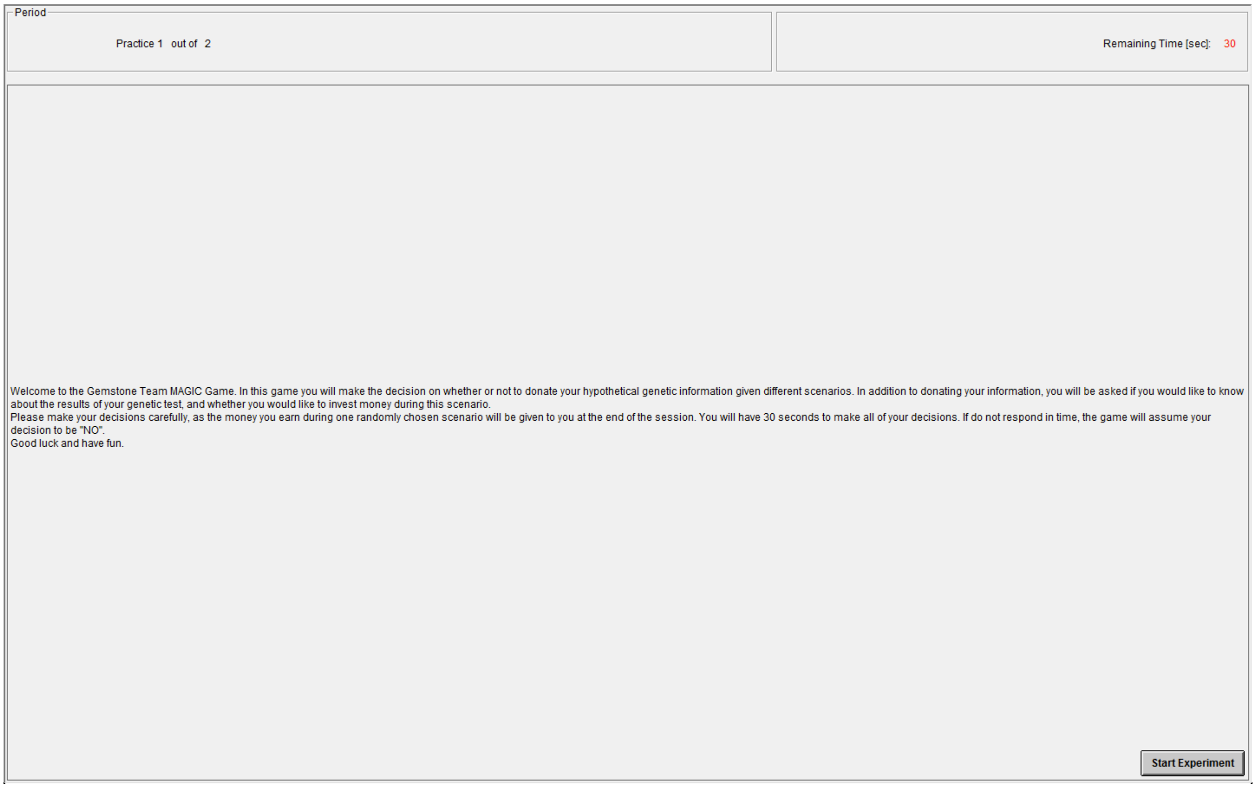
8.3.2.2 Screenshots

COMPUTER NUMBER



Computer Number: 1

INTRODUCTION PAGE

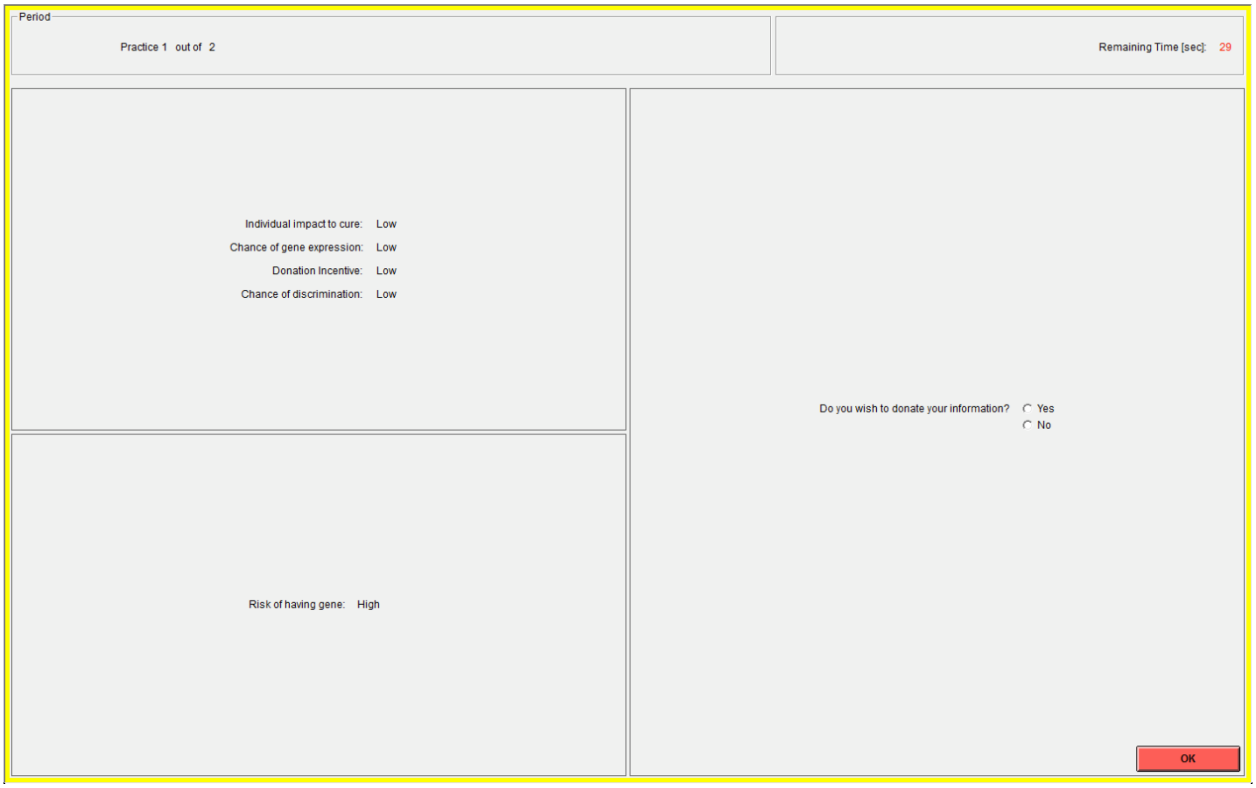


Welcome to the Gemstone Team MAGIC Game. In this game you will make the decision on whether or not to donate your hypothetical genetic information given different scenarios. In addition to donating your information, you will be asked if you would like to know about the results of your genetic test, and whether you would like to invest money during this scenario.

Please make your decisions carefully, as the money you earn during one randomly chosen scenario will be given to you at the end of the session. You will have 30 seconds to make all of your decisions. If do not respond in time, the game will assume your decision to be "NO".

Good luck and have fun.

