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Informed consent to genetic research: Student participation and perception of risk

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Informed consent to genetic research: Student participation and perception of risk

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ABSTRACT

This experimental deception study explored how undergraduate online research participants from a large Midwestern university (n = 182) perceived, comprehended, and acted upon consent documents involving potential loss of genetic privacy. Risk perception, willingness to participate, and consent behavior were measured across manipulations of four randomly assigned experimental consent documents composed of two levels of privacy risk (identifiable or anonymous genetic storage) and two monetary compensation values ($10 or $100). Poor comprehension of the consent information was observed. When risk level was comprehended, identifiable genetic storage was associated with lower participation. Monetary compensation of $100 did not alter willingness to participate or consent behavior, but it significantly decreased risk perceptions, suggesting participants may be susceptible to undue influence.

CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW

Introduction

The use of genetic analysis and data banking in psychological research has increased with improvements in our understanding of its influence in personality and behavior. As with most psychological research, undergraduate student-participants account the majority university based research samples, although questions remain about students' ability to assess risk and objectively evaluate information provided in an informed consent document. The purpose of this study was to investigate the impact of risk to privacy and monetary compensation, presented in an informed consent document, on undergraduate research participants' willingness to participate in genetic sampling research. Additionally, this study explored how payment influences participants' potential behaviors and perception of risk. The primary research question aimed to determine to what degree students were concerned about guarding their genetic privacy, and to what extent these concerns were mitigated by monetary compensation.

Through the use of a 2 (level of risk) by 2 (level of monetary payment), between subjects, completely randomized factorial design, 182 student volunteers, enrolled in undergraduate psychology courses, participated in this study. Participants responded to a questionnaire packet including demographic items and several measures examining social desirability, sensation seeking, and several personality factors. At the end of the questionnaire packet, students were offered, in writing, a chance to participate in an additional study by means of an informed consent document. The second study informed potential participants that they would be asked to provide a genetic sample that would be entered into a genetic repository (GENBEH Repository). In contrast to the realistic

presentations, the second informed consent forms were experimental manipulations of the cross between level of risk to privacy and monetary compensation, resulting in four treatment conditions/informed consent documents. These manipulations were used to evaluate differences in participation, willingness to participate, and the perception of risk among students. While the second study included a consent form, stating there would be a future collection of a buccal/DNA swab, no genetic collection, analysis, or data banking actually occurred in this study. The true purpose of the mock informed consent forms were to serve as a deceptive element allowing the collection of a behavioral measure of participants' willingness to provide a genetic sample.

In this investigation, there was random assignment of four treatment conditions, delivered through the information provided in the informed consent form. Each version of the informed consent was identical except for variations in level of risk to privacy and monetary compensation. There were two levels of risk to privacy. Participants were either told their sample would be entered into an anonymous repository (low risk), or told their sample would be entered into an identifiable repository (high risk) at the conclusion of the research. The experimental informed consent also included a statement regarding monetary compensation for samples selected for analysis. Two levels of monetary compensation, $10 or $100, were crossed with level of risk to privacy to make up the four treatment conditions. Figure 1 shows the four treatment conditions and corresponding questionnaire packet forms. The four treatment conditions included Anonymous-$10 (low-low), Anonymous-$100 (low-high), Identifiable-$10 (high-low), and Identifiable-$100 (high-high).

Figure 1
Treatment Conditions and Corresponding Informed Consent Forms

			PRIVACY RISK: Low — Anonymous	PRIVACY RISK: High — Identifiable
MONETARY COMPENSATION	Low	$10	(Low-Low) Form 11	(High-Low) Form 51
	High	$100	(Low-High) Form 15	(High-High) Form 55

Because the second study utilized deceptive elements, no genetic analysis was performed, and therefore, no compensations were made beyond the credit promised for participation in the original study. A full debriefing, including a description of the deception, its purpose, and information regarding how students can protect their genetic privacy was provided following data collection.

Unlike the majority of studies examining informed consent that utilized participants' responses to hypothetical studies, the behavioral methodology and data collected in this study permitted drawing conclusions beyond theoretical assumptions. In providing this information, one goal of this study was to provide empirical data on how and why students decide to participate in research involving privacy risk. A potential benefit of this line of research includes the potential to inform policymaking of research regulatory bodies, such as institutional review boards, regarding the use of monetary compensation with undergraduate students involved in genetic research.

Literature Review

Respect for the individual and valuing of autonomous decision-making are the moral and ethical cores underpinning informed consent (Greenwald, Ryan, & Mulvihill, 1982). This written, and often oral, process provides important information that aids potential participants in their decision to participate in a research study. By providing adequate and comprehensible information, an informed consent enables independent decision-making and may minimize participant harm. Basic ethical principles such as beneficence, nonmaleficence, fidelity, integrity, justice, and respect for persons help guide our understanding of informed consent; however, the practical application of such a process is rarely as simple or easy as theory might suggest (Corrigan, 2003).

While appreciation for protecting the rights of research participants is not new, the concept of an ethical and legal obligation to acquire a full informed consent for research participation is a more contemporary concern. Since the latter half of the 20th century, informed consent has received increasing attention. The study of comprehension of informed consent forms has been heavily researched. Yet, as technology, science, and medicine advance, our understanding of informed consent has also changed. In moving towards a "genetic age," new and unforeseen issues regarding the rights and welfare of individuals in behavioral genetic research will continue to develop, and with these changes, so shall the informed consent process.

Our current *theoretical* understanding of informed consent is widely accepted as an essential component to conducting ethical research (Berg, Appelbaum, Lidz, & Parker, 2001; Burns & Grove, 2001); however, empirical research using *behavioral* measures of research participation is still scarce (Lansimies-Antikainen et al., 2007). These studies, while

important to the body of literature, have been limited in there conclusions and generalizations as a result of issues regarding the study designs.

Researching informed consent, particularly for medical research, can be a complex and difficult task (Corrigan, 2003). Factors including level of risk and monetary compensation have the potential to influence willingness to participate in research, risk perception, comprehension, and other aspects of acquiring a fully informed consent. Among scholars and human rights advocates, there is great concern that the current informed consent procedures are insufficient given the development of new technologies, such as genetic repositories (Haddow, Laurie, Cunningham-Burley, & Hunter, 2007).

The following review of the literature traces the steps toward our current understanding of informed consent. This examination of the available research has also focused on some of the difficulties encountered when researching informed consent, as well as recent findings regarding the influences on willingness to participate, particularly payment of participants and risk perception. The latter half of this review focuses on how the concern for privacy is becoming an emerging area of interest regarding genetic research. The concluding section will describe the intended contributions of this study.

Development of the Basic Biomedical Ethical Principles

Modern biomedical ethical principles provide guidelines for physicians and researchers who engage in treatment or research with patients/clients. These principles are not novel concepts; rather, they are the result of a long history of progress toward respecting the rights and human dignity of individuals. Many of the historical developments in the creation of these ethical principles have been the result of medical atrocities performed on

vulnerable individuals such as those held in concentration camps by the Nazis during World War II.

From times as early as ancient Greece and Rome, philosophers, scholars, and researchers have debated the theoretical aspects of the ethical treatment of humans. These ancient philosophers spurred insight on ethical decision-making through works such as the Hippocratic Oath. The British doctor Thomas Percival (1740-1804) is believed to have coined the term "medical ethics" and wrote on medical jurisprudence, that is, the theory and philosophy of law as it applies to the medical practice. In the modern era, developments in the understanding of biomedical ethical principles have transferred theoretical concepts to legal and ethical guidelines and obligations. Influential ethics documents of the last century, starting in this review with the Nuremberg Code, have guided what are now considered the basic biomedical ethical principles of respect for persons, beneficence, and justice.

Although a great deal of content has been added in the modern era, and our understanding of informed consent has been increased, the elemental concepts regarding human rights have remained mostly unchanged since early ancient works. Contributions such as the Declaration of Helsinki (1964, most recent revision in 2008) and the Belmont Report (1979) have greatly improved the understanding and clarification to these basic concepts. The fruits of these efforts have been widespread and have included the development of professional association codes of ethics, the informed consent document, and institutional review boards.

Nuremberg Code

During World War II, many individuals detained in concentration camps by the Axis forces in Germany were subjected to research abuses by Nazi doctors undertaking medical

and behavioral research (Shirer, 1960). These prisoners were subjected to horrific physical and mental hazards (e.g., extreme cold, anoxia, amputation, chemical exposure), were provided no medical treatment, and allowed no escape from these tortures often resulting in death. After Germany's surrender, a total of twelve judicial trials, followed by the Nuremberg Military Tribunals, took place to try those responsible. The first of these trials, known as "The Doctor's Trial" (officially, *United States v. Karl Brandt et al.*) was held to try those who had conducted human experimentation abuses.

