2012

Compensation's effect on risk perception in behavioral genetic research

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by

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A thesis submitted to the graduate faculty

in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Major: Psychology

Program of Study Committee:

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Iowa State University

Ames, Iowa

2012

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ACKNOWLEDGEMENTS

I want to express my gratitude to my major professor, mentor and friend, Dr. Norm Scott. He has demonstrated infinite patience with me through this process, and the final product is a direct result of his eye for detail and nurturing spirit. Thanks also to Dr. Doug Bonett for sharing his gift of turning complicated statistical output into a meaningful narrative over the hours of consultation he has been so generous with. As I try to become a successful scientist-practitioner, Dr. David Vogel has my gratitude for having provided me great encouragement in both this project and in my clinical work as I attempt to juggle both worlds.

Finally and perhaps most importantly, thanks to my wonderful wife Megan for her patience in the long nights of writing and analysis, her frequent lunch and dinner runs to make sure that I don't forget to eat in the depths of my work, and her kind and adventurous spirit that has her on this journey with me. And to my daughter and the apple of my eye, Rowyn Emma, for an always ready smile, an adorable giggle, and the kind of hugs that keep a father working hard in hopes of providing a brighter future for such a growing star. I love you both.

ABSTRACT

There have been multiple studies of how monetary compensation affects perceived willingness to participate in medical research. However few studies have addressed perception of risk, especially risk to privacy associated with genetic or behavioral genetic investigations. One recent study, an M.S. thesis investigation by Ascheman (2009), identified several difficulties in studying undergraduate perceptions of risk from participation in such investigations: low levels of comprehension of informed consent documents, and difficulties in separating participants' perceptions of risk to privacy from the potential influences of money offered for participation. This study expands the work of Ascheman (2009) by using a vignette story format for presentation of the experimenter-constructed informed consents. It also included a baseline privacy risk without compensation condition in a 2 (level of privacy risk) X 2 (level of compensation) mixed within-between subjects design. The study was conducted as an online investigation with undergraduate research volunteers. The presented levels of risk had a significant effect on participants' willingness to participate and perception of risk at all presented levels of risk and compensation. However, no significant risk-by compensation interactions were found. Moreover, the compensation offered (ten versus one hundred dollars) in the vignettes did not have a significant differential effect on either willingness to participate or perception of risk at any of the presented levels of risk. Additionally, monetary compensation did not demonstrate a main effect on either of these measures with the exception of a willingness to participate variable that asked how participants believed others would react to the presented vignettes. Compared with prior studies, the use of a short vignette in a story-format informed consent, substantially increased comprehension of the essential experimenter constructed informed consent information about

risk to privacy and monetary compensation. Comprehension checks demonstrated between 62.4% and 84.2% accurate comprehension of essential risk or money information from the experimenter constructed informed consents at various levels of risk and money.

CHAPTER 1

INTRODUCTION

The use of genetic analysis is rapidly increasing in a variety of research fields. Moreover, as insight has been gained into how genetics affects personality and dysfunctional behaviors, there has been an increase in behavioral genetic research in psychology (Leonardo & Hen, 2006). There is research relating to the potential ethical concerns unique to genetic research, (Burgess, Laberge, & Knoppers, 1998, Pelletier & Dorval, 2004) however the implications of obtaining genetic information may frequently extend beyond a given individual's unique genetic code (Burgess, Laberge, & Knoppers, 1998). Thus, the unique, enduring, and personally identifying nature of DNA may make the loss, or potential loss of an individual's genetic information, their genetic privacy, potentially severe. The field of bioethics has seen several major shifts in the past several decades, from a 'doctor knows best' model of frequently uninformed consent to the current central focus on autonomy of the individual for their own care and information. The idea that genetic information about one individual and their testing or treatment may profoundly affect another individual or even an entire family or ethnic group is still a relatively new concept within bioethics (Green, 1999).

Many areas of science are undergoing significant transformations based on genetic research. Some groups have now renewed the specter of the eugenics movement of the early 20th century around the advent of new genetic screening techniques and emerging genetic research (Petersen, 1999). The eugenics movement is predicated on the Darwinian idea of selecting and ultimately creating of individuals with the best possible genetic make-up and thus limiting the number 'bad' or 'unhealthy' genes being introduced or passed down. While many gay rights groups have heralded research on the so-called 'gay gene' that attempts to demonstrate that

sexual orientation is an inherently biological factor, many other groups in the same vein argue that the ability to genetically screen for this gene, for example by expectant parents, could potentially allow parents to decide what sexual orientation their children have and eliminate the LGBT community entirely (Green, 1999).

Also in the realm of criminal justice, forensic genetic profiling has become much more commonplace, with scientists now able to uniquely identify an individual based on 13 highly variable parts of the human genome unless that individual has a twin. All fifty states also now contribute genetic sample data to the Combined DNA Index System (CODIS), with more than half of states taking genetic samples from all felons and over 20 states collecting samples from anyone convicted of a misdemeanor (Ossorio & Duster, 2005). While helpful for proving the innocence of wrongly-convicted persons, this practice raises concerns around the frequently demonstrated higher rates of racial minority convictions and the subsequent research that is taking place on these databases for behavioral 'explanations' of criminal activity (Ossorio & Duster, 2005). These kinds of ethical concerns are unique to behavioral genetic research, but very little attention has been paid to how aware are research participants to these potential risks, and wider implications of their participation, or how informed and accurate are their perceptions of informed consent for research participation.

Participants' Risk Perceptions, Monetary Compensation, and involvement in Research

Several studies have attempted to assess how level of risk and variations in monetary compensation affect individuals' willingness to participate in medical research (Halpern et al. 2004, Bentley & Thacker, 2004). While the literature appears mixed on how monetary compensation affects willingness to participate, one consistent finding is that increased risk does indeed lead to decreased willingness to participate in these studies. For example, in a seminal

article pertinent to online research studies, Couper, Singer, Conrad & Groves (2008) conducted a series of large sample (3672 participants) web-based vignette experiments investigating how likely subjects would be to participate in surveys varying in topic sensitivity and risk of disclosure. It was found that *objective* risk did not have an effect on willingness to participate. However, topic sensitivity and general attitudes toward privacy, as well as *subjective perceptions* of risk, harm and benefit did have effects. However, much of the existing research that jointly examines risk and monetary compensation on persons' willingness to participate in research focuses specifically on medical studies such as drug trials. Many of these studies do not address the unique concerns pertinent to behavioral genetic research, the substantial risk to privacy and long-range welfare from the misuse of specific person identifying DNA.

Ascheman (2009) did address some of the perceived privacy risks in behavioral genetic research by examining how online research participants perceived, comprehended and acted upon informed consent documents involving potential loss of genetic privacy. A major difficulty encountered in his study was participants' extremely low levels of comprehension of a written informed consent. Only 14% of participants demonstrated an understanding of the potential risks (will my DNA sample have my name attached to it?) as well as amount of compensation (how much will I be paid for my participation?) as assessed by a comprehension check after a reading a hypothetical experimenter-constructed informed consent and by use the joint most stringent comprehension criterion.

In the Ascheman study the informed consent documents were the experimental manipulations, with four different combination of either high or low monetary compensation combined with ether high or low risk to loss to genetic privacy. However, with the assessed low rate of comprehension of the consent information, only a segment of the total participants (14%)

could be considered to be sufficiently "informed" to justify their inclusion in the data analyses. Thus, the generalizability of findings was compromised. Recent research (Pedersen, Neighbors, Tidwell & Lostutter, 2011) which focused on undergraduate student research participants' reading comprehension and memory (recognition and recall) for information in consent forms also indicated limited comprehension and poor recall. In a study of two hundred and sixty undergraduate research participants at a research- focused university, it was found that the majority of them (between 69% and 80% across all conditions) were unable to recall information from the consent forms when presented in either in-person or online formats. They were also relatively poor at recognizing important aspects of the form including risk to participants and confidentiality procedures.

This study was designed to expand the findings of Ascheman (2009) by using a series of new methods aimed at improving participant comprehension and more clearly separating the potential effects of the variables of monetary compensation and perception of risk by creating an additional no-compensation condition in order to establish a baseline of risk perception. Further, this study has attempted to gain additional insight into how levels of monetary compensation influence perception of risk in genetic studies through a mixed design that allowed all participants to react to both high and low levels of risk but with the amount of compensation being offered held constant for each participant.

CHAPTER 2

LITERATURE REVIEW

The basic principles underlying modern ethical principles that currently govern genetic and other biomedical research fields have developed over human history, beginning in ancient Greece and Rome. However, even with such a long history underpinning it, researching informed consent for biomedical research is complex (Corrigan, 2003). The purpose of this literature review is to provide an examination of the relevant history and current state of ethical principles, and additionally to provide a brief overview of the current biomedical and genetic-medical ethical concerns.

History of Biomedical Ethics

Modern ethical decision making in biomedical and related fields can be traced back to the philosophical discussions of ancient Greece and Rome. Perhaps the best-known example of the fruits of these ethical discussions is the Hippocratic Oath, one of the earliest explicit ethical codes of conduct for medical professionals. While the phrase 'do no harm' is arguably the most famous and memorable parts of the Oath, North's (2010) translation perhaps best captures the essence of the Oath with, " Into whatever homes I go, I will enter them for the benefit of the sick, avoiding any voluntary act of impropriety or corruption." The Oath also serves as a cohesive structure for early physicians, creating a professional structure akin to a family structure with one's teacher seen as, "equally as dear to me as my parents," and requiring that the student see his teacher's children as, "equals to my own siblings, and to teach them this art, if they shall wish to learn it, without fee or contract," (North, 2010). The Oath also contains an exclusion criterion, stating that any physicians bound by the Oath would not teach their art to anyone who did not

also abide by the Oath, effectively limiting the ability of outsiders to draw from the Hippocratic lineage of knowledge of medicine and biology without accepting their ethical code.

Unfortunately, not all medical professionals since the inception of these concepts have been adherent to these same principles. Many atrocities have been committed throughout history in the name of advancing science, leading ultimately to an ethical backlash against such acts and the development of more explicit ethical codes of conduct, especially with respect to biomedical research.

The Nuremberg Code

Prior to and throughout the second World War, Nazi forces routinely captured and imprisoned individuals that did not conform to the 'Aryan ideal' espoused by leading figures of the Third Reich including a large number of Jewish individuals and families, Gypsies, political dissidents and individuals perceived to be homosexual. These individuals were transported to concentration camps where they were forced to work in brutal and inhumane conditions that were justified by their captors as fitting of their sub-human status (Shirer, 1960). At several specific sites, known best in modern times as the 'death camps', prisoners were experimented on by medical professionals, often in search of more efficient methods of euthanasia for those that did not fit the ideal model of genetics being dictated by the political will of the time. Even after liberation of these camps, discoveries of euthanasia programs for the mentally ill and disabled that then became the foundation for these death camp programs well prior to the war came into international awareness (Lopez-Munoz et al., 2008).

At the end of the war, twelve military tribunals were convened in the city of Nuremberg in the southern German state of Bavaria. These tribunals were created to hold accountable by rule of law those that had committed atrocities and war crimes among the defeated Axis forces,

particularly those among the then-dismantled Nazi party. The first of these trials has been most commonly known as the 'Doctors' Trial' but formally was recorded as *United States of America v. Karl Brandt et al.* Of the twenty-three defendants, twenty were physicians who faced charges centered on conspiracy to commit or actually committing war crimes or crimes against humanity. The trial concluded on August 20, 1947 and resulted in seven acquittals, ten sentences ranging from ten years to life imprisonment and seven sentences of death by hanging (Lopez-Munoz et al., 2008). The major perpetrators of much of the medical injustice had been tried and subsequently sentenced, yet the question of how to prevent such atrocities as came to light over the course of the trial remained.

During the Doctors' Trial, Dr. Leo Alexander drafted and submitted six points defining 'legitimate medical research' to the Counsel for War Crimes, which were adopted in the subsequent trial verdict with the addition of four more points. These ten points became known as the Nuremberg Code (*Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*, 1949). Central to this document was the idea that human subjects should have 'voluntary consent' to any procedure and what information needed to be provided in order to ensure that the participant had enough information to give consent; it became the first internationally recognized code for research ethics and provided the foundation for future guidelines of research ethics (McCormick, 2005).

The Declaration of Helsinki

While the Nuremberg Code offered considerable tools and new insights into how ethical research could be conducted in the future, this code in practice was difficult to apply. To address growing concerns with this framework, in 1964 the World Medical Association (WMA) gathered 100 delegates from 32 national-level medical associations in Helsinki, Finland. The goal of the

delegates was to draft more comprehensive guidelines for human research, as well as to distinguish differences between therapeutic and non-therapeutic research (Corrigan, 2003). The resulting document was named The Declaration of Helsinki, which reiterated the principles espoused by the Nuremberg Code while recognizing the difficulties faced by researchers in particular around the rigid structure of the Code. In particular, the Declaration of Helsinki reinforced the need for participants in human research to have the "liberty to abstain from participation" and be "free to withdraw his or her consent to participation at any time" (World Medical Assembly, Declaration of Helsinki, 1964; section I., item 9) but relaxed the required that consent be "absolutely necessary" in all circumstances. This shift was aimed at those studies in which full disclosure of all elements of the study could potentially bias the results, such as pharmaceutical studies in which knowledge on the part of the participant regarding their placement in either experimental or placebo conditions could bias their responding.

Additional aspects of the Declaration of Helsinki focused on human research, in particular how it is conducted, reviewed and disseminated. Of particular importance to how research is conducted and reviewed, the Declaration of Helsinki was the first document to identify a need to consider the relationship between the risks and benefits of a given study. The focus on potential risk to participants, as well as the recognition of the need for disclosure of risk to obtain truly informed consent, represented a major shift from previous ethical doctrines in terms in protection and empowerment of participants.

With regard to participants' consent, the Declaration of Helsinki recommended that consent be obtained in writing. This principle, while clearly and logically espoused in this document, was not put into widespread practice until unethical experiments began to be exposed by investigators and independent whistleblowers. Several instances of experimentation on

people living in poverty and racial minority groups without their knowledge, and subsequently also without their consent, were brought into public awareness, forcing a shift towards collection of written consent among researchers and clinicians (Corrigan, 2003).

A major contribution to the process of reviewing research was the declaration's recommendation of examination and review of human research studies by independent groups. While it did not create or dictate any specific regulatory agencies for this purpose, it laid the groundwork for creation of bodies such as institutional review boards for oversight of the research process.

Since the first Declaration of Helsinki was drafted by the World Medical Association in 1964, there have been a total of five revisions, with the most recent having occurred in 2008. Early revisions focused primarily on relatively minor changes to address new considerations that arose naturally over time. Examples of this included guidelines for seeking consent of minors when possible, further examining the potential functions of independent review committees, and statements regarding ethical treatment during international human research trials. However, later revisions created considerable controversy, particularly over directives drafted around efficiency and utility of research (Stockhousen, 2000). Major controversy emerged over the use of placebo drug trials and their ethical implications in international populations, particularly between developing versus developed countries (Nicholson, 2000). However, the most recent revision (2008) has seen very little controversy emerge as it constituted a limited revision to the fifth revision (2000). Additional controversy has sprung up over the differential application and reference to the declaration, especially around concerns with the United States' Food and Drug Administration not recognizing any revisions since the third (1989) and eventual complete

abandonment of reference to the declaration in favor of its own 'Good Clinical Practice' guide (Obasogie, 2008).

The Belmont Report

Arguably one of the most important pieces of literature pertaining to modern research principles, the Belmont Report of 1979 laid the groundwork for both the current concept of informed consent and many of the ethical principles underlying all current research using human subjects. As part of the National Research Act of 1974, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was created not only to reassess the ethical principles that should be guiding biomedical and behavioral research, but also to develop procedures that allowed for adherence to these ethical principles. After over four years of work, the commission put forth the Belmont Report (1979) which stood as a unique document for its time; the report provided a broad interpretation of ethical principles that allowed it to be used under a variety of both common and unique circumstances, which in turn set the precedence for the development of legal standards and professional codes of conduct. The three broad principles set forth in the Belmont Report set the stage for the later development of current biomedical codes, as well as the APA Ethical Principles (2002).

Respect for Persons

The first principle is respect for persons, which refers primarily to respect for the autonomy of persons. This principle aims to allow individuals to act in their own best interest, provided their interest is not clearly and directly harmful to others, and to provide additional protections for those who may have decreased autonomy due to factors such as immaturity, decreased cognitive ability, or incarceration. While consent may still be gathered from these populations, this principle recognizes the need for special considerations to avoid infringing

upon these individuals' rights and dignity. In total, this principle makes impermissible to hinder individuals' freedom to make careful and total consideration regarding their potential participation in studies without convincing reason.

Beneficence

The second principle defined is beneficence, which explicitly defined as researchers focusing their efforts on "doing good" or moving toward positive change. However, underlying that factor is the idea that researchers should also attempt to avoid doing harm, though because of the nature of the majority of human research, in which the investigators are often looking for sources of harm, the aim then should be to maximize the good done while minimizing real or potential harm. The search for this balance largely defines the process of risk assessment in research, focusing researchers on finding ways to do the most good with the least risk of harm in order to justify a study.