DONATION SCREEN



Period

Practice 1 out of 2

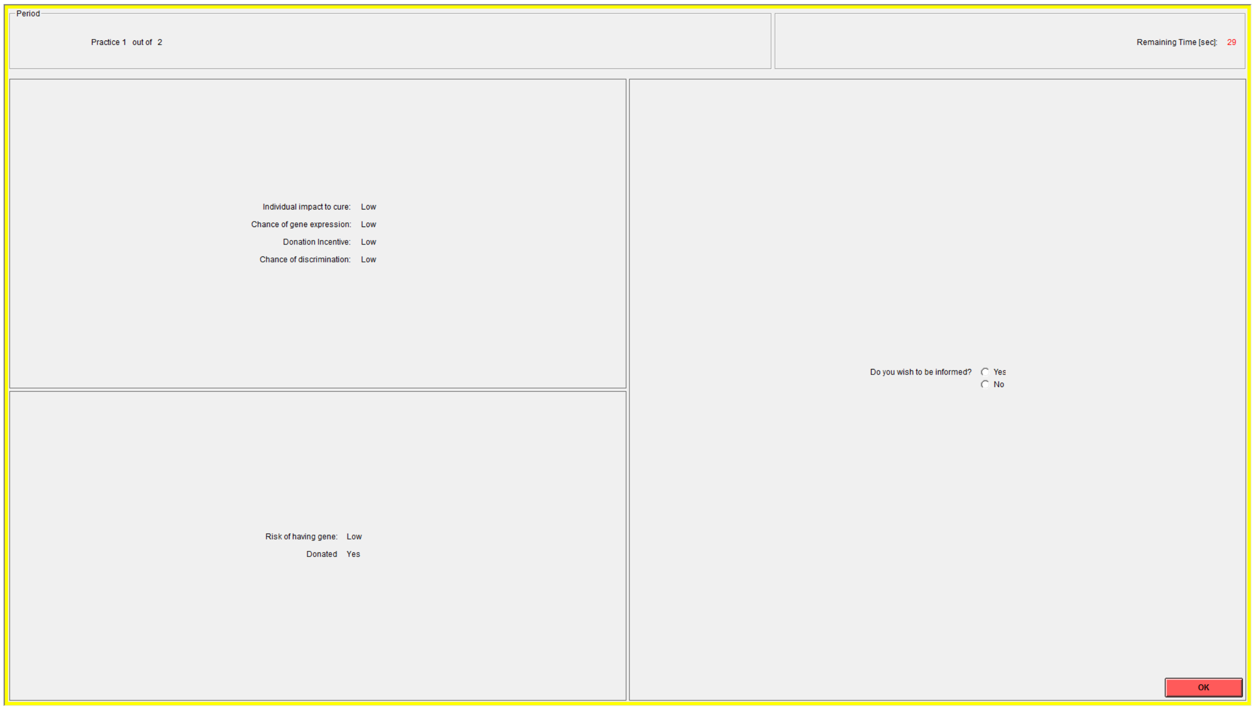
Remaining Time [sec]: 29

Individual impact to cure: Low
Chance of gene expression: Low
Donation Incentive: Low
Chance of discrimination: Low