In 1947, 23 defendants (including 20 physicians) were tried in Nuremberg, Germany, on the following charges: War crimes and crimes against humanity, performing medical experiments without subjects' consent and on prisoners of war and civilians of occupied countries, and participation in the mass murder of concentration camp inmates ("The Medical Case," 1949, *p*. 173). Fifteen of the 23 defendants were eventually found guilty, seven of which were sentenced to death. As a result of these trials, a memorandum detailing permissible medical research was drafted by the Allied nations. The resulting document, based largely on an examination of these crimes, called the Nuremberg Code, became the first internationally recognized code of research ethics and a prototype for later ethics codes (McCormick, 2005).

Considered the modern foundation of informed consent procedures (Greenwald et al., 1982), the Nuremberg Code contains 10 principles, the most paramount being the right of an individual to make an autonomous decision with regard to his/her participation. This first principle reads, "The voluntary consent of the human subject is absolutely essential" ("The Nuremberg Code," 1949, *p*. 181). Among the remaining principles, the need for competence, comprehension, and full information disclosure were outlined. Initially, many believed the

code was not relevant to research conducted outside of Nazi Germany; however, when a more general statement was issued a year later in the Universal Declaration of Human Rights, the right of all individuals to freely consent or decline research participation was made clear (Corrigan, 2003; Katz, 1987).

Declaration of Helsinki

Despite the contributions of the Nuremberg Code, the proposals appeared insufficient to tackle complex situations. They were often inapplicable, difficult to apply, and at times conflicted with each other. In 1964, the World Medical Association (WMA), comprised of 100 delegates from 32 national medical associations, met in Helsinki, Finland, to draft more comprehensive human research guidelines and distinguish between therapeutic and non-therapeutic research (Corrigan, 2003). The Declaration of Helsinki, now in its sixth revision (2008), reiterated the principles identified by the Nuremberg Code, further expressing the need for potential participants 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). However, understanding the complexities of research, the declaration relaxed the requirement that consent is "absolutely necessary," moving toward an understanding of exceptions to informed consent, the most obvious being the potential need to withhold potentially biasing information related to a study (e.g., placebo trials, disguising the purpose of a study).

Several additional contributions from the Declaration of Helsinki greatly improved how research is conducted, reviewed, and disseminated. In an addition to the recommendations for information disclosure provided by the Nuremberg Code, the need to carefully assess risks in comparison to benefits was acknowledged. Unlike the previous

deontological principles, the relativistic consideration of the interaction between risks and benefits in the Declaration of Helsinki represented a significant step in determining ethical conduct and improving potential participants' ability to make truly informed decisions.

In terms of reviewing research, the declaration stipulated that experimental procedures should be clearly formulated and made available for consideration and comment by independent agents. While it did not directly identify the creation of a regulatory review (e.g., by an institutional review board), it laid ground for future development in this area.

One of the last principles identified was the recommendation to obtain informed consent in writing. This was a dramatic change from previous approaches to obtaining an individual's consent. However, while researchers and clinicians were advised to use a written consent form, the process of collecting documented consent was not routinely practiced until whistleblowers wrote of unethical experiments being conducted on impoverished and minority individuals without their knowledge or consent (Corrigan, 2003).

Belmont Report

As part of the National Research Act of 1974, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974) was created to reassess the basic ethical principles guiding biomedical and behavioral research and develop procedures to ensure adherence to the stated principles. Additionally, the commission was asked to consider the selection of human participants, how to best use risk-benefit assessments in determining the appropriateness of research, and circumstances in which the nature and definition of informed consent might vary.

After more than four years of work, the commission put forth The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979), a

document that provided needed elucidation regarding research ethics procedures, such as informed consent, and set down a means for oversight of researchers engaging in human subjects research. Unlike previous documents, the Belmont Report provided a more broad interpretation of ethical principles that allowed it to be used in various settings and under unique circumstances. While the commission had intended to provide only an analytical framework to judge ethical issues, its impact set precedence for the development of legal standards and professional codes of conduct.

Three basic ethical principles, respect for persons, beneficence, and justice, were identified in the Belmont Report, and in tandem to these principles, applications were described. The principle of respect for persons provided a basis for an improved concept of informed consent, while risk and benefit assessment and selection of subjects found grounding in the principles of beneficence and justice, respectively. Delineation of the assumptions of these principles is followed by a description of their application in research.

Respect for persons. Respect for persons requires individuals to be treated as autonomous agents, with protective provisions for those with diminished autonomy. Respect for the autonomy of the individual requires permitting her to act in her own interest provided these interests are not clearly harmful to others. Under this principle, it is impermissible to impinge upon one's freedom to make considered judgments, or withhold information needed to make these judgments, without convincing reason. Not all individuals are capable of self-governance. Immaturity, illness, mental disability, or incarceration may potentially limit an individual's ability to make autonomous decisions. In such circumstances, it is necessary to take special considerations in respecting these individuals' rights and dignity.

Beneficence. Beneficence may be best defined with the dictum "do good and avoid evil." It connotes not only kind or merciful acts, but is supererogatory, that is an obligation to do more than has been asked. Similar to concepts like altruism, the focus of beneficence is the promotion of doing good for others. Also, while better defined by the concept of nonmaleficence (i.e., "do no harm"), in the context of biomedical ethics, beneficence includes the obligation to protect others from harm.

These different obligations are not always congruent; in fact, at times doing good and avoiding harm may be directly opposed. It is not always possible to avoid some harm when we wish to learn what is harmful, and when we seek to learn what is beneficial, at the same time we may be exposed to risk. It is this objective of maximizing potential benefits while minimizing possible harms that helps researchers decide what is justifiable.

This conflict of risk and benefit is exacerbated by expanding the assessment to the larger society. Is it ever permissible to put participants at greater than minimal risk when there is no immediate direct benefit to the individual but great benefit to the society? With few exceptions, there is no easy answer to this question, and ethicists routinely disagree about what constitutes a reasonable risk to benefit ratio. What is agreed is that researchers must give careful consideration to the intersection of doing good and avoiding harm.

Justice. Justice is a commonly evoked right in societal debate, but has often been overlooked in the realm of scientific research despite a long history of injustices. One major point in American medical history that epitomizes the need for justice in research is the Tuskegee syphilis study, a federally funded study that began in 1932 (Katz, 1987). Just fewer than 400 poor rural African-American men experienced horrific symptoms due to the withholding of known medical treatments for syphilis as part of a study aimed at cataloging

the course of the disease. The callousness involved in this experiment pushed the broader medical community to enact standards of practice and is partially responsible for the development of the Belmont Report.

In the context of biomedical ethics, justice is seen as a distributive rather than retributive concept. Justice as the proposition that there should be equitable distribution of the benefits and burdens associated with research is likely the most contested of the biomedical ethical principles. There are several philosophical points of view that have the potential to conflict regarding the best course of action in distributing the fruits of research. Who should receive the benefits of research? Who should carry its burdens? And, in the context of distributive justice, how are these benefits allocated: equally, based on need, effort, merit, or societal contribution?

This issue has most traditionally been associated with impoverished or minority groups subjected to research with which they will not have access to its rewards, although it also applies to healthy volunteers, especially students, as research participants. Are these groups selected because they are easily recruited, may be required by courses to participate, or are easily influenced by inducements? Additionally, do students receive a fair share of the benefits that are derived from research in which they have participated?

Without doubt, there are many questions regarding the application of this and other ethical principles. While it is unlikely that we will ever be able to fully answer these questions, left unanswered, there is always the potential for research misconduct. As a result of the Belmont Report, a greater appreciation for ethical standards fostered the development of professional codes of conduct and federal regulations. Additionally, it helped develop the concept of mandated review of research, implemented by Institutional Review Boards as a

means of tackling difficult ethical questions and ensuring the ethical conduct of researchers. The following sections draw attention to the establishment of the ethical principles guiding psychologists, the development of federal protections for human research participants, and the role of institutional review boards in making determinations of the value and utility of a study. This is followed by an application of the biomedical ethical principles, in the context of genetic research.

Impact on Psychological Research

Ethical Principles of Psychologists

With the growing attention to medical ethics, and new legislation requiring IRB approval of human subjects research, organizations such as the American Psychological Association (APA) have drafted codes of ethics to provide guidance and standards of professional conduct. Unlike federal regulations, the purpose of these ethics codes are not to assess civil liability, but to provide a more clear delineation of how general ethical principles apply to psychologists. In the American Psychological Association's *Ethical Principles of Psychologists and Code of Conduct* (2002), explication of five general principles is followed by a more specific set of ethical standards. The five basic ethical principles are Beneficence and Nonmaleficence, Fidelity and Responsibility, Integrity, Justice, and Respect for People's Rights and Dignity.