This often contradictory task of "doing good" while also "doing no harm" is frequently treacherous to navigate, though as almost all studies pose some even infinitesimal risk nearly all researchers must frequently navigate it. Cases where participants may be placed at a greater-than-minimal risk with no benefit to themselves but a potential for a longer-term benefit to society as a whole prove even more difficult to navigate. While there is no clear and quantifiable definition of acceptable risk for harm in these cases, it is agreed that researchers must consider these questions with great care to meet the spirit of this principle.

Justice

The third and final principle is that of justice, a historically abstract concept that has resulted in great debate over time over what justice should look like in a societal context. The Belmont Report roughly defines justice in a research context as an equal distribution of benefits

and burdens associated with research. Even this more focused definition raises a series of difficult questions: How should benefit and burden be distributed? Is it possible to truly equally distribute these concepts? If not, how can they be distributed such that the core principle of justice is maintained? These questions are not easily answered, and even when answered are subject to the whims and dictates of the current zeitgeist.

While justice continues to be a difficult concept to apply even in the narrow lens of research, this principle in particular has lead the way for foundational changes in how research is reviewed and treated. Entities such as institutional review boards, which help assess the ethicality of research being conducted, are themselves strongly rooted in the tradition of justice and serve as safeguards for potential participants in human research to ensure that benefit and risk are distributed in as balanced a manner as is possible. These principles as a whole have created a foundation for the development of ethical guidelines for many professional bodies, including psychology as examined in the following section.

Ethics in Modern Psychological Research

The American Psychology Association (APA) expanded on the principles set out in the Belmont Report (1979) by interpreting the original three principles and adding two new principles, as well as adding a series of specific ethical guidelines in the publication *Ethical Principles of Psychologists and Code of Conduct* (2002) and also as modified in 2010 (American Psychological Association, 2010). In addition to beneficence and nonmaleficence, justice, and respect for people's rights and dignity, which closely mirror the principles in the Belmont Report, the APA also added integrity as well as fidelity and responsibility to their ethical principles. These principles add additional weight to considerations in the process of informed consent for researchers, adding the ethical expectations of awareness of professional and societal

responsibilities, as well as an obligation to promote accuracy and honesty in our work (American Psychological Association, 2002). This is especially meaningful for informed consent in deception studies, in which it is by definition impossible to fully inform the participant of what will occur in the research, which then places it in conflict with the principle of integrity. To clarify this matter, the APA ethics code specifically addresses deception studies in section 8.07, stating, "(a) Psychologists do not conduct a study involving deception unless they have determined that the use of deceptive techniques is justified by the study's significant prospective scientific, educational, or applied value and that effective non-deceptive alternative procedures are not feasible." This qualification allows deception studies to continue without creating methodologically crippling flaws through the process of informed consent, but still leaves the researcher with the obligation to rectify any mistrust resulting from the deception. As an additional protection to participants, after all aspects of the study have been revealed the participants must be given the opportunity to withdraw their data to minimize potential harms experienced during the study (American Psychological Association, 2002, Sections 8.07 and 8.08).

While the principles set forth by the APA are highly directive towards researchers and practitioners within the association, action at a federal level has also been taken to set guidelines and restrictions for all researchers. In 1994 under then President Bill Clinton the National Bioethics Advisory Commission (NBAC) was developed to investigate alleged human research abuses and provide recommendations for the study of genetics. The law put into place as a result of the NBAC's work, published under Annas, Glantz & Roche (1996), was entitled The Genetic Privacy Act of 1996. A major consequence of this act was that it gave clear legal ownership of genetic samples to the individuals providing those samples. Further, the Genetic Privacy Act

required researchers to obtain consent from participants to collect, store, analyze and further disseminate any genetic samples. Unfortunately, while this laid out very clear guidelines for appropriate research using genetic material the NBAC did not have any means of enforcing these rules. The more recent Genetic Information Nondiscrimination Act of 2008 is able to more directly enforce the prohibition of the use of genetic information in employment and health insurance determinations, it still leaves easily exploited loopholes in the areas of life insurance and long-term disability insurance.

Risk Perception in Biomedical Research

Due to the limited nature of studies on perceptions of risk specific to behavioral genetic research, the primary focus of this section will be to review literature in the most closely related field to genetics: medicine. In a study focusing on risks and compensation in clinical trials, Halpern et al. (2004) found several informative results relating to the biomedical and behavioral research fields. First, they found a main effect showing that a higher potential risk in hypothetical placebo-controlled clinical drug trials related to a decrease in willingness to participate among potential volunteer participants in that study. Additionally, by using a clustered ordinal logistic regression model, Halpern et al. (2004) found that willingness to participate in hypothetical placebo-controlled clinical drug trials decreased with lower monetary compensation, using proposed values between $100 and $2,000. While the study is not readily generalizable to other fields of research, it does raise the long-contested question of how much money is required before monetary compensation becomes an unreasonably strong inducement.

Bentley & Thacker (2004) also found that across three levels of medical risk, pharmacy student research participants were *less willing* to participate at *higher levels* of potential risk. Levels of risk in this study were varied so that higher levels of risk involved clinical drug trials

(high risk involved a stage one, untested drug trial while medium risk involved a bioequivalency drug trial for a generic version of a common drug) while the low level of risk involved giving a saliva sample for a hormone check. The study also discovered that *lower* levels of monetary compensation correlated with *decreased* willingness to participate. Much like Halpern et al. (2004), this study focused primarily on medical risks, though this study required much longer required participation times to achieve the stated monetary compensation. For the hypothetical major medical trials proposed in this Bentley and Thacker (2004) study, participants would need to stay under direct observation for two 24-hour periods in addition to participating in 12 half-hour sessions. The substantial monetary compensation in this study ranged from $350 to $1800, an hourly payment range of $6.48 to $33.00 per hour. It is also important to note that the study included a no-payment condition in which there was significantly *lower willingness* to participate than other conditions.

Ascheman (2009) sought to follow up on Bentley & Thacker (2004), but aimed to specifically consider undergraduate students' concerns about their genetic privacy at varying levels of risk and monetary compensation. In an attempt to elicit unfiltered information from students, the study used a number of deceptive elements, beginning with a 140-item personality questionnaire that was designed to appear to be the core component of the study. In reality the questionnaire was merely a distractor leading up to a second study 'invitation' wherein subjects were given a second informed consent document for a study that would take place at a later date. The informed consent document itself was the actual manipulation, with each participant receiving one of two levels of risk to privacy, either high risk where the genetic sample donated in the second study would be identifiable as the participant and entered in an easily accessible national database, or low risk where the genetic sample donated would be stripped of identifying

information and entered into an experimenter restricted access repository that would be destroyed at the end of the researchers' work on this particular study. The informed consent document also contained one of two levels of monetary inducements, either $10.00 or $100.00, provided that the sample was accepted into the repository. As the repositories were fictitious and payment hinged on the acceptance of a participant's sample being accepted into one of the repositories, no money was ultimately paid to participants though they were instead compensated with research credit for introductory psychology classes.

Ascheman's (2009) findings reflected many of the findings of Bentley & Thacker (2004), including a similar effect of risk and compensation on willingness to participate. However, a notable difference that contradicted one of Ascheman's (2009) hypotheses was the presence of a statistically significant effect on perception of risk at different levels of monetary compensation. The study found that as monetary compensation increased participants' perceptions of the risks of the study decreased. Due to the low level of comprehension among participants in Ascheman (2009), it is difficult to draw any conclusions about potential differences between the perceptions of risk in genetic studies compared to medical studies as examined in Bentley & Thacker (2004). However, this proposed study's aim has been to explore the disparity between Bentley & Thacker (2004) and Ascheman (2009) by increasing comprehension of consent documents, clarifying differences between treatments, and establishing a baseline of risk perception at various levels of induced risk to loss of genetic privacy not confounded by compensation.

Unique Features of this Study

In Ascheman's (2009) study, low comprehension of informed consent was observed for many participants, and it compromised the generalizability of findings. This study's aimed to elaborate on the topic of risk perception and monetary inducement in behavioral genetic research

through modifications and changes in methodology. This study is unique in that it provided an assessment of how compensation affects perception of risk and how risk to privacy and monetary compensation affect willingness to participate in behavioral genetic studies. Through a mixed-method approach, each participant was exposed to only one level of monetary compensation but both levels of risk to loss of privacy. This design was used in hopes of gaining greater insight into the degree of impact from experimental manipulations in participants' perceptions of the potential loss of privacy of their personal genetic information through the use of the mixed within-between approach. In addition, the study aimed to improve comprehension of informed consent by use of an alternate format for information presentation, a vignette story description.

This study used a short vignette format instead of the traditional format informed consent documents used in the previous study in an effort to improve participants' level of comprehension of the risks to privacy and monetary compensation. While using actual informed consent documents would increase external validity and allow findings to be more readily generalized to informed consent occurring in current research, several challenges have been made to the current process of informed consent that must be considered. Several studies have demonstrated that there is a significant disparity between the reading capabilities of participants and the reading level of many informed consent documents (Hammerschmidt & Keane, 1992; Hochhauser, 1999; Ogloff & Otto, 1991). Early research by Sachs et al. (2003) demonstrated that even the average healthy adult participant may not have a sufficient capacity to fully understand some informed consent documents. As such, this study chose to focus participants on potential risk, possible compensation, and to assess their willingness to participate by using a simple story-like paragraph vignette format. While this strategy may enhance comprehension, it

may reduce the generalizability of findings, as consent has been manipulated in a manner different than the usual IRB formatted documents.

Statement of Purpose

The purpose of this study is to examine how undergraduate college students' perceptions of risk to the privacy of their genetic information vary across several levels of risk of loss of privacy and monetary compensation. This study has aimed to improve on previous research in this field in two aspects. First, this study utilized a short vignette format to communicate the levels of risk and compensation. While previous studies have utilized faux informed consent documents to communicate potential risks and degrees of compensation to participants, extremely low levels of comprehension were identified. Ascheman (2009) summed up what many participants had to say when asked about their perceptions of the study with a single participant's poignant response: "I didn't really pay attention that closely, I figured that the statements were the same for every study." As examining how participants perceive the informed consent process itself was beyond the scope of this study, this study instead chose to use short vignettes as the primary source of information about the hypothetical studies with the goal of presenting participants with a more brief and novel information process.

Second, this study used a mixed between-within subjects method that includes two treatment conditions containing baseline measures, or perception of risk without monetary compensation. By adding a no-compensation level within the independent variable of monetary compensation the study aimed to develop an initial understanding of how participants perceive the levels of risk to the loss of their genetic privacy without the presence of any additional variables. The addition of a baseline of risk perception has significantly disentangled the

independent variables and has allow for more direct analyses of the separate potential effects of money and risk on willingness to participate.

The goal of the overall project has been to gain insight into how monetary compensation affects perception of risk, and particularly how it may affect perception of risk to loss of genetic privacy. While Bentley & Thacker (2004) did not find any effect of compensation on willingness to participate in medical drug trials, Ascheman's (2009) findings appear to point to an effect of monetary compensation on risk perception with genetic sampling when examining data from those participants that could demonstrate comprehension of the study's primary manipulation. As the literature appears to reveal a differential impact of monetary compensation based on the context of a given study, this study's aim was to determine if there is an effect of monetary compensation separate from or in conjunction with presented risk information accorded to potential research participants in behavioral genetic studies. These findings may help create a more clear understanding of these differences for ethical bodies such as Institutional Review Boards, such that they may be able to make more informed decisions about research projects.

Hypotheses

Willingness to Participate with Joint Consideration of Risk and Compensation

- Hypothesis1: Willingness to participate (WTP) will differentially increase as compensation increases in both high risk and low risk conditions.
    - A test of this interaction hypothesis will determine whether increased compensation *differentially* leads to increases in participants' willingness to participate in behavioral genetic studies across **both** levels of associated risk to genetic privacy. This interaction hypothesis is indicated on Diagram 1 as depicted by

the difference between the two points (greater difference in ratings of willingness to participate) in the high compensation condition compared the lesser difference between the two points in the low compensation (smaller difference in ratings of willingness to participate).

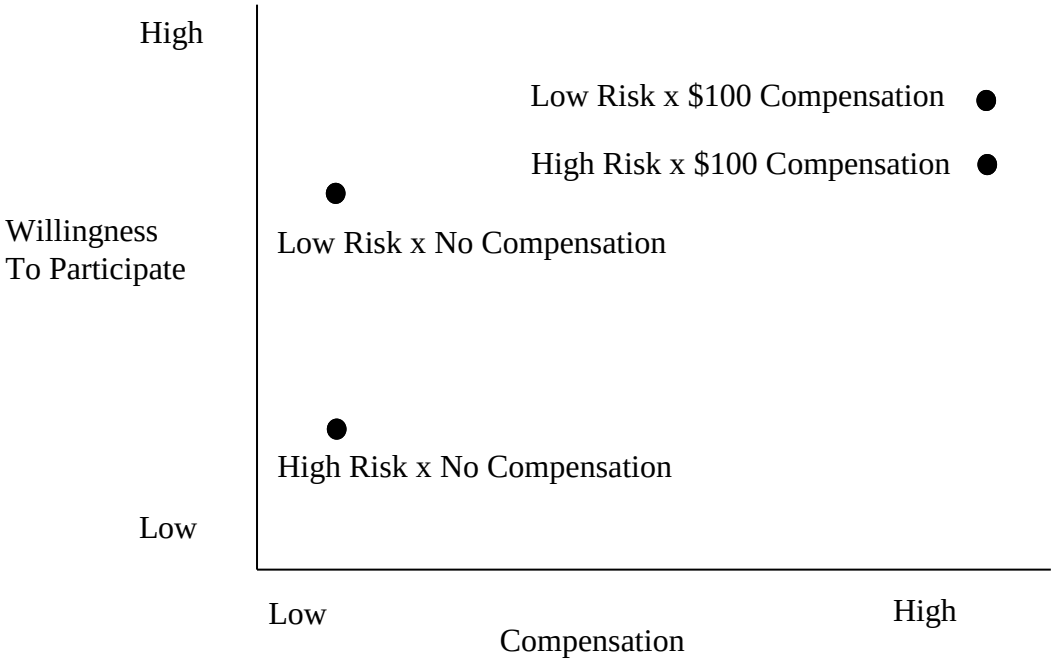
- Analysis: Two separate 2x2 mixed ANOVAs were conducted. One was performed on of each of the two willingness to participate questions (*'After reading the description, how willing would you be to participate in this study?*' and *'How likely would other students like you be to participate in this study?'*). These analyses were conducted using compensation as a between-subjects measure and risk as a within-subjects measure in order to determine if there were significant interactions between level of risk and level of compensation.

- Hypotheses 1A and 1B:
  - 1A. There will be a main effect of risk on WTP.
  - 1B. There will be a main effect of money on WTP.
    - Analysis: Main effects analyses were conducted to test whether there was an effect of risk across both levels of compensation and to determine if there was a separate effect of money across both levels of risk.

Perception of Risk with Joint Consideration of Risk and Compensation

- Hypothesis 2: Risk Perception will differentially increase as compensation increases in both high risk and low risk conditions.
  - This interaction hypothesis will determine whether increased compensation *differentially* leads to increases in participants' perception of risk to loss of privacy in behavioral genetic studies across **both** levels of associated risk to genetic privacy.

Diagram 1



The proposed model for willingness to participate in behavioral genetics studies at varying levels of monetary compensation.

- Analysis: Two separate 2x2 mixed ANOVAs were conducted. One was performed on each of the two risk perception questions (*'How concerned are you regarding the loss of the privacy of your personal information in this study?'* and '*How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?'*). These analyses were conducted using compensation as a between-subjects measure and risk as a within-subjects measure in order to determine if there were significant interactions between level of risk and level of compensation.

Hypotheses 2A and 2B:

- 1A. There will be a main effect of risk on Risk Perception.
- 1B. There will be a main effect of money on Risk Perception.
    - Analysis: Main effects analyses were conducted to test whether there was an effect of risk across both levels of compensation and to determine if there was a separate effect of money across both levels of risk.

CHAPTER 3

METHOD

Design

The independent variables in this online study are risk to privacy and monetary compensation. The study used a 2 (level of risk to privacy) by 2 (level of compensation) mixed design, with level of risk to privacy as a within subjects measure and level of compensation as a between subjects measure. Thus all participants received both high and low levels of risk but were randomly assigned to either a high or low compensation condition**.** Levels of risk to privacy are defined as either high risk in which participants were told, by an investigator constructed informed consent, that the fictitious researchers will be entering a person's identifiable genetic data into a national repository for which multiple researchers, privately funded research groups, life and medical insurance companies, as well as local and national law enforcement agencies, will have access. In contrast in the low risk condition, participants were informed by the consent document that the fictitious researchers will be entering genetic data stripped of all identifiers into a repository database that will be destroyed after five years and only be accessible to those researchers associated with the study.

Levels of compensation are defined as none ($0 for participation) or high ($100 for participation). While the high ($100) condition was identified as an appropriate level in the pilot study for Ascheman (2009), the additional no compensation ($0) condition was added to this study to serve as a baseline for perception of risk. By adding this new condition the study has attempted to create a quantifiable perception of risk without having any monetary compensation potentially influencing participants' responses, which was one of the major difficulties encountered by Ascheman (2009). Each participant received one of four possible treatment

orders designed to counterbalance the order in which participants will respond to each vignette. This counterbalanced order was used to deal with possible carryover and differential carryover effects by having each vignette viewed in each possible order a roughly equal number of times across the whole data set (see Table 1). In essence, this means that participants will be randomly assigned to one of four possible treatment orders with an approximately equal number of participants in each treatment order. Please also see Figure 1, the Flow Chart Diagram-Sequence of Experimental Tasks (Page 33 or Appendix A).