Risk of having gene: High

Do you wish to donate your information? ○ Yes ○ No

INFORMED CHOICE SCREEN



Period

Practice 1 out of 2

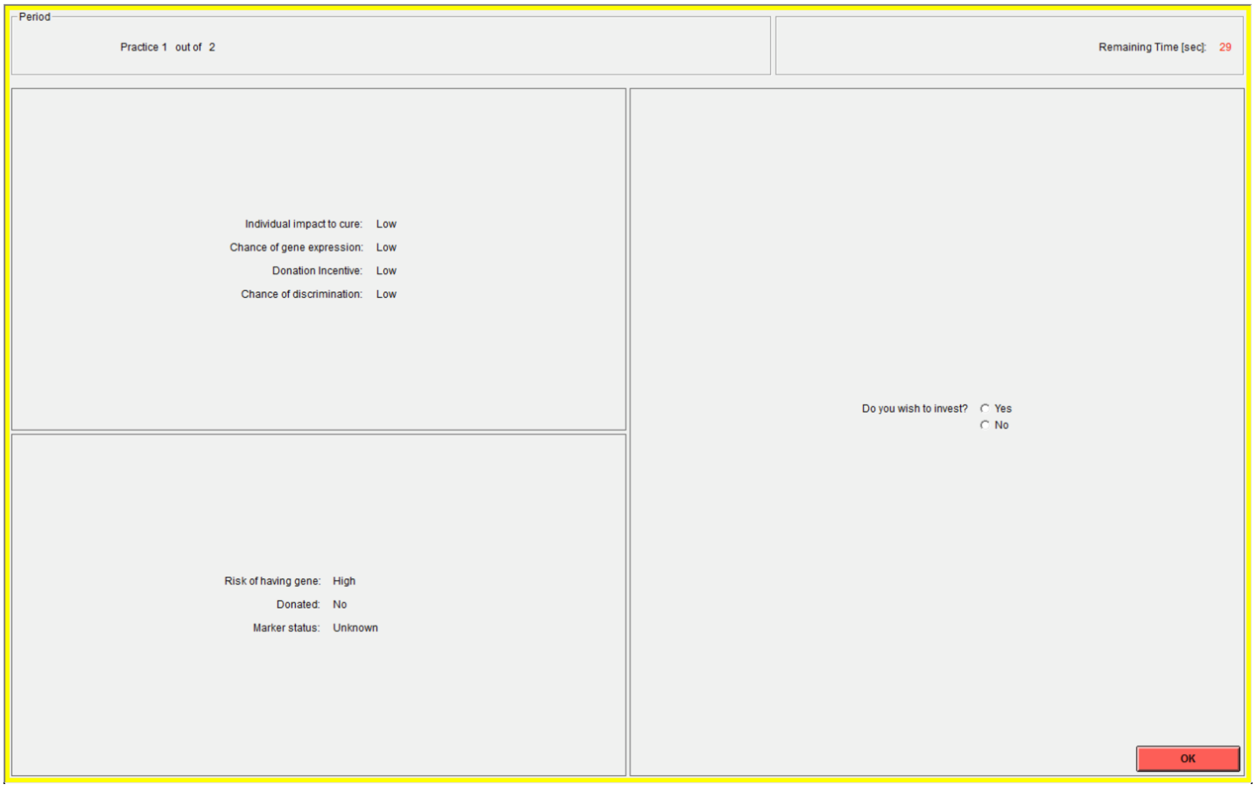
Remaining Time [sec]: 29

Individual impact to cure: Low
Chance of gene expression: Low
Donation Incentive: Low
Chance of discrimination: Low