In addition to the three biomedical ethical principles described in the Belmont Report, the APA General Principles include two concepts relevant to the practice and science of psychology: fidelity and responsibility, and integrity. The principle of fidelity and responsibility states that psychologists work to establish and maintain trust in relationships and are aware of their professional and societal responsibilities. In research, this principle

suggests researchers should take into account the impact of their study on the wellbeing of individuals and the society at large. Additionally, psychologists are concerned with the ethical compliance of fellow researchers and practitioners.

The principle of integrity expands the principle of fidelity and responsibility in that it dictates that psychologists promote accuracy and honesty in their work, whether it is teaching, science, or practice. A unique aspect of this principle is that it bars the intentional misrepresentation of fact, while accepting the need for carefully considered deception in research. When deception is used in research, this principle requires psychologists to consider the impact of their deception and make efforts to rectify mistrust or other harm resulting from such actions. The APA ethics code also directly addresses deception in research (see Section 8.07). It states, "(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 nondeceptive alternative procedures are not feasible."

Section 8.07 also states that deception is not reasonable when the research is likely to cause physical pain or severe emotional distress. Most importantly, when deception is used, researchers fully disclose relevant aspects of the design and procedures as soon as possible, no later than the end of the study. During such a debriefing, participant confusion should be corrected by providing appropriate information regarding all aspects of the design and findings. Participants should have the opportunity to withdraw their data and researchers should be diligent in their effort to minimize harms experienced during the study (see Sections 8.07 & 8.08).

Federal Regulations Regarding Human Subjects & Genetic Research

A number of federal regulations and laws have been passed regarding both human subjects research and more recently the use of genetic information. Of these regulations, the most relevant to the present study include federal regulations for the Protection of Human Subjects ("Protection of Human Subjects," 2001), the Health Insurance Portability and Accountability Act (HIPAA): Security and Privacy Regulations (1996), and a number of genetic privacy acts, most recently the Genetic Information Nondiscrimination Act of 2008. The following section provides a brief overview of the development of the United State's current protection of genetic privacy.

In 1992, in an effort to protect the basic rights of research participants, the Department of Health and Human Services (DHHS) laid out an unambiguous set of regulations regarding the approval of research by review boards and the required information to be provided to potential research participants. Some of the criteria for IRB approval of research include the minimization of risk to subjects, particularly in relation to the anticipated benefits, the equitable selection of participants, the appropriate documentation of informed consent, and protection of privacy and confidentiality of data. As science progressed into the genetic age, regulations became outdated and it became clear that new legislation was needed to ensure the basic fundamental principles that protected individuals from harm.

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. Before this commissions report, there were no restrictions on the collection and ownership of genetic data. The Genetic Privacy Act of 1996 prohibited the unauthorized collection and analysis of identifiable genetic

information and addressed consent and privacy related to DNA samples and other genetic data (Annas, Glantz, & Roche, 1996). In sum, the act clearly stated the ownership of this information was under the direct control of the individual. It required consent be given to collect, store, and analyze genetic samples, and maintained the individual's right to autonomous decision-making regarding the dissemination of that sample (Annas et al., 1996).

Despite the Genetic Privacy Act's prohibition of these activities, it lacked the teeth to enforce these rules and institutions were slow to develop their own genetic privacy policies. Even privacy rules that followed, such as the Health Information Privacy Portability Act (HIPPA), lacked clear rules on genetic information, and many critics were concerned that, if misinterpreted, these rules would severely limit the ability of researchers to conduct research using banked genetic data.

Most recently, the Genetic Information Nondiscrimination Act (GINA) of 2008 was signed into law by former President George W. Bush. GINA prohibits the use of genetic information in employment and health insurance determinations. Health plans and insurers are barred from denying coverage to otherwise healthy individuals and may not base premiums on genetic predispositions. Similarly, employers are not allowed to use genetic information to hire, fire, place, or promote individuals. While GINA received broad support in both the House of Representatives and Senate, opponents argued that the bill was overly broad and did not provide protection from genetic discrimination in the cases of health insurance and long-term disability insurance.

It is important to note that GINA is not the first legislation regarding genetic privacy, and it will certainly not be the last. Legislation in this area is passed on almost a yearly basis and varies in level of impact on human subjects research, often focusing on medical

diagnosis and treatment to the exclusion of research. Despite a vast array of legislation regarding human research and genetic privacy protection, the ground level oversight of an institutional review board is still needed to prevent intentional or unintentional misuse of research participants and their genetic materials and information. The following sections describe the basic considerations of an institutional review board and explain how the basic biomedical ethical principles are applied during the assessment of proposed research.

Institutional Review Boards

Throughout the modern history of research, and despite vague rules regarding genetic information, the Institutional Review Board (IRB) has served to protect the rights and welfare of research participation (McCormick, 2005). Acclaimed as one of the greatest contributions of the Belmont Report, IRBs are responsible for reviewing all federally funded institutional research and research involving human participants (Jonsen, 1996). Traditionally, IRBs are housed in academic or medical settings; however, non-profit and "commercial" IRBs are no longer uncommon. Regardless of the setting, the objective of IRB review and continued oversight is not to debate research design, but rather to safeguard the rights and welfare of research participants (Cowan, 1980).

An IRB is most commonly composed of five or more professionals and at least one community member ("IRB Membership," 1991). The role of the community IRB member is to help researchers understand the community's values and attitudes, provide a voice for the larger community, and to assist in gauging the readability of consent documents (see http://www.hhs.gov/ohrp/irb/irb_guidebook.htm). As a whole, the group is ideally heterogeneous in gender, ethnicity, and discipline, with all members having adequate expertise to make objective decisions on the ethical, legal, and practical implications of

research protocols. When vulnerable populations are studied, such as prisoners, children, or mentally retarded individuals, a member familiar with the population should be present, although members may not vote on their own projects.

Among other tasks, IRBs are also responsible for reviewing two critical aspects of any research proposal, the process of informed consent and a determination of the balance of risk and benefit to participants and society. Promoting a fully informed and voluntary consent is essential to respecting the individual's right to self-determination, while the calculation of a risk-benefit ratio maximizes the safety of research participants.

Importance of Informed Consent (Respect for Persons)

According to Greenwald et al. (1982), the procedures of informed consent are so integral to IRB review of human research that the consent documents are often the primary focus. Grounded in the principle of respect for persons, informed consent is viewed as having three elements: information, voluntariness, and comprehension.

Information

While it is impractical to provide details on every aspect of a research study, there are clear guidelines as to what information should be provided to potential participants. The American Psychological Association (APA) regularly publishes Ethical Principles of Psychologists and Code of Conduct, which was last updated December 2002. These ethical standards apply to both practicing psychologists as well as psychological researchers, and closely mirror guidelines set out by Department of Health and Human Services ("Elements of informed consent," 1980).

According to the 2002 version of the APA code of ethics, an informed consent to research requires researchers to inform participants of no less than eight key elements of the

proposed study. Participants should be made aware of the basic details of the study such as the duration and procedures, as well as, whom to contact for questions about the research or participants' rights. It should be understood that participation is voluntary and that participants may withdraw from the study at any time. Information regarding foreseeable consequences of withdrawal from participation or factors that are likely to influence willingness to participate (e.g. potential risks, discomfort, adverse effects) should be made available to participants. Additionally, participants should be made aware of possible research benefits and incentives for participation. Finally, an important element of informed consents for studies involving personal data is a statement regarding the limit to confidentiality, which may include an explanation of what will be done with personal data during and after the proposed study.

Volunteerism

Obtaining consent that is voluntary and free of coercion has been a foundation of biomedical ethics since the Nuremberg Code; although, there are a number of historical examples where researchers failed to collect informed consent or disregarded the ethical mandate. While it is clear that voluntary consent should not be obtained by coercive or unduly influential means, the concept of volunteerism should be considered within the context of the type of research being conducted. There has been a great deal of debate among scholars regarding the need for voluntary consent in areas such as naturalistic observation, use of stored genetic information, and the use of students.

Students make up a unique research population. Thousands of college students participate in psychological research each year (Daugherty & Lawrence, 1996), and some have suggested that data collected from students may comprise 90% of research in

personality and social psychology (Sieber & Saks, 1989). Regarding student volunteerism, there are a number of factors that may negatively influence voluntary consent. The teacher-student relationship is often one of authority, and when research participation is required as an aspect of a student's grade, there may be concern for freely given consent. For this reason, it is common practice to have alternative projects, such as writing assignments, for students who wish to refrain from research participation. While there has been increasing focus on the ethical treatment of experiment participants and on comprehension of informed consent materials, more knowledge regarding student consent to research is needed.