Table 1. Treatment orders. All conditions were balanced so that each level of risk is received an equal number of times in both possible orders.

	Treatment Orders		
$0 Condition	1	Low Risk x $0	High Risk x $0
	2	High Risk x $0	Low Risk x $0
$100 Condition	3	Low Risk x $100	High Risk x $100
	4	High Risk x $100	Low Risk x $100

A brief open-ended comprehension check (Appendix B) was placed after each vignette was presented. This assessment of comprehension, in addition to the initial instructions that introduce the vignettes and urge participants take their time and read each one carefully in order to render their most informed impressions, was aimed to prime participants to pay close attention to the different details of each study. In addition these procedures provide the researchers with the ability to check if participants were attending to the manipulations of the independent variables.

The dependent variables in this study are perceived risk and willingness to participate. The questionnaire used to measure the perceived risk and willingness to participate variables (Appendix C) were been adapted from Ascheman (2009) after a post hoc factor analysis of the original questionnaire demonstrated that the groupings of questions for perceived risk and willingness to participate appeared to indeed be distinctly and independently measuring separate variables (Appendixes D, E and F). Two questions for each variable were selected based on the factor analysis and modified for use in this study (Appendix C).

Participants

Based on the power analysis using the *GPower3* program, this study aimed to collect at least 112 participants in order to achieve a power of at least .80 and a significance level of .05. All participants were students enrolled in introductory level psychology or communications studies courses at a single large Midwestern university. Participants enrolled in the study through the psychology department's online research system, the SONA system, and received experimental study credit in their introductory psychology or communications studies courses. This study was reviewed and approved by the Iowa State University IRB (IRB Number 12-172; approval date 03/20/2012, see Appendix G). All participants were given the option to complete studies for credit in these courses or to complete brief writing assignments as an alternative.

There were 189 response collected in this online Qualtrics study. Of those respondents, three chose to not complete the study after reading the informed consent document and had their responses removed from the data set. An additional 21 participants agreed to participate but either stopped the survey after completing the demographics questionnaire or did not respond to any questions after the informed consent presentation and their responses were also removed from the data set. This left a total of 165 respondents, all of whom completed a minimum of

seven of eight questions related to the main manipulation. The between subjects measure, level of compensation, yielded a total of 81 responses at the $0 compensation level and 86 responses at the $100 compensation level.

Of the 166 participants with valid responses, 121(72.9%) were between the ages of 18-20, an additional 31 (18.7%) between the ages of 21-22, and 14 (8.4%) between ages 23-26. No participants identified as older than 26 years of age. Due to an error in the survey, gender data was not collected for all participants. Of the 89 responses collected for gender, 45 (50.6%) identified as male and 44 (49.4%) identified as female. Caucasian/European Americans were the most frequent participants (131 or 78.9%). Five participants (3%) identified as Black or African American, five (3%) as Hispanic or Latino/a, 19 (11.4%) as Asian or Asian American, five (3%) as Multiracial, and one (0.6%) identified as Other. Participants were also asked if they had ever undergone genetic testing or genetic counseling; eight participants (4.8%) reported that they had experienced testing or counseling. Among the participants, the majority (100, 60.6%) reported having completed five or more research studies previously, with only 32 (19.6%) having completed three to four studies previously, and 31 (19%) having completed two studies or fewer. The participants reflected a broad sampling of volunteers from the courses included in the Psychology Department subject pool. There were 48 (29%) from Psychology 101, 51 (30.9%) from Psychology 230, 33 (20%) from Psychology 280 and 32 (19.4%) from Communication Studies 101, with one participant choosing not to respond to this question.

Measures

Independent and Dependent Variables and Measures

The independent variables in this study are risk to privacy and monetary compensation. The study used a 2x2 factorial mixed design with each subject receiving one level of monetary

compensation and both levels of risk to privacy. The independent variable of monetary compensation is defined as either no monetary compensation ($0) or high monetary compensation ($100.00), and the independent variable of risk to genetic privacy is defined as either high (identifiable genetic data stored in databases accessible to law enforcement, insurance agencies and other researchers) or low (genetic data stripped of identifiers and stored in a secure database accessible only to the researchers that will be destroyed after five years).

The dependent variables in this study are perceived risk and willingness to participate. Perceived risk was measured using a modified questionnaire from Ascheman's (2009) study, using two self-report questions *('After reading the description, how willing would you be to participate in this study?'* and *'How likely would other students like you be to participate in this study?'*) with lower scores indicating a lower perception of risk. Willingness to participate was measured using two self-report questions modified from Ascheman's (2009) study (*'How concerned are you regarding the loss of the privacy of your personal information in this study?'* and *'How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?'*), with lower scores indicating a lower willingness to participate (Appendix C). These dependent variables were measured on a six point Likert-type scale.

The study additionally utilized a simple two question free response comprehension check after each vignette was presented (Appendix B). This comprehension will served two central purposes. The first was to assess whether or not participants are aware of the central features of each vignette, namely risk of loss of privacy (assessed with "Will your information be shared with people other than the researchers?") and presence of monetary compensation (assessed with "How much will you be paid to participate in this study?"). The second central purpose will be

to prime participants to attend to this particular information in each vignette more carefully with the aim of increasing comprehension of the central manipulations in each vignette.

Other Measures

Social Desirability. This study uses primarily self-report measures. Hence, a social desirability measure was added to assess participants' degree of social desirability in responding, their likelihood of self-enhancement. The 10-item Marlowe Crowne Social Desirability Scale, developed by Strahan and Gerbasi (1960) was chosen for this study due to concise nature, aiming to control against fatigue effects, as well as its well-established psychometric background (Appendix H). Responses were given in a true-false format, with half of the questions having a true response indicative of socially desirable responding and half reverse-coded so that a false response would indicate socially desirable responding. Scores on this scale range from 0-10, with higher scores indicating more socially desirable responding. Alpha coefficients for the 10-item Marlowe-Crowne range from .59 to .70, with the original comparison sample to the full item Marlowe-Crowne achieving correlations between .80 and .90.

Five-factor model of personality. For purposes of future analyses with this data set, the International Personality Item Pool version of the NEO Personality Inventory Revised (IPIP-NEO) was been included. The NEO-IP-R was developed by Coast & McCrae (1992) using factor analysis to identify the five personality domains of Extroversion, Agreeableness, Conscientiousness, Neuroticism and Openness to Experience. The original NEO-IP-R additional breaks each of these five factors into six sub-scales for each domain, totaling thirty sub-domains.

The IPIP-NEO was developed by Goldberg (1999, 2006) using a similar factor analysis process that was used to develop the NEO-IP-R. The goal of the development of this new version was to create a publicly available personality measure with a smaller item pool that has

strong correlations to the full NEO-IP-R, as well as similar validity across genders and several ethnic groups (Ehrhart et al., 2008). Correlations between these two measures average 0.77, though this increases to 0.90 when correcting for unreliability attenuation (see http://ipip.ori.org/newNEO_DomainsTable.htm). The IPIP-NEO is available in long- and short-form versions, with the long-form maintaining all thirty sub-domains originally assessed by the NEO-IP-R. For the purpose of this study, the 50-item short form of the IPIP-NEO has been selected (Appendix I). Normative sampling has been completed with over 20,000 individuals and internal reliability for all five major personality domains range from 0.77 to 0.86 (see Appendix J).

Descriptive analyses of the IPIP-NEO demonstrated fairly normal distributions of scores across each of the five subdomains. Minimum scores on all five measures ranged from 22 to 24 and maximum scores ranged from 38 to 41 out of possible scores between 10 and 50. The lowest mean and median scores were in Neuroticism (m = 28.93, median = 29) while the highest mean and median scores were in Conscientiousness (m = 31.55, median = 32). Standard deviations were also very close to one another, ranging from a low of 2.75 (Neuroticism) to 3.30 (Extraversion). These scores were comparable to previous NEO scores from the SONA research pool. As these scores did not appear to show any major deviations from a normal distribution, no further analyses were conducted on this part of the data for the purposes of this study.

Risk perception and willingness to participate. In order to measure the two dependent variables at the core of this study (perception of risk and willingness to participate), questions were developed specifically for the purpose of this study by modifying questions from Ascheman's (2009) original work. Ascheman's questionnaire demonstrates two strong underlying factors that can be identified as risk perception and willingness to participate (see

Appendixes D, E and F). These two factors are weakly correlated ($r^2 = -.19$) and demonstrate strong reliability ($\alpha = .76$ for risk perception, $\alpha = .80$ for willingness to participate) and so were chosen for use in this study's modified questionnaire. The questionnaire consisted of the two strongest items from the risk perception and willingness to participate variables previously identified, with responses given on a six-point Likert-type scale. This questionnaire will be given following each vignette (see Appendix C for the questionnaire and Appendix K for a full vignette).

Research Attitudes. Two measures for collecting information regarding participants' attitudes towards research, and specifically attitudes toward genetic research, were developed for this study. The first measure is an eight-item questionnaire that assesses attitudes toward research and research participation, and their experience as a research participant (Appendix L): the first item asks participants for an open response regarding what they view as most important to them in deciding whether or not to participate in a study, the second through fourth items gauge participants' amount of previous exposure to research, and questions five through eight assess participants' attitudes towards research on a five-point Likert-type scale. The second measure is a brief free-response item asking participants to briefly describe their attitude towards genetic research (Appendix M; "What do you think are the advantages and risks associated with scientific research on genetics?").

Procedure

Participants were recruited through the university's SONA online research system (see SONA Posting Form, Appendix N). Those who elected to participate in the study were directed by web link to the study survey hosted on the university's Qualtrics program. Participants first viewed an informed consent document, in which they were informed that their participation was

entirely voluntary and they would free to withdraw from the study at any time without penalty (see Informed Consent, Appendix O). The consent provided a deceptive description of the study (selected elements of purpose were omitted) in which participants were informed that this study aimed to examine psychology students' perceptions of upcoming behavioral genetic studies in an effort to understand and address students' potential concerns about the proposed studies before the studies received approval. After reading the informed consent the participants were asked to indicate "yes" or "no" to providing their online consent, stating also that by providing consent they attested that they had read the informed consent and understood what was being asked.

After completing the informed consent procedure, participants who did not give consent were redirected to a page debriefing them and thanking them for their time. Those that gave consent were directed to the primary survey. Participants first responded to a demographics questionnaire (Appendix P) before being directed to a research attitudes questionnaire developed for this study (Appendix L). Once participants had responded to these two questionnaires, they were randomly assigned through a Qualtrics randomization feature to one of two compensation treatment conditions, either no compensation ($0) or high compensation ($100). They were then again randomly assigned by a Qualtrics randomization feature to see either the high risk or low risk condition first (see Table 1, page 24).

They were then given a set of instructions to prime them to attend carefully to each of the vignettes (Appendix K) that were being presented. Participants were then presented with the first vignette to which they been assigned, after which participants answered two brief open ended comprehension questions (Appendix B). In addition, there was one additional comprehension question presented after the vignette for the high risk and no compensation (high risk x $0) condition, specific to this condition regarding their perception of the risks associated

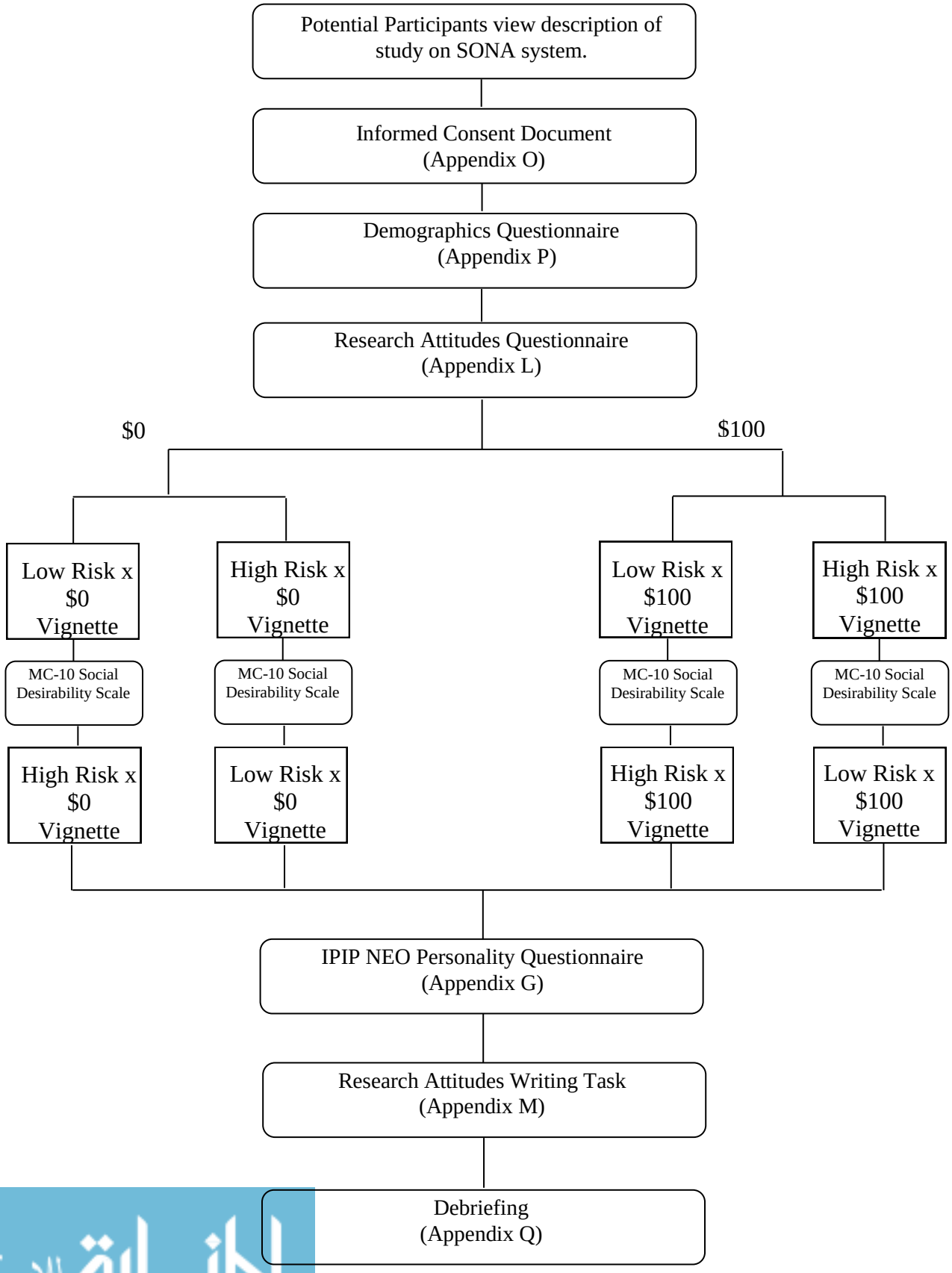
with the study. Following the comprehension questions, four questions derived from Ascheman (2009) regarding participants' perceptions of the risks and willingness to participate were presented (Appendix C).

After viewing the first vignette, participants were presented with the Marlowe-Crown 10-item Social Desirability Scale (Strahan & Gerbasi, 1972), a task designed to gather additional information (Appendix H). Presentation of this scale was also intended to separate the vignettes so as to minimize inattentive "same responding" across vignettes, to foster attention to the content of each vignette by requiring the participant to shift attention and cognitive focus, as well as to help prevent fatigue. Following the final vignette questionnaire, participants were asked to complete the 50-item version of the IPIP NEO, a short scale designed to measure the five major personality traits of openness to new experiences, conscientiousness, extroversion, agreeableness and neuroticism (Appendix I). This version of the NEO has strong, multiple, and domain specific correlations to the full NEO personality scale measures (Costa & McCrae, 1992). Finally, participants were asked to engage in a brief free-writing exercise to assess their beliefs about the advantages and risks associated with studying behavioral genetics (Appendix M).

After completing the questionnaires, participants were directed to a debriefing form (Appendix Q) designed to explain the true nature of the study, as well as the focus and purpose of the research. Participants were then shown a two-page brochure regarding genetic testing, privacy protections, and informed consent (Appendix R). The sequence of participant tasks is conveyed by the flowchart displayed in Figure 1 (Page 33). Appendix A contains the flowchart of the all measures being used and their relative positions throughout the study as seen in Figure 1. A full set of all vignette variations can be found in Appendix S. This study and all materials

were reviewed and approved by the Iowa State University Institutional Review Board before data were collected (IRB Number 12-172; approval date 03/20/2012, see Appendix G).