Risk of having gene: Low
Donated Yes

Do you wish to be informed? ○ Yes ○ No

INVESTMENT SCREEN



Period

Practice 1 out of 2

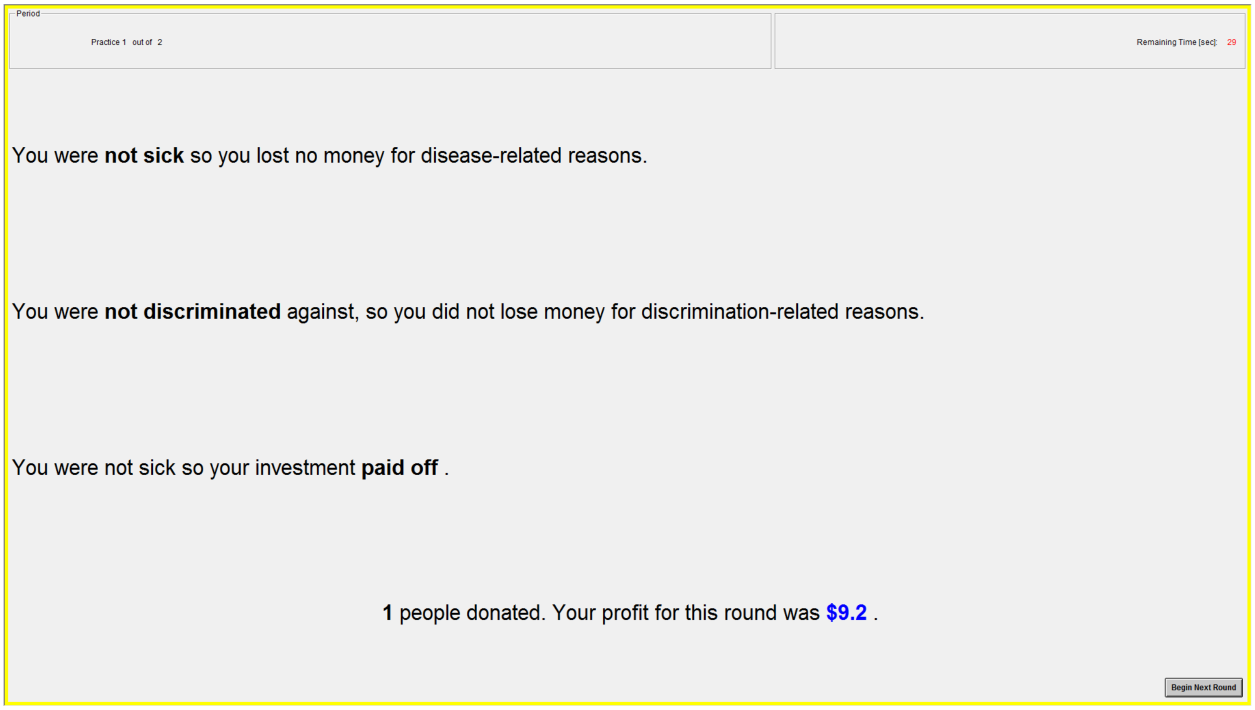
Remaining Time [sec]: 29

Individual impact to cure: Low
Chance of gene expression: Low
Donation Incentive: Low
Chance of discrimination: Low

Risk of having gene: High
Donated: No
Marker status: Unknown

Do you wish to invest? ○ Yes ○ No

OUTCOME SCREEN



Period

Practice 1 out of 2

Remaining Time [sec]: 29

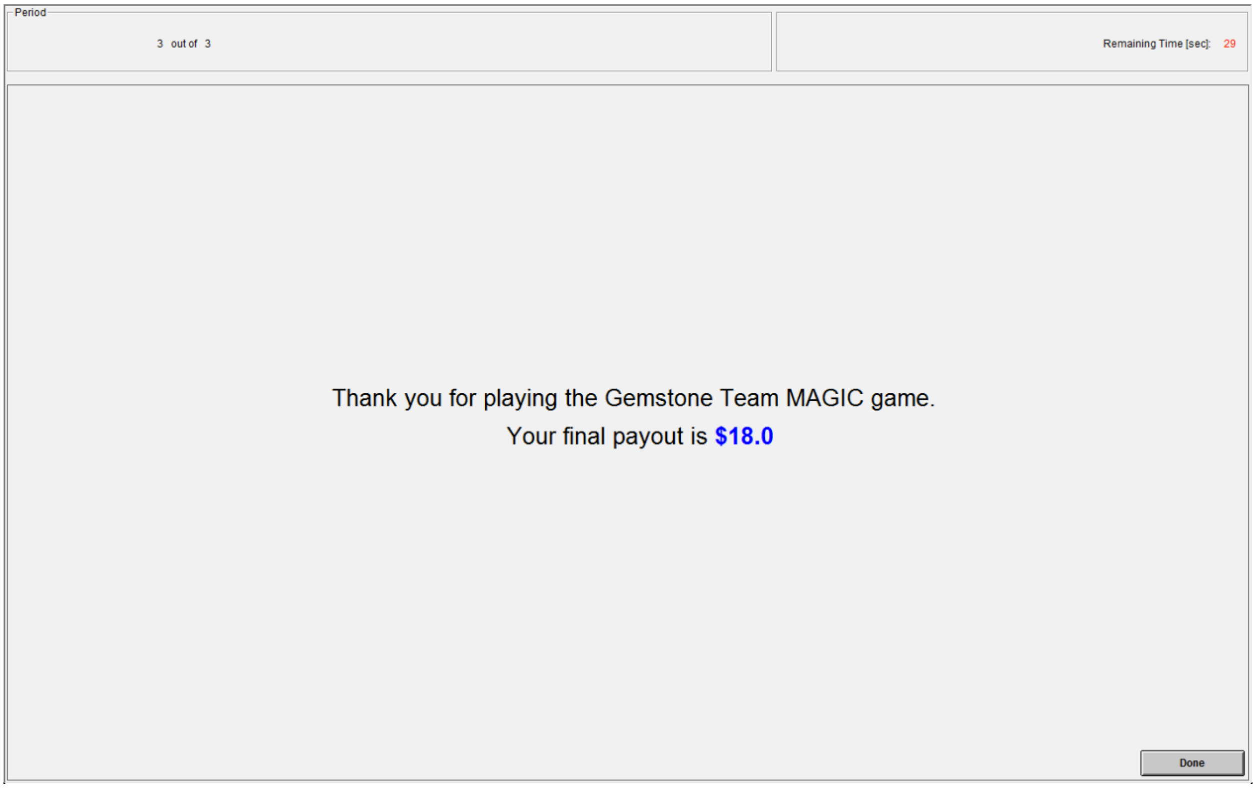
You were **not sick** so you lost no money for disease-related reasons.