Comprehension

It is critical that prospective participants understand and appreciate what they will be asked to do and what will happen to them during and after research participation. Consent comprehension is the idea that for individuals to give a truly informed consent, they must understand each element of the study, particularly the risks and benefits of participation. In reality, there is a significant gap between the reading capabilities of participants and the reading level of many consent documents (Hammerschmidt & Keane, 1992; Hochhauser, 1999; Ogloff & Otto, 1991).

The concept of comprehension regarding informed consent is unique in that deficits in comprehension can be caused by either the researcher or participant. From the side of researchers, comprehension can be hindered by longer, more technically worded documents, or documents that have confusing formats or writing styles (Greenwald et al., 1982; Imber et al., 1986; Mann, 1994; Philipson, Doyle, Gabram, Nightingale, & Philipson, 1995).

As a process, the methods of obtaining informed consent may also play a role in comprehension; these aspects include who obtained consent, the amount of time a participant

has to read and sign the consent document, and the format of the document. Wogalter, Howe, Sifuentes, and Luginbuhl (1999) found higher comprehension when consent forms were presented less formally, included oral recitation, and did not include a time pressure for signing.

Even when participants are provided the relevant information in formats conducive to comprehension, some individuals may still lack the cognitive ability to make an informed decision regarding participation. When vulnerable potential research participants are children, mentally ill, mentally retarded, or otherwise lack sufficient judgment, questions about the legal and ethical aspects of competence should be raised (APA, Section 3.10). Research involving vulnerable populations makes up the majority of studies on informed consent comprehension (McCormick, 2005). As a result of this line of research, it has become well recognized that children, adolescents, and the cognitively impaired are potentially unable to understand and appreciate important aspects of consent, particularly risk, that are needed to make a fully informed consent.

At least one author has suggested that we cannot fully understand what level of competence should be expected from vulnerable populations until we document cognitively normal individuals' ability to comprehend (Sachs et al., 2003). Early research developed from this supposition suggests that even the average healthy adult volunteer may lack the ability to fully comprehend the information presented in an informed consent (Sachs et al., 2003). This limitation of volunteers to comprehend consent information capitalizes the need for careful consideration of the risks and benefits of the study by researchers and IRB committee members.

Balancing Risks and Benefits in Research (Beneficence)

The biomedical ethical principles of beneficence and nonmaleficence undergird the focus on risk-benefit assessment within an IRB evaluation of a proposed study. Drawn from these principles, the concept of maximizing benefits and minimizing risks is reiterated in a number of scientific and ethical guidelines (e.g., the Nuremberg Code, APA Ethics Code, 2002, and the federal regulation, Protection of Human Subjects). The IRB has a clear mandate to evaluate all potential risks and benefits that may result during the course of a research study. This IRB evaluation focuses on the balance of costs to benefits, that is, research studies should produce the greatest amount of benefit while incurring the fewest costs to both individuals and society. Studies that involve greater than minimal risk draw the most attention from IRB review. Any proposed study in which the risks are higher than the benefits is unlikely to be approved by these committees. The risks associated with these costs are not limited to a single domain, and may include physical, psychological, social, or economic risks.

Risks to Participants

Physical. The most obvious physical risks are side effects resulting from experimental treatment. In genetic studies, physical risk is most likely related to the physical effects of blood or tissue collection. Thankfully, due to the method used in collecting DNA samples, most procedures are low in discomfort and side effects. Collection of buccal DNA can be as simple as swishing mouthwash and spitting into a cup or rubbing the inside of one's cheek with a sterile cotton or rayon swab.

Psychological. Psychological risks are varied, but may include the full spectrum from high to low risk. Low psychological risks, such as transient stress or discomfort, are common

in human science studies. Risks in the low category may include discomfort from answering sensitive questions or disclosing personal information to a researcher. These types of risks are not always considered "minimal," but are less severe than other potential risks such as exposure to pictures of death or carnage, or experiencing social embarrassment that may have effects that are more lasting. In genetic research, psychological risks related to the use of results might include being informed of a predisposition for a disease or having this information provided to family members. This information can be difficult to accept, and therefore, it is the responsibility of the researcher to make efforts to minimize the impact of the news.

Social. If a breach in the privacy of a genetic sample were to occur, it would undoubtedly cause psychological harm and may cause social harm. Social harm is related to psychological harm in that it often causes distress, but is more specifically related to implications in families, friendships, and places of employment. The most common types of social harm are related to breaches of confidentiality or privacy (Levine, 1981). Exposure to these types of harm can create future difficulties in establishing trusting relationships with researchers or in social relationships. Genetic privacy has increasingly become a concern in the public's eye because of its potential to label or stigmatize individuals with genetic predispositions.

Economic. Efforts to minimize economic harm include disclosing potential costs and identifying payers for future treatment or care; however, hidden costs (e.g., transportation to the study, loss of income from taking time to participate) can present a potential for economic harm (Levine, 1981). Coercion and undue inducement are also relevant economic

risks that potentially remove the autonomy of the individual to make an educated assessment of the risks and benefits of research.

Risks to Society

Societal risks may also include physical, psychological, social, and monetary components. An example of a physical risk to society might be the dissemination of inaccurate results that leads to negative changes in treatment. Psychological risks to society might include fear produced from these inaccurate results. If these inaccurate results were specific to a certain class or race, they may cause social harm to society, and if the resulting error changes government funding of programs or is otherwise costly to correct, it could pose an economic risk to society. Further, physical or psychological harm that is caused by a research study may incur costs to governmental or oversight bodies.

Benefits to Participants and Society

The potential benefits received from studies are diverse, numerous, and far-reaching (Fryberg, 1998). Individually, benefits may include diagnostic or treatment benefits, financial compensation, or increased knowledge or self-esteem. An increased sense of pride may also result from an individual's belief in their contribution to scientific progress. Scientific discovery and improved technologies are major societal benefits, but must be gauged against the benefits to the participant. Research in academia benefits students by providing them with exposure to research practices that may benefit there training and education.

Institutional review boards use all of the above elements of risk and benefit to evaluate the utility and value of a research proposal. Regarding risks, the IRB evaluates whether the expected benefits from new information, knowledge, or treatments is justifiable in light of the potential risks to individuals and society. When risks are unreasonable in

relation to the potential benefits, the proposal for study should be declined. Proposed studies that lack adequate privacy protections should also be denied by IRBs. This is a difficult consideration and it is not simply a mathematical equation, but a careful consideration of participants' welfare and the advancement of science. Given the complexity of this evaluation, it might be surprising that any studies are ever conducted and even more surprising that individuals would be willing to subject themselves to potential risks as a research participant. Despite these concerns, research participation is commonplace, and is most notably the norm of behavior among college students.

Research Participation among College Students

A number of reasons why students participate in research have been examined by researchers. According to Singer & Bossarte (2006), three major motives, altruism, appeal, and egoistic reasons, have emerged through this research. While some research has attempted to look at these aspects individually, a more realistic approach may be to view these aspects as synergistic. Additional person and contextual factors influencing willingness to participate that have been supported through research are described in later sections.

The first major motivator as described by Singer et al. (2006), altruism, is best described as motives that satisfy social obligations or desires for learning. In a study of student participation in research by Flagel, Best, & Hunter (2007), 95% of students reported that their research participation was valuable in helping them learn about psychological research. While not all researchers agree that students find research as a valuable learning experience, there is a body of evidence suggesting students value their participation as a learning experience and an opportunity to help researchers (Flagel et al., 2007; Landrum & Chastain, 1995).

The egoistic type of motivator is best described by interest in the tangible benefits of a study. Results from a study by Flagel et. al. (2007) investigating reasons why students participate in research indicated that the most reported motivator (98% of respondents) was to receive credit or bonus points. Money or credit plays an important role in much of the research involving students in various academic settings. Students are often required to meet research requirements as part of their coursework, with participation in research studies as the primary means of satisfying these requirements. For this reason, among students, it is not surprising that credit would be rated so highly. Interestingly, in the same study, Flagel et al. also reported that 95% of respondents identified altruistic motivators. These findings suggest that multiple aspects of a research study may influence willingness to participate.

Motivation to participate in research is not limited to interest in credit or the value of research. A number of differences have been found between volunteers and nonvolunteers, including: education level, social standing, intelligence, need for social approval, sociability, arousal-seeking, conventionality, conformity, and self-disclosure (Rosenthal & Rosnow, 1975; 1991). Researchers have additionally found differences between volunteers and nonvolunteeers in areas such as change-seeking (M. L. Russell & Garlington, 1985), personality characteristics (Cowles & Davis, 1987; Waite, Claffey, & Hillbrand, 1998), memory (Kreiner, Alvarado, & Shockley, 1997), conservativeness (Joe, Jones, & Ryder, 1977), and course performance (Padilla-Walker, Zamboanga, Thompson, & Schmersal, 2005).