Figure 1: Study Flowchart



CHAPTER 4

RESULTS

Preliminary Analyses

Data Cleaning

In this study, 189 individuals chose to participate by signing up through the university's SONA research system. Of those 189 persons, three chose not to continue participation after reading the informed consent document. An additional 21 participants either completed only the demographics questionnaire or did not answer any questions. After removing data points for individuals who did not consent to participate and those who did not complete the survey beyond the initial demographics questionnaire, data for 165 participants remained. All of these participants answered at least six of the eight questions related to willingness to participate and perception of risk, the main dependent variable measures for this study, and so were retained for further data analysis. Of these remaining 165 participants, the groups were nearly equal for those exposed to the two levels of the between subjects measure condition, monetary compensation (n=81 for \$0 condition, n=85 for \$100 condition).

Tests for Normality and Homoscedasticity

All four dependent variable measures (two measures of risk and two measures of willingness to participate) were examined to determine if they met the necessary assumptions for carrying out analysis of variance testing, with each variable measure being tested within its between-subjects split of level of compensation. Levine's test of homogeneity of variance demonstrated no significant heterogeneity in the variances of any of the dependent variable measures at any compensation levels (see Appendix T). However, all levels of the dependent variables demonstrated significant non-normality (see Appendix U). Several articles have

indicated that such variations in normality do not have strong effects on finding false positive significance when using analysis of variance (Glass et al., 1972; Harwell et al., 1992; Lix et al., 1996) and so plans to use an ANOVA method for analysis were maintained. All dependent variables at both levels of risk were also examined for inter-correlations, and demonstrated similar correlation levels to results from Ascheman (2009) (see Appendix V)

Social Desirability Correlation

As this study relied on self-report measures, the 10-item Marlowe-Crowne Social Desirability Scale (Strahan & Gerbasi, 1972) was also given to all participants in order to assess for socially desirable responding that may have affected the ways in which participants responded to questions about their potential willingness to participate in studies. Correlations between each of the dependent variables at both levels of the between subjects variable, compensation, and social desirability demonstrated no significant correlations (see Table 2), and as such plans to use social desirability as a covariate in analyses were discarded.

Table 2: Correlations between dependent variables and social desirability scale, separated by between-subjects condition (compensation).

Social Desirability Correlations

	$0 Condition			$100 Condition	
WTP1xLow	Pearson Correlation	.088	WTP1xLow	Pearson Correlation	-.042
	Sig. (2-tailed)	.458		Sig. (2-tailed)	.706
WTP2xLow	Pearson Correlation	.117	WTP2xLow	Pearson Correlation	-.135
	Sig. (2-tailed)	.321		Sig. (2-tailed)	.228
RiskP1xLow	Pearson Correlation	-.065	RiskP1xLow	Pearson Correlation	.057
	Sig. (2-tailed)	.581		Sig. (2-tailed)	.611
RiskP2xLow	Pearson Correlation	-.097	RiskP2xLow	Pearson Correlation	-.002
	Sig. (2-tailed)	.412		Sig. (2-tailed)	.987
WTP1xHigh	Pearson Correlation	.115	WTP1xHigh	Pearson Correlation	-.032
	Sig. (2-tailed)	.329		Sig. (2-tailed)	.777
WTP2xHigh	Pearson Correlation	.013	WTP2xHigh	Pearson Correlation	-.108
	Sig. (2-tailed)	.915		Sig. (2-tailed)	.333
RiskP1xHigh	Pearson Correlation	.023	RiskP1xHigh	Pearson Correlation	.100
	Sig. (2-tailed)	.849		Sig. (2-tailed)	.371
RiskP2xHigh	Pearson Correlation	-.044	RiskP2xHigh	Pearson Correlation	.054
	Sig. (2-tailed)	.712		Sig. (2-tailed)	.629
N = 74			*N = 82*		

Descriptive Statistics

Research Attitudes Questionnaire

The research attitudes questionnaire developed for this study assessed individuals' attitudes about several aspects of research and the research participation process *prior to* being exposed to any manipulations. A question regarding the importance of money in decisions whether or not to participate in studies ('How important is money in your decision to participate in studies?') demonstrated strong participant beliefs that money was not important in their decision making process with research. Ninety participants (54.9%) rated money as not at all important or unimportant (indicated as one or two on the presented scale), with an additional 49 (29.9%) rating money as somewhat important in their decisions (three on the scale). Only 25 participants (15.3%) rated money as important or very important in their decision to participate in studies (four or five on the scale; scale total M = 2.45, SD = 1.04, N = 164). Participants were also asked to rate how serious loss of privacy would be in a study ('How serious would you loss of privacy in a study be?') on a one (not at all serious) to five (very serious) scale. Only 15 participants (9.1%) rated a loss of privacy as not at all serious or not serious; 37 participants (22.4%) rated this as somewhat serious and 113 (68.5%) rated a potential loss of privacy as serious or very serious (total scale M = 3.85, SD = .93, N = 165).

Participants also responded to a question about their perceptions of general risk in genetic studies ('How risky are studies in which genetic samples are taken?'). A majority of participants (84, 51.2%) rated genetic studies as somewhat risky, with 42 (25.4%) rating them as not at all risky or not risky and 28 (23.1%) considering them to be risky or very risky (total scale M = 2.99, SD = .80, N = 164). Overall, participants seem to indicate on this scale that tend to believe they are not strongly influenced by money in decisions to participate in research studies and have

fairly high concern for the seriousness of loss of privacy with only mild concerns about genetic studies. See Table 3 below for a complete list of the descriptive statistics for this section of the research attitudes questionnaire.

Table 3: Research Attitudes Questionnaire Descriptive Statistics

Item	M	SD	Range
Enjoy Research Participation	3.01	.77	1 (Do not enjoy) - 4 (Enjoy)
Importance of Money for Participation	2.45	1.04	1 (Not at all important) - 5 (Very important)
Value of Research to Education	2.96	.91	1 (Not at all valuable) - 5 (Very valuable)
Seriousness of privacy loss	3.85	.93	1 (Not at all serious) - 5 (Very serious)
Risk of Genetic Studies	2.99	.80	1 (Not at all risky) - 5 (Very risky)

IPIP-NEO Personality Scale

Descriptive statistics were generated for each of the five personality factors measured by the 50-item IPIP-NEO scale. All five scales demonstrated remarkably similar means and variances. Minimum scores on all five measures ranged from 22 to 24 and maximum scores ranged from 38 to 41 out of possible scores between 10 and 50. The lowest mean and median scores were in Neuroticism (m = 28.9324, median = 29) while the highest mean and median scores were in Conscientiousness (m = 31.5461, median = 32). Standard deviations were also very similar, ranging from a low of 2.752 (Neuroticism) to 3.297 (Extraversion). These findings,

based on a frequency histogram plot, appear to indicate a fairly normal distribution for each of the five scores. These scores were also correlated with the dependent variables to determine if any personality measures would be appropriate for use a covariates in further analysis. None of these correlations were statistically significant (see Appendix W).

Open-Ended Risk and Compensation Perceptions

After reading each vignette but before responding to the dependent variable questions, participants were asked to write in how much they would be compensated for participation in the presented study vignette ('How much would you be paid to participate in this study?') as well as whether or not their information would be kept confidential ('Will your information be shared with people other than the researchers?'). In Ascheman's (2009) study, comprehension checks similar to these yielded a comprehension rate of approximately 14%.

However, in this study, initial conservative analyses of these comprehension questions, which only considered a response as a correct, accurate comprehension response (stated exactly the correct amount of compensation) or directly and correctly stated the risk (whether or not information would be shared with parties other than the researchers) indicated very positive results. Of the 165 participants, 133 (80.5%) were able to correctly identify the amount of compensation indicated in the low ($0) compensation condition, and 130 (78.8%) correctly identified that correct amount of compensation in the high ($100) condition. Of those who responded correctly, 121 (73.3% of the total sample) correctly identified the amount of compensation in both vignettes they viewed, while 19 (11.5% of the total sample) correctly identified only one of two compensation amounts in the vignettes they viewed.

Comprehension of questions regarding who else data may be shared with showed similarly strong comprehension ratings. Participants correctly identified that their information

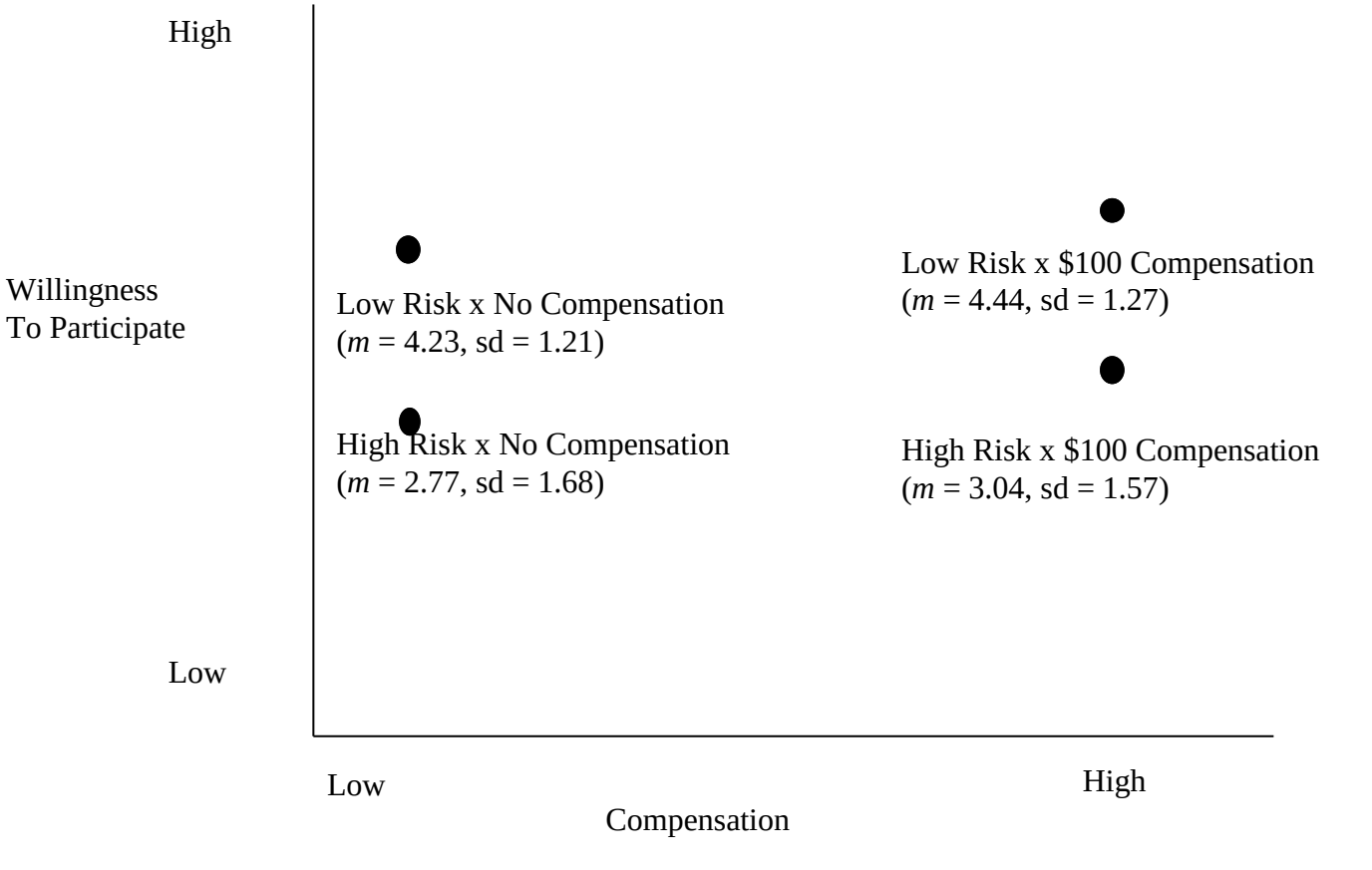
would not be shared outside of the immediate research in 139 of 165 responses (84.24% comprehension) in the low risk condition, and 103 participants (62.42%) correctly identified that their information would be shared with people other than the researchers in the high risk condition. These comprehension rates are substantially higher than those found in the results of Ascheman (2009). The implications of these findings will be further explored in the discussion section of this thesis.

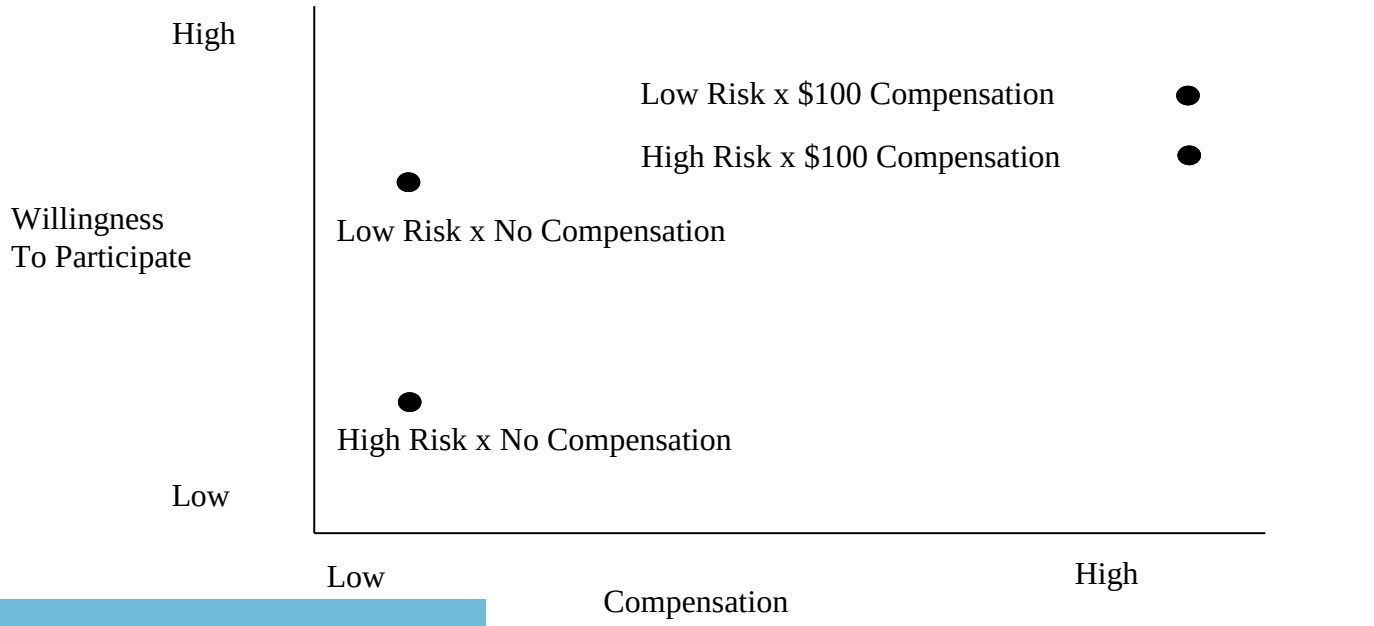
Hypothesis 1: Willingness to Participate

Hypothesis 1: Interaction of Risk x Compensation on WTP

In order to assess for an interaction effect between amount of compensation and level of risk to loss of genetic privacy, separate 2x2 mixed ANOVAs were conducted on both Willingness to Participate dependent variable measures. The first WTP measure (*'After reading the description, how willing would you be to participate in this study?'*) did not have a significant interaction effect ($F(1, 160) = .04$, $p = .84$). The second WTP measure ('*How likely would other students like be to participate in this study?'*) also did not have a significant interaction effect ($F(1, 162) = 0.00$, $p = .99$). These findings suggest that level of monetary compensation does not have a differential effect on willingness to participate at different levels of risk. This finding does not support one of the original hypotheses of this study, namely that willingness to participate would be more strongly influenced by monetary compensation in the high risk condition than in the low risk condition, in essence causing participants to ignore more of the risks that are more strongly present in that condition and as such be more willing to participate (see Diagram 2 for comparison of models).

Diagram 2: Results Model of WTP1 (Top) and Original Hypothesis Model (Bottom)





Hypothesis 1A: Main Effect of Risk on WTP

Analyses of main effects were carried out on both WTP questions following interaction testing. The first WTP measure (own willingness to participate) demonstrated a strong main effect of risk (F (1, 160) = 101.43, $p < .01$) with a fairly large effect size in both the no compensation ($d = 0.99$, $r = 0.45$) and the $100 compensation ($d = 0.98$, $r = 0.44$) conditions. The second WTP measure (perceived willingness of others) also demonstrated a strong main effect of risk (F (1, 162) = 103.03, $p < .01$) and similarly large effect sizes in both no compensation ($d = 0.96$, $r = 0.43$) and $100 compensation ($d = 0.97$, $r = 0.44$) conditions, both of which are considered large effect sizes (Cohen, 1988). These findings support the original hypothesis and suggest that the levels of risk presented in the vignettes had a powerful effect on participants' willingness to participate and perceptions of others' willingness to participate in the each vignette study.

Hypothesis 1B: Main Effect of Money on WTP

Analyses of main effects from the 2x2 ANOVA for monetary compensation yielded mixed results across both WTP measures. An analysis of WTP on *participants' own willingness* to participate did not reveal a significant main effect of monetary compensation (F (1, 160) = 1.97, $p = .16$) though given the sample size and near-significance of the finding, it is possible that a larger sample size may be able to detect a small main effect. An analysis of WTP for *participants' perceptions of others' willingness to participate*, however, did yield a significant main effect of monetary compensation (F (1, 162) = 4.77, $p = .03$) with a small effect size ($d = 0.31$, $r = .15$) as defined by Cohen (1988). Thus, the findings suggest that participants are not significantly affected in *their own* decision of willingness to participate in the vignette studies by levels monetary compensation presented in this study. However, the data also suggest that these

participants believe *others* would be more influenced by the levels of monetary compensation than they indicate for themselves. These findings will be explored in greater depth in the discussion section of this paper.