You were **not discriminated** against, so you did not lose money for discrimination-related reasons.

You were not sick so your investment **paid off** .

1 people donated. Your profit for this round was **$9.2** .

END SCREEN



Thank you for playing the Gemstone Team MAGIC game.
Your final payout is **$18.0**

8.3.2.3 Demographics Survey

Computer Number: ___________

Date: ______________________

Demographics

This information will be combined with others' data and only the researchers will have access to it.

1. What is your gender?

- ☐ 1 Male
- ☐ 2 Female

2. What is your age?

- ☐ 1 18-24
- ☐ 2 25-34
- ☐ 3 35-44
- ☐ 4 45-54
- ☐ 5 55-64
- ☐ 6 65-74
- ☐ 7 over 75

3. What is your marital status

- ☐ 1 Married (except separated)
- ☐ 2 Divorced
- ☐ 3 Separated
- ☐ 4 Widowed
- ☐ 5 Never Married

4. What is your race (select the one race you most consider yourself to be):

- ☐ 1 White
- ☐ 2 Black or African American
- ☐ 3 Asian
- ☐ 4 Native Hawaiian or Other Pacific Islander
- ☐ 5 Spanish/Hispanic, Latino
- ☐ 6 Other, please specify: __________________________

5. What is your religion (select the one race you most consider yourself to be):

☐ 1 Christian - Protestant
☐ 2 Christian - Catholic
☐ 3 Christian - Mormon
☐ 4 Christian – Jehovah’s Witness
☐ 5 Christian - Orthodox
☐ 6 Christian – Other Christian
☐ 7 Jewish
☐ 8 Muslim
☐ 9 Buddhist
☐ 10 Hindu
☐ 11 Other World Religions
☐ 12 Other Faiths
☐ 13 Unaffiliated – Secular Unaffiliated
☐ 14 Unaffiliated – Atheist
☐ 15 Unaffiliated – Agnostic
☐ 16 Don’t Know

6. What political party do you best affiliate yourself with?

☐ 1 Democrat
☐ 2 Republican
☐ 3 Independent
☐ 4 Other

7. How would you rate your computer skills?

☐ 1 None
☐ 2 Very little
☐ 3 Average
☐ 4 Quite extensive
☐ 5 Very extensive

8. How often do you use a computer?

☐ 1 Once a month
☐ 2 Once a week
☐ 3 3-4 times a week
☐ 4 Once a day
☐ 5 Multiple times a day

9. In general, would you say your health is:

☐ 1 Excellent
☐ 2 Very good
☐ 3 Good
☐ 4 Fair
☐ 5 Poor

10. Do you have a chronic illness? (check all that apply)

☐ 1 No, I don't
☐ 2 Heart Disease/Congestive Heart Failure (CHF)
☐ 3 Diabetes (Sugar)
☐ 4 Asthma
☐ 5 Cancer (any type)
☐ 6 High Blood Pressure/Hypertension
☐ 7 AIDS/HIV
☐ 8 Arthritis
☐ 9 Hypothyroidism
☐ 10 Back problems/surgery
☐ 11 High cholesterol
☐ 12 Depression
☐ 13 Known genetic disorder (any type)
☐ 14 Other, Please Specify: ___________________________