Women and younger students are more likely to volunteer, and are more likely to have a positive view of psychology and research (Rosenthal & Rosnow, 1975; Waite &

Bowman, 1999); although, a study of male college students reported participation increased positive emotional reactions to research (Daugherty & Lawrence, 1996).

One attempt to address the multiple aspects of the decision-making process regarding participation in research was developed by Groves, Singer, & Corning (2000). The leverage-saliency theory suggests this type of decision-making results from multiple factors including those related to the survey or experiment, the person, or the physical environment. Each potential participant may be exposed to the same aspects of a study; however, their appraisal of the risks and benefits will be idiosyncratic. An individual with risk-taking traits is likely to approach this decision-making process in a way characteristically different from an individual who is more risk-averse. An area of research that is still emerging is the relationship between study-related factors such as perception of risk and benefit and personal factors and traits.

Influence of Monetary Compensation on Risk Perception and Willingness to Participate

Paying participants for research participation is neither a new concept nor an uncommon practice, yet it continues to be a hotly debated topic within research communities. While many agree that providing some type of inducement is necessary to attract research participants to a study, the determination of what constitutes a reasonable amount is often contested. The greatest concern is that coercive or undue inducements would invalidate an informed consent by robbing participants of voluntariness or blind them of the risks of their participation (Grady, 2001). Despite these concerns, there are no clear and consistent guidelines from federal regulations or oversight bodies on what constitutes a permissible or coercive inducement. Additionally, within the realm of research, while volumes have been

written debating the various ethical perspectives on inducements, few empirical research studies have been conducted to address this issue (Bentley & Thacker, 2004).

Coercion & Inducements

One reason for the lack of empirical studies on payment of participants may be the apparent ambiguity about when payment constitutes a coercive or undue inducement. Several authors have attempted to define coercion in the context of research. Faden, Beauchamp, and King (1986) characterized coercion as an "extreme" pressure that "completely controls a person's decision" (p. 338). Beauchamp and Childress (1994) defined coercion as "the intentional use of a credible and severe threat of harm or force to control another or compel him or her to do something" (p. 165). For example, if a participant were told they would fail a course if they did not participate in a particular research study, this would constitute a coercive act. This definition highlights the idea of intentional threats, as opposed to unintentional undue inducement.

While most researchers would agree any factor that causes a person to participate against their will constitutes coercion, monetary incentives to participate are more difficult to cast as coercive acts. Several authors have claimed that because money is an offer rather than a threat of punishment or harm, it is difficult to classify as coercive, and may be better described as undue inducement (Faden et al., 1986; Wilkinson & Moore, 1997).

Inducements are "influences strong enough to motivate or stimulate action" (Faden et al., 1986, p. 256). The presence of an inducement does not necessarily deprive a person of her ability to make autonomous decisions. In fact, in everyday life, inducements play a welcomed role in what we decide to buy or eat, what job we take, or what opportunities we pursue; yet, inducements are not the only factor we consider. Christine Grady, of the

National Institutes of Health, provides a relevant example. “Even if we are attracted to a job by a higher salary, we still generally choose a job based on a number of other factors, including what we feel we are qualified for, what would be satisfying, as well as where, with whom, and what hours we would work” (Grady, 2001, p. 41).

Grady’s example helps illuminate the fact that there are many factors that contribute to our motivation toward or away from actions. Offers of money as inducements do not invariably conflict with the principle of voluntariness, as money may be only one of many influential motivators. While monetary inducements are offers and not threats, and therefore are generally not considered coercive, the amount or conditions of payment may still be undue or exploitative (Bentley & Thacker, 2004; Macklin, 1981; Steinbock, 1995). As a result, it is possible for an informed consent to be invalidated even though the monetary payment is not deemed coercive.

One of the major arguments against monetary inducements is that they have the potential to cause people to misperceive risk and expose themselves to higher levels of risk than they might take without inducement (McNeill, 1997). This issue is of particular importance for populations considered vulnerable to inducements, such as participants from lower socioeconomic status or participants generally considered to be unable to fully comprehend the risks of a study. McNeill points out that the groups most financially susceptible to undue inducements are also the groups most likely to have difficulty evaluating the risks of such studies (1997). From the biomedical ethical perspective of justice, inducements promote inequity between those who participate in research and those who benefit from such research and are therefore objectionable.

While McNeill has argued that payment is objectionable in any study involving risk, Macklin (1981) contends that the inducements are necessary to attract participants to research and the absence or reduction of payment does little to improve economic justice. Other writers in this area have gone further, claiming that no restrictions should be placed on monetary inducements. Brody, Gluck & Aragon (1997), and to a lesser degree Palmer (1985), take the standpoint that if the study has passed independent review and has been found to have an acceptable risk-to-benefit ratio, the size of the payment should not harm the participant. Palmer contends that only in situations with the highest acceptable risk (e.g., possibility of death) should concern about excessive payment be raised, and in these situations, Palmer comments that an IRB would be unlikely to approve the study.

Other approaches to rationalizing the use of monetary inducements include the argument that we do injustice to individuals by removing a viable means of acquiring money. This approach generally contends that we remove options for the economically destitute when we prohibit payment. The assumption is that most people motivated by the prospect of inducements also have other potential means of earning money and freely choose research participation because of the flexibility or short-term time commitment.

The influence of incentives as a motivator for research participation is well-documented (Singer, Gebler, Raghunathan, & McGonagle, 1999). In meta-analyses of various forms of surveys (i.e., mail, telephone, and face-to-face), researchers have found monetary incentives to be more effective in persuading participation compared to non-monetary incentives. In a study of in-person surveys, Singer, Gebler, Raghunathan, & McGonagle (1999) found that incentives were a useful means of increasing participation in otherwise low response studies. However, questions linger about whether incentives reduce a

nonresponse bias (i.e., tendency to decline participation) or simply increase the response rate of individuals who declined to participate only because of the lack of incentives.

Influences on Participants' Perception of Risk in Research

Several investigators in the area of risk perception (e.g., Harris, Jenkins, & Glaser, 2006; Weber, Blais, & Betz, 2002) noticed a large amount of variability in individuals' willingness to engage in various types of risk activities. Subsequently, they suggested risk-taking is unlikely to be related to a single risk-taking trait. Rather, they believe there is evidence that differences in willingness to engage in risky behaviors might be related to differences in perception of risk in different domains. Many of the influences on perception of risk delineated in this section are in areas outside of general or genetic research participation. Similarly, there are only thin threads of reference to privacy risk-taking across commonly researched risk areas. Due to the lack of information regarding participation in research involving privacy risk or genetic sampling, there are questions about whether these common measurements of risk-taking can sufficiently explain privacy related risk-taking.

While there are multitudes of influences on any individual's perception of risk, there are several factors most relevant to college populations that may also apply to the study of genetic research privacy. Demographically, there is strong evidence of age and gender differences in risk-taking and risk perception in nearly all risky behaviors, excluding social risk-taking. Personality characteristics also play a significant role in the perception of risk. Measures of sensation seeking and several of the big five personality traits and facets have been associated with differences in these perceptions and behaviors. Contextual influences may also be present. The reading level and comprehensibility of an informed consent have

both been linked with differences in perception of risk and subsequent participation in hypothetical research.

Demographic Characteristics

There is evidence suggesting perception of risk may be associated with demographic factors. Two of the most supported demographic factors are age and gender. Chauvin, Hermand, & Mullet (2007), suggested that younger individuals view sex, deviance, and addiction as less risky ($r = 0.27$, $p < .001$) compared to older groups. This same group of younger individuals also viewed weapons and medical treatments as greater risks ($r = -0.24$ & $r = -0.22$, $p < .01$ respectively). Marvin Zuckerman (1994, 2007b), a respected and longtime researcher in the area of sensation seeking, makes no reference to taking risks with one's privacy; however, because younger individuals appear to take more risks in general than their older counterparts, it may be a reasonable hypothesis that these younger participants would also exhibit privacy related risk-taking. An emerging area in concern for privacy research has examined use of internet social networking sites as a method of observing this type of risk-taking behavior. The vast majority of this research suggests adolescents and young adults are less concerned with the privacy of their personal information compared to adult populations (Caverlee & Webb, 2008; Kolek & Saunders, 2008).

Regarding gender, it has been well-documented that, in many real-world situations, men engage in more risky behaviors than do women (Byrnes, Miller, & Schafer, 1999). Harris et al. (2006) examined gender differences in perception of risk to explore why men participated in more risky behaviors. They found that men perceived a lower likelihood of negative consequences and expected more enjoyment from participation in various risky

activities (e.g., gambling, recreation, and health) compared to women. Men's lower ratings of the severity of gambling and health-related activities partially mediated a higher propensity toward participating in these risky activities. In another study, men estimated risks related to AIDS, drinking, illicit drugs, cigarette smoking, and motor vehicle accidents about 10% to 15% lower than women's' estimates (Flynn, Slovic, & Mertz, 1994). Despite these findings, little is know about why these differences occur, and additionally, how they might affect willingness to participate in activities involving risk to privacy in genetic research. Other demographic factors, such as socioeconomic status, race and ethnicity, and other student variables may be related to differences in privacy risk ratings; however, these have not been sufficiently researched.