Hypothesis 2: Perception of Risk

Hypothesis 2: Interaction of Risk x Compensation on Risk Perception

Additional 2X2 mixed ANOVAs were conducted on both measured risk perception variables to assess for interaction effects between level of risk and monetary compensation. Analysis of the first risk perception measure ('*How concerned are you regarding the loss of the privacy of your personal information in this study?'*) did not detect an interaction effect ($F(1, 162) = 1.89$, $p = .17$). Similarly, analysis conducted on the second risk perception measure ('*How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?'*) also did not show any significant interaction effect ($F(1, 163) = 2.76$, $p = .10$). As was found with analysis of willingness to participate variables, these findings do not support the original hypothesis that increased compensation would differentially affect the perception of the risks across the vignettes, leading to more substantially decreased perception of risk in higher compensation conditions.

Table 4: *Descriptive matrices grouped by Dependent Variable* [*M*(SD)]

WTP1

	High Risk	Low Risk
$0	2.77 (1.684)	4.23 (1.208)
$100	3.04 (1.571)	4.44 (1.274)

RiskP1

	High Risk	Low Risk
$0	4.37 (1.602)	2.77 (1.527)
$100	4.25 (1.542)	3.04 (1.484)

WTP2

	High Risk	Low Risk
$0	2.79 (1.515)	4.06 (1.102)
$100	3.15 (1.393)	4.42 (1.219)

RiskP2

	High Risk	Low Risk
$0	4.35 (1.450)	2.90 (1.411)
$100	4.01 (1.570)	3.01 (1.376)

WTP1: After reading the description, how willing would you be to participate in this study?

WTP2: How likely would other students like you be to participate in this study?

1 - Not at all Willing / Likely; 6 - Very Willing / Likely

RiskP1: How concerned are you regarding the loss of the privacy of your personal information in this study?

RiskP2: How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?

1 - Not at all Concerned / Risky; 6 - Very Concerned / Risky

*Table 5: Descriptive Statistics, M (*SD*), for Willingness to Participate and Risk Perception*

Risk Level	Compensation	WTP1	WTP2	RiskP1	RiskP2
Low Risk	$0	4.23	4.06	2.77	2.9
		(1.208)	(1.102)	(1.527)	(1.411)
	$100	4.44	4.42	3.04	3.01
		(1.274)	(1.219)	(1.484)	(1.376)
High Risk	$0	2.77	2.79	4.37	4.35
		(1.684)	(1.515)	(1.602)	(1.45)
	$100	3.04	3.15	4.25	4.01
		(1.571)	(1.393)	(1.542)	(1.57)

WTP1: After reading the description, how willing would you be to participate in this study?

WTP2: How likely would other students like you be to participate in this study?

1 - Not at all Willing / Likely; 6 - Very Willing / Likely

RiskP1: How concerned are you regarding the loss of the privacy of your personal information in this study?

RiskP2: How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?

1 - Not at all Concerned / Risky; 6 - Very Concerned / Risky

Hypothesis 2A: Main Effect of Risk on Risk Perception

Analyses of the main effects for of level of risk were examined for both risk perception measures following testing for interaction effects. An analysis on the first risk perception measure (concern for privacy loss) showed a strong main effect of risk ($F(1, 162) = 95.69$, $p < .01$), with a large effect sizes at both the no compensation ($d = 1.02$, $r = 0.46$) and $100 compensation ($d = 0.8$, $r = 0.37$) levels. Similarly, analysis of the second risk perception measure (risk to privacy from DNA presented in a repository) showed a strong main effect of risk ($F(1, 163) = 81.65$, $p < .01$) with a large effect size at no compensation ($d = 1.01$, $r = 0.45$) level and a medium effect size at $100 compensation ($d = 0.68$, $r = 0.32$) level. Both findings support the original hypothesis. While the differences in effect sizes at the two levels of compensation seem to suggest that compensation is playing some role in perception of risk, the absence of an interaction effect may imply that any effect is so weak as to not be statistically significant. The implications of this finding for ethical decisions will be discussed later.

Hypothesis 2B: Main Effect of Money on Risk Perception

Separate analyses for main effects on each of the respective risk perception measures did not demonstrate a main effect of monetary compensation on either the first ($F(1, 162) = .11$, $p = .74$) or the second ($F(1, 163) = .39$, $p = .54$) risk perception measure. Again as was found with analyses on willingness to participate, these findings do not support the original hypothesis that increased compensation would lead to decreased risk perception. Viewed in conjunction with the absence of a main effect of monetary compensation in the willingness to participate self-report item, the data seem to suggest that monetary compensation *does not* have a powerful effect on participants' decisions to participate in genetic research studies, nor does it seem to influence their perception of the risks as presented to them. However, given the lone main effect

of monetary compensation on the willingness to participate measure that asked participants for their perceptions of how willing others like them would be to participate, it would seem that current participants believe others will be more swayed by offers of money in genetic research than are the responding participants.

WTP and Risk Perception with Research Attitudes Covariates

The Research Attitudes Questionnaire (RAQ) was given prior to presentation of the independent variable experimental stimuli (informed consents). Thus, these responses represent *a priori* perspectives on participants' views of research. Three RAQ questions were chosen for additional ANCOVA analyses with related dependent variables in order to determine if these pre-existing attitudes influenced the effects of the manipulation. While the correlations between the dependent variables being examined and the RAQ measures were not significant in all cases (see Table 6), these additional analyses were used to explore the possibility that some error variance could be accounted for by means of RAQ score covariates, allowing the researchers to better determine if significant risk by money interaction effects are present for participants with certain pre-existing attitudes toward research.

WTP with Importance of Money for Participation Covariate

A 2x2 mixed ANCOVA using the first willingness to participate measure (own willingness to participate) with the covariate (rating responses) from the RAQ item 'When you consider whether to participate in a psychology research study, how important is the offer of being paid to participate in your decision?' was conducted to assess for interaction effects of level of risk to loss of privacy and monetary compensation on willingness to participate. The findings, as with previous analyses without the covariate, did not find any statistically significant level of risk by level of compensation interaction effect ($F(1, 158) = 0.12$, $p = .73$). This

Table 6 : Correlations for Dependent Variables and RAQ

Item	WTP1 (Low Risk)	WTP1 (High Risk)	WTP2 (Low Risk)	WTP2 (High Risk)	RiskPerc1 (Low Risk)	RiskPerc1 (High Risk)	RiskPerc2 (Low Risk)	RiskPerc2 (High Risk)
# of Research Studies	-.020	.015	.004	-.013	.005	.078	.067	.060
# of Behavioral Genetics Studies	-.008	**.195***	.038	.125	**.165***	.023	**.187***	-.018
Enrolled Course	-.067	.067	-.029	.099	.025	-.094	.044	-.038
Previous Genetic Testing or Counseling	-.099	-.048	**-.193***	-.101	-.108	.027	-.068	-.030
Enjoy Research Participation	**.179***	.132	.113	.092	-.021	.034	-.085	-.017
Importance of Money for Participation	-.139	.144	-.096	.147	**.231****	-.072	**.251****	-.078
Value of Research to Education	.044	.138	**.155***	**.168***	**.166***	.060	.104	-.052
Seriousness of privacy loss	-.067	-.114	-.045	-.038	**.288****	**.256****	**.249****	**.264****
Risk of Genetic Studies	**-.168***	.098	-.069	.131	**.290****	.071	.353**	**.204****

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

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

analysis was also consistent with the main effect findings of previous analyses on this measure. In this analysis there was a significant risk main effect ($F (1, 158) = 42.08$, $p < .01$) but no main effect of money ($F (1, 158) = 2.30$, $p = .13$). This finding suggests that pre-existing attitudes toward the importance of being paid for research participation do not affect participants' strong consideration of risk and comparatively weak consideration of monetary compensation in their willingness to participate in behavioral genetics studies.

Risk Perception with Seriousness of Loss of Privacy Covariate

A 2x2 mixed ANCOVA using the first risk perception measure (risk to loss of privacy) with the covariate (rating scores) of the RAQ item 'How serious would it be if your privacy was violated as a result of participation in a research study?' was conducted to assess for interaction effects of level of risk to loss of privacy and monetary compensation on perception of risk. These findings were again consistent with the original analyses, demonstrating no level of risk by level of compensation interaction effect ($F (1, 161) = .01$, $p = .94$), no main effect of money ($F (1, 161) = .01$, $p = .99$) and a main effect of risk ($F (1, 161) = 5.54$, $p = .02$). This suggests that pre-existing attitudes about the seriousness of loss of privacy in a research study do not have a significant effect on how participants perceive risks to loss of privacy at different levels of risk and monetary compensation in behavioral genetic studies.

Risk Perception with Risk of Genetic Studies Covariate

Finally, a 2x2 mixed ANCOVA using the first risk perception measure (risk to loss of privacy) with the covariate (rating scores) of the RAQ item 'How risky, in your opinion, are studies in which genetic samples are taken?' was conducted to assess for interaction effects of level of risk to loss of privacy and monetary compensation on perception of risk. Consistent with all previous findings, the analysis showed no level of risk by level of compensation

interaction effect (F (1, 160) = 2.63, p = .11), main effect of money (F (1, 160) = .38, p = .54) and a main effect of risk (F (1, 160) = 23.81, p < .01). Interestingly, there was a significant interaction between level of risk and the covariate, riskiness of genetic studies (F (1, 160) = 5.91, p = .02) which suggests that while pre-existing attitudes toward the riskiness of genetic studies in general has an effect on participants' perception of the risks in the presented vignettes, it still does not demonstrate a differential effect of money on risk perception at different levels of risk or a statistically significant influence of money on risk perception. All of these ANCOVA analyses had slightly varying N's, which were affected by a few non-respondents to either the dependent variable measure or the RAQ item being used as a covariate in each category, though the absence of these non-respondents did not affect the overall distribution of scores in any of these cases.

CHAPTER 5

DISCUSSION

This study was conducted to explore the separate and potential interactive influences of risk and money on participants' perceptions of risk to loss of privacy and their willingness to participate in behavior genetic research. In addition the study was designed study was to extend the work of Ascheman (2009) in novel ways that were intended to clarify the influences on willingness to participate by exposure to a condition that did not involve money, the creation of a baseline risk condition, and by presentation of informed consent information through an alternative format, a story vignette. Prior studies that focused on research participants' comprehension of informed consent documents (Ogloff & Otto, 1991; Hammerschmidt & Keane, 1992; Hochhauser, 1999; Sachs et al., 2003; Pedersen et al., 2011) indicated a low level of comprehension and recall of important points relevant to making an informed decision about research participation. A particular difficulty in several studies example has been extremely low comprehension of elements of the informed consent document. For example, recent research by Pedersen et al. (2011) examined college students' reading comprehension using both recall and recognition testing for significant elements of an informed consent document, but found that between 69% and 89% of participants across *all* conditions failed the comprehension checks. Previous research by Sachs et al. (2003) demonstrated even more broadly that the average healthy adult participant may not have a sufficient capacity to fully understand some informed consent documents.

This study addressed the challenge of enhancing comprehension of the informed consent by using a novel informational procedure, presentation of all of the standard informed consent in a short vignette, rather than an IRB form format. This approach appears to have borne fruit, with

between 78.8% and 80.5% of participants correctly identifying amounts of compensation being offered in the vignettes, 62.42% correctly identifying risks to loss of privacy and the ability of genetic data to be shared with people beyond the researchers in the high risk condition, and 84.24% correctly identifying that their information would not be shared beyond the researchers in the low risk condition. While only 43.2% of participants correctly identified the possibility of losing access to health, life or dental insurance if a pre-existing condition were identified from a contributed genetic sample in the high risk and no compensation treatment, this is a substantial improvement over the Ascheman' study's 14% overall comprehension rate and the informed consent comprehension rate of 11%-31% cited by Pedersen et al. (2011).

Risk, Monetary Compensation, and Undue Inducement

The absence of any interaction effects between money and risk in all the measures of willingness to participate and risk perception suggests that money does not have a differential effect on how willing participants are to engage in behavioral genetic research at either low or high risk of loss to privacy of their genetic information in the context of this online study that involves *hypothetical* decision making. Moreover, there was a consistent absence of main effects of money on participants' own willingness to participate or on any measure of their perceptions of risk. This finding demonstrates how relatively small the effect of proposed monetary compensation is on urging participants to ignore risks posed by behavioral genetic research for the sake of getting paid to engage in a study.

The medium-to-large effects of risk to loss of privacy that were found for all willingness to participate and risk perception measures demonstrates the capacities of participants, when appropriate levels of comprehension and informed consent are present, to distinguish the levels of risk in behavioral genetics studies and accordingly adjust their willingness to engage in

participation. It appears that participants are able to distinguish risks and act in an appropriately informed manner without being unduly influenced by the amounts of compensation that were being offered in the vignettes of this study.

Self-Perception of Influence of Money vs. Perception of Money's Influence on Others

One particularly interesting finding is the significant main effect of money on the willingness to participate measure that asked participants to rate how likely others 'like themselves' would be to participate in the presented vignette studies. This is made more interesting by the absence of a significant main effect on the willingness to participate measure looking at participants' own willingness to participate in the vignette study. The absence of this main effect also seems to be consistent with self-reports regarding the importance of money in the research attitudes questionnaire, which demonstrated a trend toward low concern about being paid for study participation (m = 2.45, sd = 1.04, N = 164).

This finding seems to suggest that participants believe that others, even others who are similar to themselves, are more easily influenced by money to participate in behavioral genetic research than are the participants. The use of perception of risk as a measure instead of actual risk also leaves open the question: did participants perceive this study as a concrete exercise in a potential future risk or an abstract one in which they would not be expected to fully appreciate the level of risk. The distinction between the results from the two willingness to participate variables appears to demonstrate that participants did not perceive this as an entirely abstract exercise, given that there was a significant difference between their own willingness to participate and their believe in others' willingness to participate. However, it may be helpful to additionally examine not just participants' perception of others' willingness to participate, but

their perception of the degree of risk others might experience from being involved in a behavioral genetic study.

Informed Consent Comprehension

It has been thoroughly documented that informed consent processes are problematic and often demonstrate poor retention and recall of important elements of consent (Ogloff & Otto, 1991; Hammerschmidt & Keane, 1992; Hochhauser, 1999; Sachs et al., 2003; Pedersen et al., 2011). This was again highlighted by the 14% comprehension rate of participants responding to questions about elements of risk and compensation in a manipulation of traditional informed consent documents in Ascheman (2009). The present study focused on increasing through use of novel short vignettes that were carefully designed to contain the same elements of information present in traditional informed consent documents. The vignette method used in this study to substantially increased comprehension rates for risks and compensation compares to Ascheman's prior study.

Several long-standing areas of concern remain, however. Higher risk conditions showed decreased comprehension rates relative to low risk conditions (62.42% in high risk compared to 84.24% in low risk) when addressing potential loss of privacy of genetic data. Many of the non-comprehension responses in the high risk condition simply stated that there was no risk of loss to genetic privacy or that information wouldn't be shared beyond the researchers of the presented study, which mirrored many of the responses in the low risk category that were, indeed, correct. This may mean that some of the 'comprehending' responses in the low risk condition were lucky guesses borne of a confidence that, as with most if not all other studies the participants had experienced through the university's SONA research system, data access is always restricted to just the researchers for the current study.

This concern is further highlighted by the comprehension question presented only to participants in the high risk and no compensation condition, "What are the risks associated with this study?". This question was purposefully selected only for the high risk and no compensation condition so that this study could assess whether or not participants were identifying the central manipulation of risk to loss of genetic privacy and the implications of this. The high risk condition manipulation of the vignette read as:

> "After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be submitted and stored indefinitely with the participant's name and unique personal code, linking the individual to the sample, into a national repository of genetic data that is accessible to other researchers, law enforcement agencies (including but not limited to local, state and federal law enforcement agencies), medical practitioners and medical, dental and life insurance companies. As a result, if your genetic data shows a predisposition for serious health conditions (e.g., heart disease, diabetes, cancer) or serious mental illness (e.g., major depression, bipolar disorder, schizophrenia) you may be unable to receive health insurance in the future."

The underlining in the above example was not added for emphasis for the sake of this manuscript, but rather was identical to what participants saw in the high risk conditions. Despite this rather direct attempt at drawing attention to the serious potential risk of the inability to receive health insurance in the future if genetic data are submitted to this fictitious database, only 43.2% of participants that viewed the high risk and no compensation vignette (N = 81) correctly identified this risk. An additional 35.8% of these participants correctly identified the risk at the very bottom of the vignette, potential for some psychological discomfort from the questions and

a potential for a minor swelling reaction from buccal swabbing. While many of those that correctly identified the risk of losing access to healthcare as laid out in the vignette also identified the psychological and cheek-swelling risks, the respondents that only identified this may have only been searching for the 'correct' answer and stopped after believing they had found it, which may also indicate they did not carefully read the vignette.