11. Do you have a loved one (e.g. father, mother, sister, close friend) with a chronic illness? (check all that apply)

☐ 1 No, I don't
☐ 2 Heart Disease/Congestive Heart Failure (CHF)
☐ 3 Diabetes (Sugar)
☐ 4 Asthma
☐ 5 Cancer (any type)
☐ 6 High Blood Pressure/Hypertension
☐ 7 AIDS/HIV
☐ 8 Arthritis
☐ 9 Hypothyroidism
☐ 10 Back problems/surgery
☐ 11 High cholesterol
☐ 12 Depression
☐ 13 Known genetic disorder (any type)
☐ 14 Other, Please Specify: _______________________________

12. Which category represents the total combined income of your <u>household</u> during the past 12 months?

☐ 1 Less than $10,000
☐ 2 $10,000 to $14,999
☐ 3 $15,000 to $24,999
☐ 4 $25,000 to $34,999
☐ 5 $35,000 to $49,999
☐ 6 $50,000 to $74,999
☐ 7 $75,000 to $99,999
☐ 8 $100,000 to $149,999
☐ 9 $150,000 to $199,999
☐ 10 $200,000 or more

13. What is the highest level of school you have completed or the highest degree you have received?

☐ 1 8th grade or less
☐ 2 Some high school, no diploma
☐ 3 High School Graduate or equivalent (For example: GED)
☐ 4 Some college but no degree
☐ 5 Associate degree in college
☐ 6 Bachelors degree (For example: BA, AB, BS)
☐ 7 Master's degree (For example: MA, MS, MEng, MEd, MSW, MBA)
☐ 8 Professional/Doctorate Degree (For example: MD,DDS,JD,PhD,EdD)

Additional Comments/Suggestions:

____

____

____

____

THANK YOU FOR YOUR ENDURANCE AND PARTICIPATION!

8.3.2.4 Consent Form

Project Title	
Purpose of the Study	*This research is being conducted by Gemstone Team MAGIC at the University of Maryland, College Park. The purpose of this research project is to determine how people make choices regarding the sharing of their personal health information.*
Procedures	*The procedures involve following a simulation and making decisions about sharing personal health information based on the provided situation. Decisions made will affect monetary rewards for participants. All decisions will be based on hypothetical scenarios and no personal healthcare information will be gathered.*
Potential Risks and Discomforts	*There may be some minimal risks from participating in this research study including: fatigue during the experiment, anxiety due to different hypothetical disease conditions*
Potential Benefits	*There are no direct benefits to you. However, possible benefits include monetary gain from this study. We hope that, in the future, other people might benefit from this study through improved understanding of the decisions made in this experiment.*
Confidentiality	*Any potential loss of confidentiality will be minimized by storing the data on a password protected computer. Additionally, all data collected is hypothetical.* *If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.*
Medical Treatment	*The University of Maryland does not provide any medical, hospitalization or other insurance for you in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.*
Right to Withdraw and Questions	*Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to*

<table>
<tr><td></td><td colspan="2"><i>participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</i>

<i>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</i>
<i>Ritu Agarwal</i>
<i>ragarwal@rhsmith.umd.edu</i>
<i>Van Munching Hall</i></td></tr>
<tr><td>Participant Rights</td><td colspan="2"><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i>

University of Maryland College Park
Institutional Review Board Office
1204 Marie Mount Hall
College Park, Maryland, 20742
E-mail: irb@umd.edu
Telephone: 301-405-0678

<i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></td></tr>
<tr><td>Statement of Consent</td><td colspan="2"><i>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</i>

<i>If you agree to participate, please sign your name below.</i></td></tr>
<tr><td rowspan="3">Signature and Date</td><td>NAME OF SUBJECT [Please Print]</td><td></td></tr>
<tr><td>SIGNATURE OF SUBJECT</td><td></td></tr>
<tr><td>DATE</td><td></td></tr>
</table>