Personality Characteristics

In an effort to identify influences on participation in genetic research, the proposed study utilizes two personality measures, the Sensation Seeking Scale, Form 5 (SSS-V) and the International Personality Item Pool representation of the NEO-PI-R. While much has been written about the influence of these measures regarding other types of risk, no known studies have investigated concern for privacy of genetic information using these measures. Scales highly correlated to risky participation are likely to identify individuals with inherent tendencies to engage in such behaviors and may provide good covariates for statistically accounting for an individual's predisposition toward these behaviors. The following section provides a brief description of the potentially relevant personality traits and facets and a statement of how these factors may influence perceptions of genetic privacy risk and willingness to participate in genetic research.

Sensation Seeking. Sensation seeking is defined as "a trait defined seeking varied, novel, complex, and intense sensations and experiences, and the willingness to take physical, social, legal, and financial risks for the sake of such experience" (Zuckerman, 1994, p. 27). Research on sensation seeking has examined risk appraisal and risky behaviors across a number of domains (Zuckerman, 2007a). Most popular among these domains are physical risk-taking, such as extreme sports, sexual behavior, and drug use. Other non-physical risks, such as financial risk-taking, have also been examined; however, to date, none of the available research attempted to evaluate sensation seeking related to research participation involving privacy risks.

The Sensation Seeking Scale, an extensively researched instrument developed by Marvin Zuckerman, began with the hypothesis that "individual differences in optimal levels of stimulation and arousal, expressed in certain kinds of human activities" (*p*. 29) would be measurable with a self-report questionnaire (Zuckerman, 1994). What began as an effort to examine the excitatory and inhibitory processes in the central nervous system grew into an examination of many factors across the biopsychosocial landscape. Zuckerman's Sensation Seeking Scales have become a common method in research for identifying high and low sensation seekers, enabling the study of participants' behavior and biology. This study utilizes the Sensation Seeking Scale, Form 5 (SSS-V).

Big Five Personality Traits. The "big five" personality traits model is a widely accepted conceptualization of personality and has been used in a number of studies examining the intersection of risk perception/behaviors and personality. Costa and McCrae (1985) developed one of the most well-known self-report measures of the five-factor model of personality called the NEO Personality Inventory (NEO-PI), now revised (NEO-PI-R)

(Costa & McCrae, 1992). The primary factors of the NEO-PI-R are Extraversion, Neuroticism, Openness to Experience, Agreeableness, and Conscientiousness (see the Measures section of the Main Study for descriptions). A recently developed research representation of the NEO-PI-R, was developed by the International Personality Item Pool (IPIP). The IPIP-NEO, which was utilized for this study, was developed by IPIP to match the basic constructs of the NEO-PI-R and provide simplified scoring protocols.

A number of studies (e.g., Paunonen & Ashton, 2001; Vollrath, Knoch, & Cassano, 1999; Vollrath & Torgersen, 2002), including a more recent article by Chauvin et al. (2007), utilized the NEO-PI-R, or the IPIP-NEO, to study risk perception. Like those studies using the SSS-V, most research on risk perception using a five-factor personality model has focused on physical risk-taking (e.g., sports, sex, deviance, drug use). However, based on previous research regarding physical risks, and logical assumptions regarding the NEO factors, a tentative prediction has been made regarding the potential relationships between the five personality factors and perception of privacy risk in genetic research. That is, the openness to experience factor of the NEO-PI-R, appears to be the most conceptually similar construct to research risk-taking. This factor was therefore expected to be the more related to participants' evaluations of risk, compared to other factors of the NEO-PI-R.

Context Characteristics

Two important contextual variables have been found to impact participants' ability to provide fully informed consent to research: readability and comprehension. First, the reading level of an informed consent document limits the ability of individual's with lower reading levels to understand the information. A great deal of research has been conducted in this area, fairly consistently finding consent documents written with higher vocabulary or structure

than suitable for the common reader. Second, comprehension, that is, the ability to grasp the meaning of information, can be severely impacted if potential participants do not fully understand or read the documents presented.

Reading level of the informed consent document. To investigate the readability of informed consent documents, Ogloff & Otto (1991) reviewed 108 randomly selected consent forms across a Midwestern university IRB pool using two standardized measures of readability. They concluded that consent forms were typically written above the reading level of the populations being sampled. Even when research was conducted on non-college samples, the reading level was no different from studies conducted using college samples.

The readability of the experimental informed consent documents included in this study using the Flesch-Kincaid Grade Level formula produced a grade level of 11.2. While this was adequate for a college population, it did not meet the expected 6th or 8th grade reading level stated by many critics in this area (e.g., Paasche-Orlow, Taylor, & Branca, 2003). The difficulty of writing at this level is that the syllable count in words like "participation," "personality," and "information," and the assumed complexity of words like "genetic" or "repository," is unavoidable. For this reason, many researchers have looked to other analyses of readability.

Other researchers have suggested that standardized measures of readability do not show the whole picture. Mark Hochhauser (2003) has argued that understanding a consent document involves more than a grade level estimate calculated by counting syllables, words, or sentences. In his article, Hochhauser utilized Doak, Doak, and Roots' (1996) model for improving the comprehension of individuals with low literacy skills and proposed a framework for using alternative wordings for commonly misunderstood words. These words

are divided into three types, concept, category, and value judgment words. The ability of participants to grasp the meaning of words in each area was improved primarily by providing concrete examples or words that are more common. Where applicable, the informed consent document used in this study has utilized more understandable and descriptive terms, as described by Hochhauser, to improve readability.

Comprehension. Two problems remain, despite these improvements in readability. The first problem is participants' inability to understand probabilistic reasoning, and the second problem, the issue of participant inattention. The lack of understanding of statistics and probabilities has been a well-documented source of the reduced comprehension. One of the greatest difficulties in this decision-making process is that most individuals cannot predict how their appraisal of risk will change over time. The inability to judge changes in thoughts and feelings about risk also limits the individual's ability to comprehend the potential consequences of risks that turn into realities (Redelmeier, Rozin, & Kahneman, 1993). Sadly, "the evidence suggests that the inability to assess risk information in this way is the rule, not the exception" (Iltis, 2006, p. 186). Even in instances where investigators used procedures to improve comprehension, many adults were still unable to appreciate risk using this new information (2006).

Even if an individual has the capacity to comprehend information, if the individual does not attend to the document through careful reading, the reading level and wording of a document are meaningless. Cassileth, Zupkis, Sutton-Smith, and March (1980) points out that many individuals are willing to consent without reading the entire consent document. For this study, if the individual does not read the consent document and blindly consents to participation in any treatment condition, it will severely limit the ability to draw conclusions

about the perception of risk and willingness to participate. For this reason, the consent document used in this study has been intentionally kept brief and written in simple language. In addition, a series of comprehension questions have been included in the exit survey as a check for comprehension. These items were open-ended questions about the risk, benefits, and privacy statements presented in the experimental informed consent documents. While these questions attempted to assess basic awareness and memory of the content, they were unable to fully evaluate the understanding and comprehension of the material. Given these limitations, assessment of the level of comprehension, as measured by the stated items, was used to filter and define subsamples for additional analyses.

Ensuring fully informed consent is not an easy task, and by no means are the areas described above the only difficulties encountered by informed consent researchers. The following section describes some of the difficulties associated with planning and conducting informed consent research and identifies best practices for overcoming these barriers.

Researching Informed Consent

Interest in the process of informed consent has increased in the last decades, but continued research is needed as new medical technology and initiatives emerge and present new and unique challenges, such as protecting genetic privacy (McCormick, 2005). By understanding how research in this area is conducted and what barriers are present will illuminate the need for additional research.

The current premise behind research involving informed consent is to have an individual read a hypothetical informed consent vignette and either answer questions about the information or perform a “fill in the blank” style measure called a Cloze test. Using a hypothetical design has been the preferred approach for researching consent because

comprehension, measured using this design, is relatively easy to examine and generally produces consistent findings. The problem with this type of research is that hypothetical designs do not allow researchers to draw conclusions regarding actual consent behavior.

Some more ambitious approaches have utilized existing research projects unrelated to informed consent; however, this type of study is attempted in far less frequency than the hypothetical vignette approach. Part of the reason for a lack of this type of research is due to the difficulty of examining real and ongoing informed consent procedures. Among these difficulties are design and procedural issues, resistance from researchers to open studies to examination, and issues regarding the accuracy of responses from participants reviewing informed consent procedures. While "piggybacking" on other research projects provides greater external validity, it can be wrought with confounds and is difficult to initiate.