These findings are particularly unsettling given that if these participants had been in a real study such as this one, they may have unwittingly signed away their genetic privacy *permanently*. Studies that do not have a comprehension check associated with their informed consent, whether that is a lab assistant asking questions or a written comprehension check that is examined by a researcher or assistant for comprehension, may have even lower rates of comprehension as these participants would not be primed to go back and read over at least part of the consent document. It is important to note that if a participant does understand the risks associated with the permanent loss of their genetic privacy and consents to submit it regardless, that is entirely their decision and the researcher will have done their due diligence in the informed consent process. However, in the current 'sign here if you understand this document' mode of collecting 'informed' consent documentation these problems may not surface until after a participant realizes what has happened, though in that case we are able to contend that they signed the document attesting that they understood what was happening. The question then becomes who is ultimately responsible for informed consent; the participant or the researcher?

Implications for Ethical Bodies

The findings of this study appear to validate the status quo of ethical decision making bodies such as institutional review boards. The relatively large amount of money and the short amount of time necessary to contribute a genetic sample via buccal swabbing create what

Ascheman (2009) identified as a 'large reward' in a pilot study. Even given this large reward, participants were not significantly swayed in either their willingness to participate or their perception of risk at either of the presented levels of risk. Additionally, the finding of an effect of compensation on our perceptions of others' willingness to participate would suggest that, if these ethical bodies are similarly susceptible to this effect, that ethical decision boards would likely be more hesitant to approve studies with large monetary inducements for concern that others would be more heavily influenced than they may actually be. More research on this finding will need to be conducted before this assertion can be made, however.

Limitations of the Study

One of the major limitations of this study is the manner in which the vignettes were presented to participants. Since the vignettes were presented as studies that were pending approval from a university institutional review board, there was no immediate risk to participants if they stated that they would have been willing to participate in the study at a future date. While the researchers attempted to help manage this limitation through the use of a social desirability scale to try and identify desirable responding, which in this case would be agreeing to being willing to participate if the studies were run and viewing them as not very risky, a study that could present these as real studies wherein participants would immediately have a sample taken might present different findings.

An additional limitation to the generalizability of this study is the short vignette format used for the manipulation. While this technique appears to have generated substantially improved comprehension rates of the same elements that are present in traditional informed consent documents, the reality is that the traditional documents are what are actually being used in real behavioral genetics studies. There is a demonstrable difference in comprehension

between this study's vignettes and Ascheman's (2009) traditional informed consent document manipulation, which also means that these same comprehension difficulties are more likely to be occurring in the field due to the more similar format Ascheman used.

The sample for this study was most representative of a Caucasian/European American population, and while it had higher than anticipated inclusion of persons from other ethnic backgrounds the findings may not be as readily generalizable to populations of college students where larger proportions of the population are not Caucasian. The study also did not have a sufficient sample size to detect statistically significant small effects. While this does not change the finding that monetary compensation does not appear to have a strong effect on willingness to participate or risk perception, particularly compared to the strong effects level of risk to loss of privacy appear to have, it may be helpful to identify if there is a significant but small main effect of money on these measures.

This study was completed entirely through the Qualtrics online data collection system, which means there was no control over the conditions in which participants completed the surveys presented. As such, it is impossible to know if participants were consistently or intermittently attentive to the study's measures, only whether or not they were able to comprehend the manipulations through the open-ended manipulation checks. Response times were reported by the program, which indicated an overall mean response time of 36 minutes, though this is trimmed considerably to a mean response time of 15 minutes if outliers of four hours or greater are removed. This study was also examining participants' reactions to a hypothetical situation, and as such participants may have reacted differently in a more 'real' setting that presented immediate, direct consequences for decisions to participate. Additionally, the SONA system allows potential participants to view the titles and descriptions of studies

before signing up, and as such there may be some participant self-selection along lines of individual interest taking place in the sample.

Directions for Future Research

The findings of this study and the performance of the novel short-vignette format for informed consent information lead to several potential directions for future research. One area that may be potentially useful for a wide variety of social science studies would be an examination of what allowed for such greatly improved comprehension using the short vignettes as opposed to more traditional consent documents. The vignettes were selected for this study for their novelty compared to the traditional consent process, but if merely the novelty aids the increased comprehension then this would not be helpful for future studies as constantly changing the format of informed consent in research would be extremely impractical. If, however, some other element or elements of the short-vignette format are contributing to increased comprehension, such as the abbreviated length or narrative format, then these could be simple but extremely beneficial in modifying the informed consent process to increase comprehension.

Further examination of the effects of risk to loss of privacy and monetary compensation in behavioral genetics studies may also prove useful. In particular, a study that could maintain the core manipulations but modify the deceptive elements to have participants believe they would be consenting to giving a genetic sample immediately if they give consent may yield more powerful and generalizable results. Coupling this with a larger sample size and ideally a more ethnically and geographically diverse population would also substantially increase the generalizability of the findings. Additionally, examining a mediation model in which perceived risk acts as a mediator for willingness to participate in addition to the actual risk presented in the vignettes could yield substantial differences.

Finally, more research on how we perceive how strongly others are affected by offers of monetary compensation in research studies beyond just behavioral genetic studies may prove helpful both to advance our understanding of how our perceptions of others' ability to be influenced by differs from the actual amount of influence. This research would not only further this understanding of our perceptions of others, but also help further inform ethical decision making bodies regarding what is considered undue inducement from a monetary standpoint.

Conclusion

This study demonstrates that potential college student volunteer research participants in behavioral genetics studies take seriously the risks of participation in this line of research and are not powerfully swayed by promises of payment for their contribution. An institutional review board does its job of assessing risk and ensuring that these risks are appropriate to the study, are adequately described and that participants are informed before they give consent. When this occurs this study paints a very positive picture of potential participants' ability to make an informed decision.

A recurrent issue and ongoing challenge for this and all other studies dealing with risk in behavioral research is the continuing and documented low comprehension rates of informed consent documents. Researchers and review boards can be as careful as possible to spell out all possible risks associated with a study, but if the information is presented in a format that is incomprehensible or is ignored by potential participants choosing to just sign on the dotted line then that work is futile. The key to informed consent is the very concept of being 'informed', which leads once again to the question: who is responsible for making sure consent *is informed*?

Given the size and sheer volume of social science research occurring at institutions around the world, it would likely be impractical to quiz every individual participating in research

over the details of an informed consent document. In many cases, the likelihood of harm coming to a social science participant who hasn't been fully informed by the consent process is very low, a protective consequence of the institutional review process necessary to conduct research. However, finding different ways to convey to an inform potential participants about varying levels of risk and the direct consequences to them from participation in social science research may become more important than ever now that collaborative medical, neuroscience and psychology investigations are becoming more frequent.

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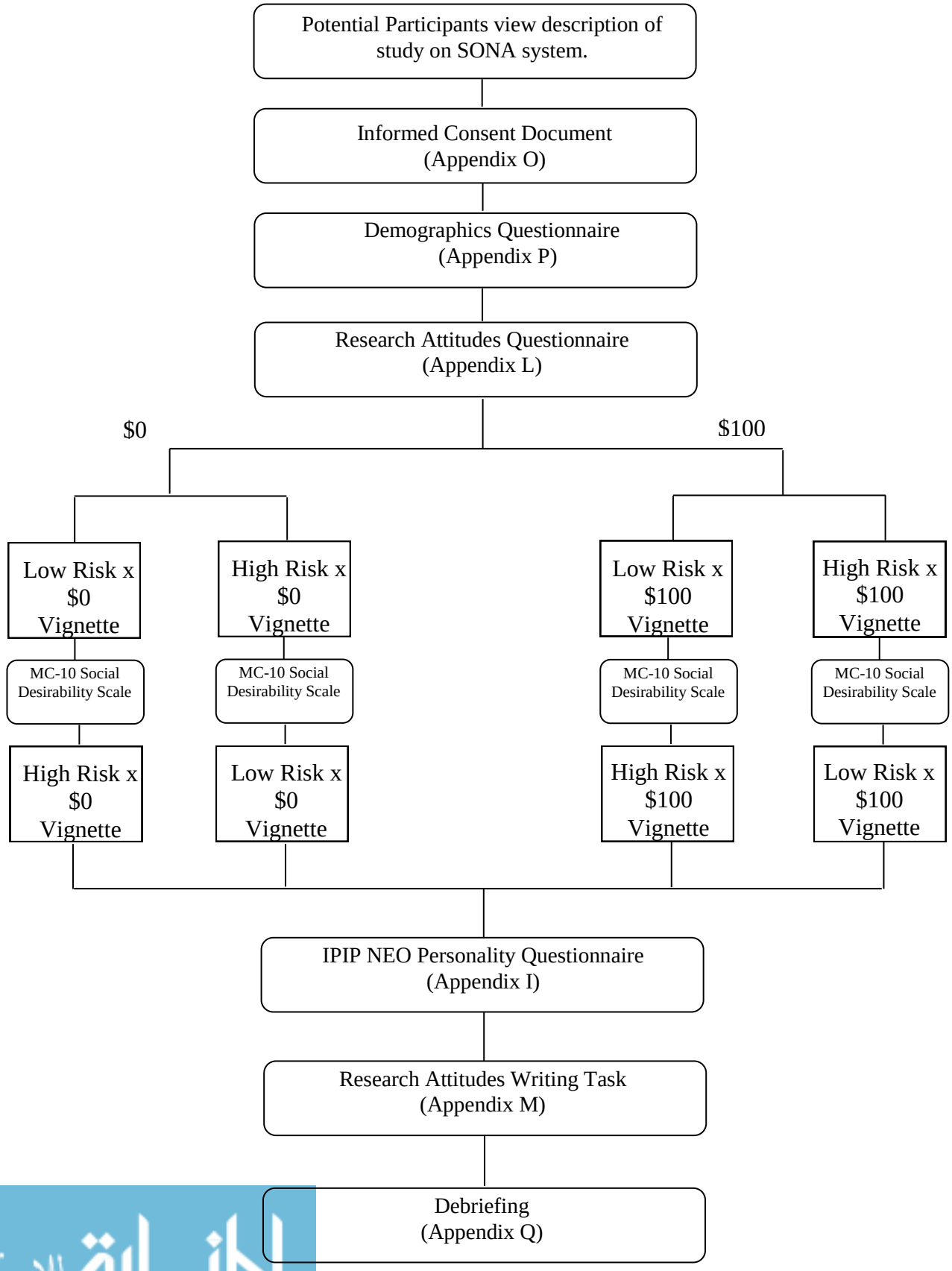
APPENDIX A – STUDY FLOWCHART



APPENDIX B – COMPREHENSION CHECK QUESTOINNAIRE

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

3) *[High Risk, $0 condition only]* What are the risks associated with this study?

_____

APPENDIX C – VIGNETTE QUESTIONNAIRE

1. (Willingness to Participate) After reading the description, how willing would you be to participate in this study?

2. (Willingness to Participate) How likely would other students like you be to participate in this study?

3. (Risk Perception) How concerned are you regarding the loss of the privacy of your personal information in this study?

4. (Risk Perception) How much risk to your privacy do you feel it is to have your DNA sample put in the repository being used for this study?

APPENDIX D – FACTOR ANALYSIS OF ASCHEMAN'S (2009)

RISK AND WILLINGNESS SCALES

Rotated Component Matrix(a)

	Factor	
	1	2
*PRIVDNA 145) How much risk to your privacy do you feel it is to have your DNA sample put in a repository?	.857	-.034
*LOSS144) How concerned are you regarding the loss of the privacy of your personal information in this study?	.763	-.161
*PROB 146) What is the probability that your personal information would be used unethically and in a way inconsistent with the wording of the informed consent?	.714	-.048
*SERIOUS 147) How serious would the negative consequences related to loss of privacy be if they occurred?	.545	-.045
*WTP 141) After reading the informed consent, but before participating, how willing were you to participate in this study?	-.215	.945
*OTHERS 142) How likely would other students like you be to participate in this study?	-.185	.714
*ENJOY 148) How much did you enjoy participating in this research study?	-.093	.487
*$IMPORTANT 143) How important was the amount of compensation in your decision to participate?	.110	.319

Extraction Method: Principal Axis Factoring.
Rotation Method: Varimax with Kaiser Normalization.
a Rotation converged in 3 iterations.

APPENDIX E – RISK AND WILLINGNESS MEASURE CORRELATIONS

Descriptive Statistics

	Mean	Std. Deviation	N
RISK	10.2143	3.84265	182
WILLING	12.0055	3.53279	182

Correlations

		ZB_RISK	ZB_WILLING
RISK	Pearson Correlation	1	-.187(*)
	Sig. (2-tailed)		.011
	N	182	182
WILLING	Pearson Correlation	-.187(*)	1
	Sig. (2-tailed)	.011	
	N	182	182

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

APPENDIX F – RISK AND WILLINGNESS MEASURE RELIABILITY

Reliability Statistics

Cronbach's Alpha	N of Items
.759	3

Item Statistics

	Mean	Std. Deviation	N
*WTP 141) After reading the informed consent, but before participating, how willing were you to participate in this study?	3.26	1.373	182
*OTHERS 142) How likely would other students like you be to participate in this study?	3.34	1.005	182
*ENJOY 148) How much did you enjoy participating in this research study?	2.54	1.065	182

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
*WTP 141) After reading the informed consent, but before participating, how willing were you to participate in this study?	5.88	2.891	.724	.517
*OTHERS 142) How likely would other students like you be to participate in this study?	5.80	4.369	.661	.618
*ENJOY 148) How much did you enjoy participating in this research study?	6.60	4.926	.444	.824

APPENDIX F (Cont.) – RISK AND WILLINGNESS MEASURES RELIABILITY

Reliability Statistics

Cronbach's Alpha	N of Items
.804	4

Item Statistics

	Mean	Std. Deviation	N
*LOSS144) How concerned are you regarding the loss of the privacy of your personal information in this study?	2.46	1.303	182
*PRIVDNA 145) How much risk to your privacy do you feel it is to have your DNA sample put in a repository?	2.60	1.278	182
*PROB 146) What is the probability that your personal information would be used unethically and in a way inconsistent with the wording of the informed consent?	2.13	.937	182
*SERIOUS 147) How serious would the negative consequences related to loss of privacy be if they occurred?	3.03	1.285	182

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
*LOSS144) How concerned are you regarding the loss of the privacy of your personal information in this study?	7.76	8.151	.661	.734
*PRIVDNA 145) How much risk to your privacy do you feel it is to have your DNA sample put in a repository?	7.62	7.862	.735	.694
*PROB 146) What is the probability that your personal information would be used unethically and in a way inconsistent with the wording of the informed consent?	8.08	10.142	.628	.763
*SERIOUS 147) How serious would the negative consequences related to loss of privacy be if they occurred?	7.19	9.236	.497	.817

APPENDIX G – INSTITUTIONAL REVIEW BOARD APPROVAL

IRB ID: 12-172

RECEIVED
MAR 09 2012
By IRB

INSTITUTIONAL REVIEW BOARD (IRB)
Application for Approval of Research Involving Humans

Title of Project: Compensation's Effect on Risk Perception in Behavioral Genetic Research

Principal Investigator (PI): **Zachary R. Batchelder**		Degrees: Bachelor of Science
University ID: **925500576**	Phone: 702-343-1954	Email Address: zacharyb@iastate.edu
Correspondence Address: W113 Lagomarcino Hall		
Department: Psychology		College/Center/Institute: College of Liberal Arts and Sciences

PI Level: ☐ Tenured, Tenure-Eligible, & NTER Faculty ☐ Adjunct/Affiliate Faculty ☐ Collaborator Faculty ☐ Emeritus Faculty
☐ Visiting Faculty/Scientist ☐ Senior Lecturer/Clinician ☐ Lecturer/Clinician, Ph.D. or DVM ☐ P&S Employee, P37 & above
☐ Extension to Families/Youth Specialist ☐ Field Specialist III ☐ Postdoctoral Associate ☒ Graduate/Undergrad Student ☐ Other (specify:)

FOR STUDENT PROJECTS (*Required when the principal investigator is a student*)		
Name of Major Professor/Supervising Faculty: Norman A. Scott, Ph.D.		
University ID: 018670561	Phone: 515-294-1509	Email Address: nascott@iastate.edu
Campus Address: W206 Lagomarcino Hall		Department: Psychology
Type of Project (check all that apply): ☒ Thesis/Dissertation	☐ Class Project	☐ Other (specify:)

Alternate Contact Person:	Email Address:
Correspondence Address:	Phone:

ASSURANCE

- I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies. Misrepresentation of the research described in this or any other IRB application may constitute non-compliance with federal regulations and/or academic misconduct according to ISU policy.
- I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any problems to the IRB.
- I agree that modifications to the originally approved project will not take place without prior review and approval by the IRB.
- I agree that the research will not take place without the receipt of permission from any cooperating institutions, when applicable.
- I agree to obtain approval from other appropriate committees as needed for this project, such as the IACUC (if the research includes animals), the IBC (for research involving biohazards), the Radiation Safety Committee (for research involving x-rays or other radiation producing devices or procedures), etc.
- I agree that all activities will be performed in accordance with all applicable federal, state, local, and Iowa State University

Signature of Principal Investigator Date

Signature of Major Professor/Supervising Faculty Date
(*Required when the principal investigator is a student*)

- I have reviewed this application and determined that departmental requirements are met, the investigator(s) has/have adequate resources to conduct the research, and the research design is scientifically sound and has scientific merit.