The difficulties in the previously mentioned designs are exacerbated when attempting to conduct true experimental research. Because participants are traditionally required to receive an informed consent prior to participation, it would seem necessary to have an informed consent for reading an informed consent (somewhat of a "catch-22"). While this has been done with success in hypothetical studies, using informed consent vignettes, the data collected from such designs are limited to conclusions based on theory, rather than behavioral measures, because the individuals know they will be asked to review informed consent documents. When participants know that they will not be required to complete the study's protocols dictated by the consent form, they are less likely to produce responses consistent with those of individuals who must actually decide if they wish to participate, thus generally poor external validity.

In practice, it can be difficult to acquire the needed permission of a fellow researcher to examine her informed consent procedures. Often researchers are reluctant to open themselves to the scrutiny a researcher of informed consent might have of them, her staff, or her research. Further, there is the potential that the additional research might detract from or even bias the primary research study. Methodologically, there is a concern that when a researcher is aware they are being observed she or her staff may act in ways inconsistent with normal consent procedures.

One possible alternative to the limitations related to the use of hypothetical informed consents and the difficulties of conducting joint research is to use mock informed consent procedures in a faux or deception study. Use of this type of design would eliminate the problems created by relying on existing research and would allow behavioral observation and more useful conclusions than hypothetical studies. This form of study would also require careful articulation to ensure that participants engaged in a deception study were adequately protected.

Under the APA's Ethical Principles and Code of Ethics, the use of deception is allowed only under specific circumstances. The deceptive techniques in research are used quite selectively; however, the need for a behavioral understanding of consent, paired with the limitations of other research designs, and the relative lack of risk to the participant, make its use appropriate in circumstances such as the present study. In presenting a mock informed consent in a manner that leads participants to realistically evaluate their potential participation, the deception allows a behavioral measure of willingness to participate, as well as, a more authentic appraisal of risk perception and the influence of monetary compensation.

Statement of Purpose

The objective of this study was to explore the effects of risk and monetary compensation on research participation and perception of risk to privacy among college research participants. Several studies have previously examined the effect of risk and monetary compensation on medical patient populations and healthy adult populations (see Bentley & Thacker, 2004); however, few studies examining these factors have accomplished a behavioral measure of willingness to participate, and no study to date has used this methodology to examine college students' participation in genetic research. College student populations make up an astounding proportion of research participants in the field of psychological and health research, including research on informed consent, yet knowledge about the motivates of college students to participate in risky research and the influences monetary compensation has been limited by hypothetical and survey methodologies. The present study proposed to examine the influence of monetary compensation on two levels of risk to privacy using a true behavioral measure, while accounting for demographic, personality, and context variables.

The deceptive elements of this study represent an improvement on existing approaches to examining willingness to participate without requiring actual participation in a risky study or exposing participants to greater than minimal risk. This approach maximized the ability to control variables within the study and removed the potential for negative influences on another study, a problem common with piggybacked research. The additional benefit to the deceptive element was that no personally identifiable data or genetic material was actually processed, thereby providing a learning experience for participants who may participate in future studies involving genetic research or risk to privacy. The potential

negative effects of the deception were further tempered by the inclusion of an extensive written debriefing and informational material on protecting personal privacy.

Hypotheses

This study was designed with the assumption that students-participants are capable of comprehending information provided in written form and are able to retain this information. This does not imply an assumption that all students would make use of these capabilities. In addition to the stated hypotheses, this study subsequently assessed comprehension and recall of informed consent information, as well as opinions related to the use of genetic information. Based on the prior cited literature, the following hypotheses were formulated. References and rationale associated with each hypothesis are bulleted below.

Hypothesis 1a*: Participants in the high risk groups will be less willing to participate compared to the low risk groups.*

Hypothesis 1b*: Participants in the high risk groups will be less likely to participate compared to the low risk groups.*

- Bentley & Thacker (2004) found significant differences in willingness to participate across three levels of medical risk ($F_{(2, 260)} = 8.90$, $p < .001$, partial eta$^2 = 0.06$). Higher levels of risk were associated with lower levels of willingness to participate. While these studies investigated hypothetical, rather than actual participation, similar results were predicted for the present study.
- Halpern, Karlawish, Casarett, Berlin, and Asch (2004) also found higher risk of adverse events was related to decreases in willingness to participate ($p < .001$).

Hypothesis 2a*: Participants in the high payment groups will be more willing to participate compared to the low payment groups.*

Hypothesis 2b: *Participants in the high payment groups will be more likely to participate compared to the low payment groups.*

- Bentley & Thacker (2004) also found a significant effect of monetary compensation on willingness to participate ($F_{(2,260)} = 4.26$, $p = .02$, partial eta$^2 = 0.03$). Lower levels of monetary compensation were related to lower willingness to participate. It should be noted that the above was a hypothetical study of major medical trials; the amount of monetary compensation suggested by Bentley & Thacker was significantly higher than the amounts tested in this study. The payments in their study ranged from $350 - $1800 for 54 hours (two 24-hour stays and 12 half-hour sessions). When converted to an hourly wage, the payments range from $6.48 - $33.00; numbers somewhat lower than those proposed in this study ($10 & $100).
- Halpern et al. (2004) found results similar to those of Bentley and Thacker (2004). They found, using clustered ordinal logistic regression modeling that willingness to participate decreased with lower payment levels ($p < .001$). The above study used payments ranging from $100 - $2000.

Hypothesis 3: *The effects of monetary payment on willingness to participate will not vary across levels of risk.*

- Both Bentley & Thacker (2004) and Halpern et al. (2004) found no significant interaction between level of risk and level of monetary compensation. This suggests that although higher amounts of monetary compensation (as noted in the respective studies) served as incentives, they did not lead individuals to overlook the research-related risks. It is unclear whether $100 will produce a similar response.

Hypothesis 4*: The perception of risk, measured by the risk rating scale, will not vary across levels of monetary compensation.*

- Bentley & Thacker (2004) used an original 5-item measure of perception of risk to assess participants' views of the likelihood and severity of negative consequences of participation. As they expected, significant differences were present in risk ratings across three levels of risk ($F_{(2,260)} = 275.95$, $p < .001$, partial eta$^2 = 0.68$). However, monetary compensation did not influence perception of risk. Additionally, no interaction was found between level of risk and momentary compensation in relation to risk rating.

Hypothesis 5*: Women's ratings of risk will be higher in each condition compared to men's risk ratings for each condition.*

- A study by Harris, Jenkins, & Glaser (2006) found that compared to men, women's risk ratings (likelihood and severity of negative consequences) where significantly higher for gambling and health activities. Women also had higher risk ratings of likelihood, but not severity, for recreational activities. No differences were found in the social domain. Because privacy risk does not fit cleanly in any of the domains previously examined, it is unclear what role gender might play, although, the most likely direction is for this novel type of risk to follow a similar pattern.
- Regarding participation, McQuillan, Pan, & Porter (2006) found women were less likely to consent to research involving DNA sample storage compared to research that did not store samples. Women still participated in large numbers; however, relative to the mean participation rate (85.3%; $n = 2000$), women (83.6%) and blacks (81.3%) were least likely to consent (95% confidence interval).

Hypothesis 6: *Participants with higher scores (+1.5 SD above mean) on measures of Experience Seeking (SSS-V) and Openness to Experience (IPIP-NEO) will be more likely to participate in any treatment compared to participants with lower scores on these measures.*

- Marcus & Schutz (2005) examined personality correlates of participation in research by comparing respondents and nonrespondents. Regarding Openness to Experience, they found a significant difference between groups ($p < .05$, $d = .37$). They also found that regression coefficients indicated, when holding other variables constant, high Openness to Experience and low Conscientiousness had independent effects on increased rate of participation.
- Zuckerman (1994) found a moderate positive correlation between the SSS-V's Experience Seeking and the NEO-PI-R's Openness to Experience (r = .51). Use of the SSS-V has routinely found that participation in risky activities is related to higher total sensation seeking scores, and that higher scores in Experience Seeking are related to increased participation in educational and novel endeavors. There is no information regarding participation in studies involving privacy risk.

Hypothesis 7: *Willingness to participate without payment will be lower than willingness with payment.*

- Bentley & Thacker (2004) found that without payment, respondents were less willing to participate ($F_{(2,260)} = 6.75$, $p < .001$, partial eta$^2 = 0.05$). This finding was influenced by the level of risk, with higher levels of risk leading to lower willingness without payment ratings. Willingness to participate without payment was not influenced by the initial level of monetary compensation.