Signature of Department Chair Date

For IRB Use Only	Full Committee Review: ☐	Review Date: March 20, 2012
	EXPEDITED per 45 CFR 46.110(b): Category 7 Letter	Approval/Determination Date: March 20, 2012
Approval Not Required: ☐		Approval Expiration Date: March 19, 2013
Not Research: ☐	EXEMPT per 45 CFR 46.101(b):	
No Human Subjects: ☐	Not Approved: ☐	Risk: Minimal ☑ More than Minimal ☐
IRB Reviewer's Signature	Kelly A Spittel	March 20, 2012

APPENDIX H – MARLOWE-CROWNE 10-ITEM SOCIAL DESIRABILITY SCALE

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally.

1) I am always willing to admit it when I make a mistake
2) I always try to practice what I preach.
3) I never resent being asked to return a favor.
4) I have never been irritated when people expressed ideas very different from my own.
5) I have never deliberately said something that hurt someone's feelings.
6) *I like to gossip at times.
7) *There have been occasions when I took advantage of someone.
8) *I sometimes try to get even rather than forgive and forget.
9) *At times I have really insisted on having things my own way.
10) *There have been occasions when I felt like smashing things.

*Items are reverse-coded

APPENDIX I – IPIP NEO PERSONALITY SCALE

In the following section, there are phrases describing behaviors. Please use the rating scale below to describe how accurately each statement describes you. Describe yourself as you generally are now, not as you wish to be in the future.

Very Inaccurate	Moderately Inaccurate	Neither Inaccurate Nor Accurate	Moderately Accurate	Very Accurate
1	2	3	4	5

1. Feel comfortable around people.
2. Have frequent mood swings.
3. Believe that others have good intentions.
4. Don't see things through.
5. Tend to vote for conservative political candidates.
6. Waste my time.
7. Suspect hidden motives in others.
8. Carry out my plans.
9. Am always prepared.
10. Respect others.
11. Am very pleased with myself.
12. Tend to vote for liberal political candidates.
13. Am skilled in handling social situations.
14. Don't like to draw attention to myself.
15. Feel comfortable with myself.

16. Am the life of the party.

17. Seldom feel blue.

18. Find it difficult to get down to work.

19. Insult people.

20. Don't talk a lot.

21. Panic easily.

22. Have a good word for everyone.

23. Am not easily bothered by things.

24. Do just enough work to get by.

25. Get back at others.

26. Have little to say.

27. Have a sharp tongue.

28. Make plans and stick to them.

29. Rarely get irritated.

30. Keep in the background.

31. Carry the conversation to a higher level.

32. Do not like art.

33. Accept people as they are.

34. Enjoy hearing new ideas.

35. Would describe my experiences as somewhat dull.

36. Believe in the importance of art.

37. Am often down in the dumps.

38. Avoid my duties.

39. Make people feel at ease.

40. Get chores done right away.

41. Avoid philosophical discussions.

42. Often feel blue.

43. Make friends easily.

44. Have a vivid imagination.

45. Pay attention to details.

46. Cut others to pieces.

47. Know how to captivate people.

48. Dislike myself.

49. Am not interested in abstract ideas.

50. Do not enjoy going to art museums.

APPENDIX J – IPIP NEO ITEM POOL

NEUROTICISM - *10-item scale (Alpha = .86)*

\+ keyed

Often feel blue.

Dislike myself.

Am often down in the dumps.

Have frequent mood swings.

Panic easily.

– keyed

Rarely get irritated.

Seldom feel blue.

Feel comfortable with myself.

Am not easily bothered by things.

Am very pleased with myself.

EXTROVERSION - *10-item scale (Alpha = .86)*

\+ keyed

Feel comfortable around people.

Make friends easily.

Am skilled in handling social situations.

Am the life of the party.

Know how to captivate people.

– keyed

Have little to say.

Keep in the background.

Would describe my experiences as somewhat dull.

Don't like to draw attention to myself.

Don't talk a lot.

OPENNESS TO EXPERIENCE - *10-item scale (Alpha = .82)*

+ keyed

Believe in the importance of art.

Have a vivid imagination.

Tend to vote for liberal political candidates.

Carry the conversation to a higher level.

Enjoy hearing new ideas.

– keyed

Am not interested in abstract ideas.

Do not like art.

Avoid philosophical discussions.

Do not enjoy going to art museums.

Tend to vote for conservative political candidates.

AGREEABLENESS - *10-item scale (Alpha = .77)*

+ keyed

Have a good word for everyone.

Believe that others have good intentions.

Respect others.

Accept people as they are.

Make people feel at ease.

– keyed

Have a sharp tongue.

Cut others to pieces.

Suspect hidden motives in others.

Get back at others.

Insult people.

CONSCIENTIOUSNESS - *10-item scale (Alpha = .81)*

+ keyed

Am always prepared.

Pay attention to details.

Get chores done right away.

Carry out my plans.

Make plans and stick to them.

– keyed

Waste my time.

Find it difficult to get down to work.

Do just enough work to get by.

Don't see things through.

Shirk my duties.

APPENDIX K – SAMPLE VIGNETTE

Instructions:

Your opinions and reactions as a Psychology student provide a unique perspective that is essential to a complete understanding of student perceptions of upcoming research. The following studies are currently being planned to potentially begin data collection [next semester]. As part of the review procedure it is vital that the input of students be considered in addition to experts in the relevant fields, as students will make up the majority of the individuals being sampled in these studies. Please read the overview of each study carefully and completely, as some of the language used may be similar but important details may vary. After reading the description each study please take a moment to fully and honestly complete the brief attached questionnaire. Thank you in advance for your participation. By completing this study you will be giving reviewers important insight into the opinions of students who may potentially participate in these studies.

Study Title: Genetic Variation in Genome P36 and Subjective Well-Being

Description: This study will be investigating how variations in the P36 Genome potentially affect measures of subjective well-being. Participation in this study is completely voluntary and those who choose to participate may withdraw at any time with no penalty. The study should take approximately 50 minutes to complete. Participants in this study will be asked to complete a brief well-being questionnaire, after which they will contribute a genetic sample by means of buccal (cheek) swabbing. After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be

[**Low Risk:** *stripped of identifiers, leaving no name or code linking the sample to the participant, before being entered into a secure encrypted and password protected*

electronic file database accessible only by the research team and will be destroyed after two years; **High Risk*:*** *submitted and stored indefinitely with the participant's unique personal code, linking the individual to the sample, into a national repository of genetic data that is accessible to other researchers, law enforcement agencies (including but not limited to local, state and federal law enforcement agencies), medical practitioners and medical, dental and life insurance companies. As a result, if your genetic data shows a predisposition for serious health conditions, you may be unable to receive health insurance in the future*].

Researchers will then use this data in conjunction with the self-report questionnaire in hopes of determining if there is a genetic link between subjective well-being and the P36 Genome. As benefits, participants will receive

[**No Compensation:** *no money for their genetic contribution, but will gain firsthand knowledge of how genetic research is conducted*; **High Compensation:** *$100 for their genetic contribution, and will gain firsthand knowledge of how genetic research is conducted.*]

Potential risks during the study include a minor swelling reaction to the buccal swab and potential psychological discomfort from the presented questionnaires.

Questions or information requests regarding this study should be directed to the experimenters in charge of the review study, Zachary Batchelder at zacharyb@iastate.edu or Norman Scott at nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB administrator, (515) 294-4566, irb@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

3) *[High Risk, $0 condition only]* What are the risks associated with this study?

_____

Please rate your responses to the following questions about this study using the scoring system provided:

1. After reading the description, how willing would you be to participate in this study?

Not At All Willing					Very Willing
1	2	3	4	5	6

2. How likely would students who are similar to you be to participate in this study?

Not At All Likely					Very Likely
1	2	3	4	5	6

3. How concerned are you regarding the loss of the privacy of your personal information in this study?

Not At All Concerned					Very Concerned
1	2	3	4	5	6

4. How much risk to your privacy do you feel it is to have your DNA sample put in the database being used for this study?

Not At All Risky					Very Risky
1	2	3	4	5	6

APPENDIX L – RESEARCH ATTITUDES QUESTIONNAIRE

1) For you, what is the most important factor in deciding whether or not to participate in a psychology research study?

_____

_____

2) How many research studies have you participated in?
   a) 0
   b) 1-2
   c) 3-4
   d) 5-6
   e) 7 or more
3) In how many behavioral genetics studies have you been a participant?
   a) 0
   b) 1-2
   c) 3-4
   d) 5-6
   e) 7 or more
4) Which course will be receiving credit in for completing this study?
   a) Psychology 101
   b) Psychology 230
   c) Psychology 380
   d) Communication Studies 101

5) Have you ever undergone medically related genetic testing or genetic counseling?

   a) Yes

   b) No

6) How much do you enjoy participating in research studies?

Not At All		Some		Very Much
1	2	3	4	5

7) When you consider whether to participate in a psychology research study, how important is the offer of being paid to participate in your decision?

Not Important		Somewhat Important		Very Important
1	2	3	4	5

8) How valuable did you find participating in psychology research studies in furthering your education?

Not Valuable		Somewhat Valuable		Very Valuable
1	2	3	4	5

9) How serious would it be if your privacy was violated as a result of participation in a research study?

Not Very Serious		Somewhat Serious		Very Serious
1	2	3	4	5

10) How risky, in your opinion, are studies in which genetic samples are taken?

Not Risky		Somewhat Risky		Very Risky
1	2	3	4	5

APPENDIX M – RESEARCH ATTITUDES WRITING TASK

Please thoughtfully answer the following question in a few short sentences:

What do you think are the advantages and risks associated with scientific research on genetics?

_____

_____

_____

_____

_____

APPENDIX N – SONA POSTING FORM

STUDY POSTING FORM

PRINCIPAL INVESTIGATOR (*Faculty Supervisor*): Norman Scott

RESEARCHERS: Zachary Batchelder

STUDY NAME & NUMBER: Undergraduate Perceptions of Genetic Research

BRIEF ABSTRACT:

This study is looking to gather psychology student views on behavioral genetics research projects that are currently pending approval. Online survey, maximum 50 minutes, 1 research credit for participation.

STUDY DESCRIPTION (*Must be exactly as approved by IRB*):

The purpose of this anonymous online study is to examine undergraduate students' perceptions of planned behavioral genetics studies at Iowa State University. You are being invited to participate in this study because you are an undergraduate student (age 18+) enrolled in a qualifying course.

If you agree to participate in this study, your participation will last for approximately fifty minutes. During the study, you may expect the following study procedures to be followed: You will be asked to complete an online survey about your perceptions of research projects that are pending approval. While we would like you to complete all the items, during your participation, you may skip any question that you do not wish to answer or that makes you feel uncomfortable.

ELIGIBILITY REQUIREMENTS:

DURATION (*Minimum 50min.): 50 minutes*

CREDITS: 1 credit

PREPARATION:

IRB APPROVAL CODE:

IRB APPROVAL EXPIRATION:

IS THIS AN ONLINE STUDY? Yes

APPENDIX O – WEB-BASED INFORMED CONSENT DOCUMENT

INFORMED CONSENT DOCUMENT

Title of Study: **Undergraduate Perceptions of Genetic Research**
Investigators: **Zachary R Batchelder, B.S.**
Norman Scott, Ph.D.

This anonymous online research study that will take less than 50 minutes to complete. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time. You must be 18 years old to participate in this study. As indicated in your psychology course syllabus, participation in research studies is one option for earning experimental credit.

INTRODUCTION

The purpose of this study is to examine undergraduate students' perceptions of proposed behavioral genetics studies at Iowa State University. You are being invited to participate in this study because you are an undergraduate student (age 18+) enrolled in a qualifying course.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last for approximately fifty minutes. During the study, you may expect the following study procedures to be followed: You will be asked to complete an online survey about your perceptions of research projects that are being planned. While we would like you to complete all the items, during your participation, you may skip any question that you do not wish to answer or that makes you feel uncomfortable.

RISKS

While participating in this study, you may experience the following risks: some mild personal discomfort when you respond to personal questions about yourself or your perceptions of research studies. Most often, however, students do not find these questions to be too personal or too difficult.

BENEFITS

If you decide to participate in this study there will be no direct benefit to you. It is hoped that the information gained in this study will benefit society by providing valuable information about how undergraduate students perceive and react to behavioral genetics research.

COSTS AND COMPENSATION

You will not have any costs from participating in this study. You will be compensated for participating in this study (approx. 50 minutes) with one research credit toward your ComSt 101, Psych 101, Psych 230, or Psych 280 class(es) consistent with the Psychology Department guidelines.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

CONFIDENTIALITY

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies, auditing departments of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information. To ensure confidentiality to the extent permitted by law, the following measures will be taken: All data will be collected anonymously. An arbitrarily assigned numeric code will be used on all forms instead of name. Data files will be kept for no longer than five years and will be destroyed at the end of this period. Electronic data will be stored on the investigators' computers in password protected computer files accessible only by the investigators. If the results are published, only aggregate group data, not individual responses, will be reported. Your anonymity will be assured.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study. For further information about the study contact Zachary Batchelder: zacharyb@iastate.edu or Norman Scott: nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office of Responsible Research, Iowa State University, Ames, Iowa 50011.

****

PARTICIPANT SIGNATURE

Your digital confirmation, by responding yes or no to the following question, indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. Please print a copy of this informed consent document for you records.

Do you wish to participate in this study after you have having read this form and understood what is being asked?

1-Yes
2-No

APPENDIX P – DEMOGRAPHICS QUESTIONNAIRE

Please answer the following questions:

1) What is your age?

a) 18-20

b) 21-22

c) 23-24

d) 25-26

e) 27 or older

2) What is your school classification?

a) Freshman

b) Sophomore

c) Junior

d) Senior

e) Graduate or Other

3) What is your major?

a) *open response*

4) What is your primary race/ethnicity?

a) Caucasian / European American

b) Black / African American

c) Hispanic / Latino/a

d) Hawaiian / Pacific Islander

e) Asian / Asian American

f) American Indian / Native Alaskan

g) Multiracial

h) Other

APPENDIX Q – DEBRIEFING STATEMENT

Thank you for your participation. I want to reassure you that all your responses are confidential and will be combined with the responses of other participants to protect your identity. Before exiting this survey, we would like to tell you more about the research project. We ask that you not share the information with others who might participate in our study in the future. If a participant knew the study's purpose before participating, their data would be invalid and our findings would be invalid as a result.

The true purpose of this study was not to examine students' views of potential genetic studies but rather to examine students' concern about their genetic privacy and the influence of money on the decision to participate in research that includes a risk to genetic privacy. In order to accurately evaluate students' level of concern, it was necessary to disguise the true purpose of the study. Each of the studies presented during this survey were purposefully designed studies created by the researchers to vary only on how great the risk to participants' genetic privacy was and how much money would be given to participants.

The findings of this research have the potential to provide important insights into the influence of money on perception of risk, which, in turn, may suggest strategies and interventions that could benefit society at large. We did not tell you this information before because knowing the true purpose of the study could lead participants to consciously or unconsciously alter their responses. If that were to occur, the integrity of the research findings would be compromised. Again, for the integrity of this study, we ask that you not discuss these elements with other students.

If you do not want your response data to be used in our research, you may request that it be destroyed by emailing the primary investigator at (zacharyb@iastate.edu). However, due to the anonymous nature of your responses, you must make this request immediately following the debriefing so that your completion time can be associated with the otherwise anonymous data.

APPENDIX R – INFORMATIONAL PAMPHLET

Basic Elements of Informed Consent Documents

Purpose – Why is this research being conducted?

Description of Procedures – What will I be asked to do? How long will I be expected to participate?

Risks – What are potential negative consequences from participation?

Benefits – What are the desired outcomes I can expect?

Confidentiality – How will my information be protected?

Costs & Compensation – What costs will I incur? Will I be paid for participation?

Participant Rights – What are my rights as a participant?

Contact Information – Whom do I call if I have questions or problems?

The Signature – Your signature represents a commitment to participate in the study.

No consent document may include language that asks you to waive your legal rights, or that appears to release the investigators from liability for negligence.

Genetic Information Nondiscrimination Act (GINA)

This federal law protects Americans from discrimination due to differences in DNA that may affect health. It prohibits misuse by health insurers and employers.

GINA allows people to get genetic testing for which they previously feared would be used against them by insurers or employers.

Bill of Rights for Research Participants

You have the right to information on:

Why the research study is being done

What will happen during the research study

Whether any study procedures, drugs, or devices are different from standard care

The risks, side effects, and discomforts

The benefits from taking part in the study

Other treatment choices and their risks and benefits

Treatment in case of complications

You also have the right to:

Decide to participate or not participate without penalty and under no pressure

Ask questions at any time

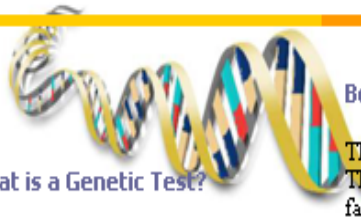
Receive a copy of the consent form

Understanding Genetic Research

Protecting your Privacy & Rights as a Research Participant

This pamphlet provides basic information regarding genetic testing, privacy protections, and informed consent.
It is important to read and understand any documents prior to consenting to participate in research or medical trials.

APPENDIX R (Cont.) – INFORMATIONAL PAMPHLET



What is a Genetic Test?

A genetic test is any analysis used to look at a person's genetic makeup. The test may examine DNA (deoxyribonucleic acid), RNA (ribonucleic acid), proteins, or other chemicals in cells that can indicate a genetic condition. This is usually done through blood, tissue, or cheek cell samples.

Genetic tests can be used to confirm a diagnosis, predict developing a disease in the future, or used for carrier screening to find out if a person has specific genes that increase the chance of a disease or birth defect occurring in his or her children.

DNA (Deoxyribonucleic Acid): A large molecule that carries all of the genetic information needed to operate a cell, make tissues, and control organ systems.

DNA Banking: The process of preserving and saving a person's DNA sample for future testing.

Benefits

There are several benefits of genetic testing. The knowledge can empower a person and family members to make important life planning decisions. Knowing about a certain disease gene might also provide important health information for a person's family. A person found to have an increased risk of a disease might want to choose preventive or therapeutic treatments.

Risks

Physical risks are usually minimal, typically not more than providing a blood sample. The greatest concern pertains to the way a genetic test result might change a person's life. The decision to have genetic testing can be stressful. You may have emotional reactions to learning you have a gene for a certain condition.

Sometimes a positive test result can affect family relationships. A person who decides to have genetic testing needs to consider whether to tell other family members. Furthermore, a genetic test may reveal unexpected relationships, such as nonpaternity (a different biological father).

FOR MORE INFORMATION ON GENETIC TESTING & GENETIC PRIVACY PROTECTION VISIT:

www.genome.gov

Other Concerns

What will happen to my sample after the genetic test is completed?

Some laboratories keep leftover samples for scientific or medical research. Some samples are submitted to DNA Banks or Repositories, where the sample may be available to you in the future. Most often, these repositories are used by researchers.

Because your genetic material contains a lot of information about you, it is important to know who will have access to this information and in what way your identifiable information can be used. A consent document should fully describe these details. If your questions are unanswered by the consent form or researchers. you

Researchers are required to provide you with important information about the study, assess your understanding of the information, and remind you that your participation is always voluntary. You should never sign a consent form without reading it and asking questions you have about your participation, privacy, and safety.

APPENDIX S – FULL VIGNETTES FOR ALL CONDITIONS

Instructions:

Your opinions and reactions as a Psychology student provide a unique perspective that is essential to a complete understanding of student perceptions of upcoming research. The following studies are currently being planned to potentially begin data collection in the Fall 2012 semester. As part of the review procedure it is vital that the input of students be considered in addition to experts in the relevant fields, as students will make up the majority of the individuals being sampled in these studies. Please read the overview of each study carefully and completely, as some of the language used may be similar but important details may vary. After reading the description each study please take a moment to fully and honestly complete the brief attached questionnaire. Thank you in advance for your participation. By completing this study you will be giving reviewers important insight into the opinions of students who may potentially participate in these studies.

Study Title: *[Low Risk x $0]* Genetic Variation in Genome CD4 and Subjective Well-Being

Description: This study will be investigating how variations in the P36 Genome potentially affect measures of subjective well-being. Participation in this study is completely voluntary and those who choose to participate may withdraw at any time with no penalty. The study should take approximately 50 minutes to complete. Participants in this study will be asked to complete a brief well-being questionnaire, after which they will contribute a genetic sample by means of buccal (cheek) swabbing. After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be stripped of identifiers, leaving no name or code linking the sample to the participant, before being entered

into a secure encrypted and password protected electronic file database accessible only by the research team and will be destroyed after two years. Researchers will then use this data in conjunction with the self-report questionnaire in hopes of determining if there is a genetic link between subjective well-being and the P36 Genome. As benefits, participants will receive no money for their genetic contribution, but will gain firsthand knowledge of how genetic research is conducted. Potential risks during the study include a minor swelling reaction to the buccal swab and potential psychological discomfort from the presented questionnaires.

Questions or information requests regarding this study should be directed to the experimenters in charge of the review study, Zachary Batchelder at zacharyb@iastate.edu or Norman Scott at nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB administrator, (515) 294-4566, irb@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

Please rate your responses to the following questions about this study using the scoring system provided:

1. After reading the description, how willing would you be to participate in this study?

Not At All Willing					Very Willing
1	2	3	4	5	6

2. How likely would students who are similar to you be to participate in this study?

Not At All Likely					Very Likely
1	2	3	4	5	6

3. How concerned are you regarding the loss of the privacy of your personal information in this study?

Not At All Concerned					Very Concerned
1	2	3	4	5	6

4. How much risk to your privacy do you feel it is to have your DNA sample put in the database being used for this study?

Not At All Risky					Very Risky
1	2	3	4	5	6

Instructions:

Your opinions and reactions as a Psychology student provide a unique perspective that is essential to a complete understanding of student perceptions of upcoming research. The following studies are currently being planned to potentially begin data collection in the Fall 2012 semester. As part of the review procedure it is vital that the input of students be considered in addition to experts in the relevant fields, as students will make up the majority of the individuals being sampled in these studies. Please read the overview of each study carefully and completely, as some of the language used may be similar but important details may vary. After reading the description each study please take a moment to fully and honestly complete the brief attached questionnaire. Thank you in advance for your participation. By completing this study you will be giving reviewers important insight into the opinions of students who may potentially participate in these studies.

Study Title: *[Low Risk x $100]* Role of the IL2 Gene in Self-Esteem

Description: This study will be investigating whether the IL2 gene has an increased prevalence in individuals with higher self-esteem. Participation in this study is completely voluntary and those who choose to participate may withdraw at any time with no penalty. The study should take approximately 50 minutes to complete. Participants in this study will be asked to complete a brief self-esteem questionnaire, after which they will contribute a genetic sample by means of buccal (cheek) swabbing. After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be stripped of identifiers, leaving no name or code linking the sample to the participant, before being entered into a secure encrypted and password protected electronic file database accessible only by the

research team and will be destroyed after two years. Researchers will then use this data in conjunction with the self-report questionnaire in hopes of determining if there is a genetic link between subjective well-being and the P36 Genome. As benefits, participants will receive $100 for their genetic contribution, and will gain firsthand knowledge of how genetic research is conducted. Potential risks during the study include a minor swelling reaction to the buccal swab and potential psychological discomfort from the presented questionnaires.

Questions or information requests regarding this study should be directed to the experimenters in charge of the review study, Zachary Batchelder at zacharyb@iastate.edu or Norman Scott at nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB administrator, (515) 294-4566, irb@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

Please rate your responses to the following questions about this study using the scoring system provided:

1. After reading the description, how willing would you be to participate in this study?

Not At All Willing					Very Willing
1	2	3	4	5	6

2. How likely would students who are similar to you be to participate in this study?

Not At All Likely					Very Likely
1	2	3	4	5	6

3. How concerned are you regarding the loss of the privacy of your personal information in this study?

Not At All Concerned					Very Concerned
1	2	3	4	5	6

4. How much risk to your privacy do you feel it is to have your DNA sample put in the database being used for this study?

Not At All Risky					Very Risky
1	2	3	4	5	6

Instructions:

Your opinions and reactions as a Psychology student provide a unique perspective that is essential to a complete understanding of student perceptions of upcoming research. The following studies are currently being planned to potentially begin data collection in the Fall 2012 semester. As part of the review procedure it is vital that the input of students be considered in addition to experts in the relevant fields, as students will make up the majority of the individuals being sampled in these studies. Please read the overview of each study carefully and completely, as some of the language used may be similar but important details may vary. After reading the description each study please take a moment to fully and honestly complete the brief attached questionnaire. Thank you in advance for your participation. By completing this study you will be giving reviewers important insight into the opinions of students who may potentially participate in these studies.

Study Title: *[High Risk x $0]* Effects of MCM6 on Exercise Habits

Description: This study will be investigating how the presence or absence of gene MCM6 affects exercise habits. Participation in this study is completely voluntary and those who choose to participate may withdraw at any time with no penalty. The study should take approximately 50 minutes to complete. Participants in this study will be asked to complete a brief exercise habits questionnaire, after which they will contribute a genetic sample by means of buccal (cheek) swabbing. After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be submitted and stored indefinitely with the participant's unique personal code, linking the individual to the sample, into a national repository of genetic data that is accessible to other researchers, law enforcement

agencies (including but not limited to local, state and federal law enforcement agencies), medical practitioners and medical, dental and life insurance companies. As a result, if your genetic data shows a predisposition for serious health conditions, you may be unable to receive health insurance in the future. Researchers will then use this data in conjunction with the self-report questionnaire in hopes of determining if there is a genetic link between subjective well-being and the P36 Genome. As benefits, participants will receive no money for their genetic contribution, but will gain firsthand knowledge of how genetic research is conducted. Potential risks during the study include a minor swelling reaction to the buccal swab and potential psychological discomfort from the presented questionnaires.

Questions or information requests regarding this study should be directed to the experimenters in charge of the review study, Zachary Batchelder at zacharyb@iastate.edu or Norman Scott at nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB administrator, (515) 294-4566, irb@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

3) What are the risks associated with this study?

_____

Please rate your responses to the following questions about this study using the scoring system provided:

1. After reading the description, how willing would you be to participate in this study?

Not At All Willing					Very Willing
1	2	3	4	5	6

2. How likely would students who are similar to you be to participate in this study?

Not At All Likely					Very Likely
1	2	3	4	5	6

3. How concerned are you regarding the loss of the privacy of your personal information in this study?

Not At All Concerned					Very Concerned
1	2	3	4	5	6

4. How much risk to your privacy do you feel it is to have your DNA sample put in the database being used for this study?

Not At All Risky					Very Risky
1	2	3	4	5	6

Instructions:

Your opinions and reactions as a Psychology student provide a unique perspective that is essential to a complete understanding of student perceptions of upcoming research. The following studies are currently being planned to potentially begin data collection in the Fall 2012 semester. As part of the review procedure it is vital that the input of students be considered in addition to experts in the relevant fields, as students will make up the majority of the individuals being sampled in these studies. Please read the overview of each study carefully and completely, as some of the language used may be similar but important details may vary. After reading the description each study please take a moment to fully and honestly complete the brief attached questionnaire. Thank you in advance for your participation. By completing this study you will be giving reviewers important insight into the opinions of students who may potentially participate in these studies.

Study Title: *[High Risk x $100]* CCR5's Correlation to Openness to New Experience

Description: This study will be investigating how presence or absence of the CCR5 gene correlates with participants' openness to new experiences. Participation in this study is completely voluntary and those who choose to participate may withdraw at any time with no penalty. The study should take approximately 50 minutes to complete. Participants in this study will be asked to complete a brief personality traits questionnaire, after which they will contribute a genetic sample by means of buccal (cheek) swabbing. After researchers have analyzed and digitally coded the genetic sample using the HiSeq 2000 genome sequencing machine, the coded data will be submitted and stored indefinitely with the participant's unique personal code, linking the individual to the sample, into a national repository of genetic data that is accessible to other

researchers, law enforcement agencies (including but not limited to local, state and federal law enforcement agencies), medical practitioners and medical, dental and life insurance companies. As a result, if your genetic data shows a predisposition for serious health conditions, you may be unable to receive health insurance in the future. Researchers will then use this data in conjunction with the self-report questionnaire in hopes of determining if there is a genetic link between subjective well-being and the P36 Genome. As benefits, participants will receive $100 for their genetic contribution, and will gain firsthand knowledge of how genetic research is conducted. Potential risks during the study include a minor swelling reaction to the buccal swab and potential psychological discomfort from the presented questionnaires.

Questions or information requests regarding this study should be directed to the experimenters in charge of the review study, Zachary Batchelder at zacharyb@iastate.edu or Norman Scott at nascott@iastate.edu. If you have any questions about the rights of research subjects or research-related injury, please contact the IRB administrator, (515) 294-4566, irb@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

Please answer the following questions regarding this study to the best of your ability:

1) How much would you be paid to participate in this study?

_____

2) Will your information be shared with people other than the researchers?

_____

Please rate your responses to the following questions about this study using the scoring system provided:

1. After reading the description, how willing would you be to participate in this study?

Not At All Willing					Very Willing
1	2	3	4	5	6

2. How likely would students who are similar to you be to participate in this study?

Not At All Likely					Very Likely
1	2	3	4	5	6

3. How concerned are you regarding the loss of the privacy of your personal information in this study?

Not At All Concerned					Very Concerned
1	2	3	4	5	6

4. How much risk to your privacy do you feel it is to have your DNA sample put in the database being used for this study?

Not At All Risky					Very Risky
1	2	3	4	5	6

APPENDIX T – TEST FOR HOMOGENEITY OF VARIANCES

Item	Levene Statistic	df1	df2	Sig.
WTP1xLow	1.285	1	161	.259
WTP2xLow	2.496	1	162	.116
RiskP1xLow	.293	1	162	.589
RiskP2xLow	.358	1	163	.550
WTP1xHigh	1.116	1	162	.292
WTP2xHigh	1.943	1	163	.165
RiskP1xHigh	.346	1	163	.557
RiskP2xHigh	.847	1	163	.359

APPENDIX U – TEST FOR NORMALITY

Group		Statistic	df	Sig.
WTP1: How willing would you be to participate? (Low Risk)	$0 Condition	.903	77	.001
	$100 Condition	.898	83	.001
WTP2: How likely would students who are similar to you be to participate? (Low Risk)	$0 Condition	.923	77	.001
	$100 Condition	.906	83	.001
WTP1: How willing would you be to participate? (High Risk)	$0 Condition	.861	77	.001
	$100 Condition	.908	83	.001
WTP2: How likely would students who are similar to you be to participate? (High Risk)	$0 Condition	.889	77	.001
	$100 Condition	.924	83	.001

Group		Statistic	df	Sig.
RiskPerc1: How concerned are you regarding the loss of the privacy of your personal information? (Low Risk)	$0 Condition	.875	77	.001
	$100 Condition	.914	83	.001
RiskPerc2: How risky is it to have your DNA sample put in the database? (Low Risk)	$0 Condition	.863	77	.001
	$100 Condition	.917	83	.001
RiskPerc1: How concerned are you regarding the loss of the privacy of your personal information? (High Risk)	$0 Condition	.858	77	.001
	$100 Condition	.885	83	.001
RiskPerc2: How risky is it to have your DNA sample put in the database? (High Risk)	$0 Condition	.892	77	.001
	$100 Condition	.903	83	.001

APPENDIX V – CORRELATIONS OF DEPENDENT VARIABLES

	WTP1 (Low Risk)	WTP2 (Low Risk)	RiskPerc1 (Low Risk)	RiskPerc2 (Low Risk)	WTP1 (High Risk)	WTP2 (High Risk)	RiskPerc1 (High Risk)	RiskPerc2 (High Risk)
WTP1 (Low Risk)								
WTP2 (Low Risk)	**.814****							
RiskPerc1 (Low Risk)	**-.364****	**-.226****						
RiskPerc2 (Low Risk)	**-.334****	**-.229****	**.774****					
WTP1 (High Risk)	**.212****	**.268****	.087	.028				
WTP2 (High Risk)	.127	**.285****	.144	.111	**.900****			
RiskPerc1 (High Risk)	-.009	-.005	**.279****	**.247****	**-.643****	**-.569****		
RiskPerc2 (High Risk)	-.018	-.017	**.165***	**.278****	**-.655****	**-.609****	**.779****	

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

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

APPENDIX W – DEPENDENT VARIABLE AND NEO CORRELATIONS

Item		NEOOpen	NEOCons	NEOExtrav	NEOAgre	NEONeur
WTP1: How willing would you be to participate? (Low Risk)	Pearson Correlation	.039	-.034	.025	.097	-.152
	Sig.	.633	.679	.757	.250	.066
WTP2: How likely would students who are similar to you be to participate? (Low Risk)	Pearson Correlation	.108	-.003	.043	.096	-.085
	Sig.	.191	.974	.599	.255	.309
RiskPerc1: How concerned are you regarding the loss of the privacy of your personal information? (Low Risk)	Pearson Correlation	-.004	.140	**.161***	.101	**.175***
	Sig.	.966	.085	**.046**	.229	**.033**
RiskPerc2: How risky is it to have your DNA sample put in the database? (Low Risk)	Pearson Correlation	.021	.092	.135	.071	.103
	Sig.	.794	.259	.096	.396	.211
WTP1: How willing would you be to participate? (High Risk)	Pearson Correlation	**.219****	.121	**.216****	**.173***	.075
	Sig	**.007**	.139	**.007**	**.039**	.364
WTP2: How likely would students who are similar to you be to participate? (High Risk)	Pearson Correlation	**.179***	**.161***	**.199***	**.179***	.090
	Sig.	**.029**	**.047**	**.013**	**.032**	.277
RiskPerc1: How concerned are you regarding the loss of the privacy of your personal information? (High Risk)	Pearson Correlation	-.100	-.005	-.029	-.020	.048
	Sig.	.223	.951	.718	.814	.561
RiskPerc2: How risky is it to have your DNA sample put in the database? (High Risk)	Pearson Correlation	-.104	-.031	-.088	-.005	.056
	Sig.	.203	.709	.275	.955	.497

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

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