Hypothesis 8*: Willingness to participate when samples are not placed in repositories will be higher than when samples are put in repositories.*

- In a study of participation in the National Health and Nutrition Examination Survey, McQuillan, Pan, & Porter (2006) found that during years where studies did not include genetic sampling and storage, 98.4% of individuals consented to participate, compared to 90.1% when genetic sampling and storage was mentioned in the consent documents (95% confidence interval). This study also noted that gender and racial differences regarding consent to genetic sampling disappeared when studies did not collect genetic samples.

CHAPTER 2. PILOT STUDY

Materials & Methods

The Pilot Study was conducted to address the following questions in preparation for the Main Study: Do students view identifiable and anonymous genetic repositories as having different levels of risk to privacy? How are elements of risk perceived differently across vignettes involving risk? What monetary values are expected or desired for participation in risky research? Through exploration of these questions, we aimed to develop the variables of interest and manipulation in the Main Study in a way that was meaningful and externally valid.

This study also sought to inform the development of hypotheses for the Main Study regarding the interaction of perceptions of risk and monetary compensation among undergraduates participating in research. One of the major objectives of the Pilot Study was to calibrate the level of risk of privacy loss mitigated by compensation for participation in research. Information collected from this pilot sample was utilized to set high and low risk scenarios crossed with high and low levels of monetary compensation for use in the Main Study. This pilot sample also allowed researchers to examine the distribution of monetary compensation expected by participants across four levels of privacy risk.

Participants

A sample of 780 undergraduate students agreed to participate in the pilot study through department research pool mass testing conducted at a large Midwestern public university. All of the volunteer-participants were enrolled in undergraduate psychology courses and participated in the study through the psychology department's SONA, online research system. Participants utilized a web-based survey site to complete a bank of surveys.

Participants received experimental credits in designated psychology courses for their participation.

The proposal for this research study was reviewed by the Iowa State University IRB and IRB approval was granted on 01/13/2009; IRB Identification Number 09-009. Please see Appendix A for examination of the approval letter and Appendix B for the participant informed consent for participation form.

Of the original sample (N = 780), 522 participants were retained who had completed all items for the pilot study (n = 149 removed for missing items) and responded in a realistic manner to the item regarding the minimum amount of money for which they would participate (≤ $10,000 for participation) (n = 109 removed for peculiar responses). Some respondents who were removed from the original sample replied to the open-ended question of the minimum amount of money for participation in a manner that could not be utilized for the analyses (e.g., "pizza" "a trillion dollars") or in a denomination to large to be considered valid requests (e.g., $100,000). While a research participant would be hard pressed to find a study with monetary compensation in the area of $10,000, it was decided that this amount was viewed as a statement about compensation rather than an expression of non-willingness (e.g., "only for a million dollars"). These stringent retention criteria were utilized to maximize the completeness and accuracy of responses, and to ensure appropriate statistical power using within-subjects analyses.

Demographic information was collected from participants as part of the survey. Participants were asked their gender, age, ethnicity, education level, and marital status. Frequencies and distributions of the demographics are listed in Appendix C. The sample was largely Caucasian, 467 persons (89.46%), followed by 16 international students (3.07%), 14

Asian Americans (2.68%), 10 Latino-Americans (1.92%), six Multiracial-Americans (1.15%), four African Americans/Blacks (0.76%), three students reporting Other (0.57%), and two Native Americans (0.38%). There were 317 female (60.73%) and 205 male (39.27%) participants. The largest percentage of students were first year students (n = 296, 56.70%), with a decreasing number of participants across the remaining education levels (126, 67, 33, respectively for sophomore, junior, and senior education levels). Participants ranged in age from 17 to 45 years, and most individuals were within the range of 18 to 22 years (96.00%, n = 501). The median age was 19 years old.

Procedures

The study was posted on the psychology department's research webpage under the title: Department of Psychology Electronic Testing (IRB #08-063). As part of their participation, undergraduate psychology students who participated in the mass testing research were asked to read a vignette (see Appendix D for Basic Vignette) describing a hypothetical research study that would involve contributing a genetic sample. After reading the Basic Vignette, participants were asked to fill out eight questions (see Appendix E) regarding willingness to participate, perception of the risks involved in the study, and an estimate of the amount of money that would be needed to motivate participation. Participants were also permitted to indicate that they would not participate for any amount of money.

Four variations of additional information about the vignettes were provided in separate addenda (see Appendixes F, G, H, & I). The variations included descriptions of the use of and privacy of the hypothetical DNA samples and personally identifying information. These variations ranged from low risk (i.e., anonymous sampling and immediate destruction of samples) to high risk (i.e., identifiable data banking of samples accessible by government

agencies). The intermediate levels of risk, which were the primary focus of the pilot study and the Main Study, involved either anonymous or identifiable entry into a university-based genetics-behavior research database. Each participant responded to the same initial eight questions (see Appendix E) for each variation. A total of 40 items, 8 questions for each of the five vignettes, were collected from each respondent. Items (excluding the open response items) were scored on a 10-point Likert-type scale. Prior to data analysis, items were recoded into a 5-point Likert-type scale to ease interpretation and make the metric similar to that used for the Main Study.

Data Analysis

The objective of the pilot study was to evaluate the level of perceived risk at three levels of risk to privacy developed by the researchers (Basic, Low-Anonymous database, & High-Identifiable database). Separate one-way ANOVA were run for each of the eight items assessed across vignettes (see Appendix E for the items). The ANOVA were followed by post-hoc tests to examine how discrete the identifiable and anonymous vignettes were from each other and from the Basic vignette. Six paired sample *t*-tests were also run, in which responses to each of the constructed risk vignettes (identifiable or anonymous) were compared to each other.

The items assessing willingness to participate and the amount of perceived risk for a given scenario were of the greatest importance for the development of the Main Study (see Appendix E for the items). Statistical differences across ratings of the vignettes were used to demonstrate directional differences in perceived risk of participation and willingness to participate. Analysis of the minimum monetary compensation for participation included

frequency distributions, scatterplots, and descriptive statistics. The proportion of individuals who stated they would not participate for any amount of money was also recorded.

The risk levels and monetary compensation amounts were decided based on the statistical analyses and consultation between the primary researchers and a statistician. The intermediate levels of risk were selected for the Main Study because they most closely mirrored real samples of genetic testing risk levels and had enough contrast as to have the potential to be perceived as significantly different in level of risk by participants.

The monetary amounts were decided based on conservative estimates from the distributions of "minimum amount for participation" and plausible amounts consistent with recorded monetary compensation amounts of active studies. The objective was to approximate moderately high and low monetary compensation amounts that would be within the scope of a reasonable research budget, but that could also be potentially coercive on the high end. Paired with the additional hypothetical question in the Main Study regarding willingness to participate without monetary compensation, the Main Study would include three levels of hypothetical compensation, two presented for each participant (i.e., the compensation amount, high or low, and the no payment hypothetical question).

Results for Pilot Study

Data Normality

To test the assumption of normality prior to examining the data, measures of skew and kurtosis were conducted (see Table 1). Examination of Table 1 shows that all variables, except minimum money amount (Min$) had acceptable skew and kurtosis. Analyses involving the (Min$) variable were analyzed using nonparametric tests. Based on the size of the sample, it was unlikely that the remaining distributions were sufficiently nonparametric

to interfere with standard statistical analyses. Upon examination of the seven items (excluding Min$), we determined that there was little need for concern regarding excessive outliers and also that the data appeared suitably normal for analyses without transformation.

Table 1
Skew and Kurtosis of the Pilot Study Variables

(#) Item	Vignette	Skew	Kurtosis
1. Based on the description of the study, how willing would you be to participate in this study? (WTP)	Basic	0.04	-1.15
	Identifiable	0.91	-0.31
	Anonymous	-0.05	-1.12
2. How likely do you think other students like you would be to participate in this study? (Others)	Basic	0.10	-0.48
	Identifiable	0.94	-0.12
	Anonymous	0.03	-0.74
3. How risky do you think it would be to participate in this study? (Risk)	Basic	2.12	3.82
	Identifiable	0.55	-0.81
	Anonymous	2.14	3.91
4. How concerned are you regarding the loss of the privacy of your personal information in this study? (PrivDNA)	Basic	0.94	-0.31
	Identifiable	0.18	-1.20
	Anonymous	1.67	1.93
5. What is the probability that your personal information would be used unethically or in a way inconsistent with the wording of the description? (Prob)	Basic	1.59	1.64
	Identifiable	0.51	-0.78
	Anonymous	1.94	2.92
6. How serious would the negative consequences related to loss of privacy be if they occurred? (Serious)	Basic	0.68	-0.81
	Identifiable	0.26	-1.21
	Anonymous	0.96	-0.34
7. How much would you enjoy participating in this research study? (Enjoy)	Basic	0.54	-0.62
	Identifiable	1.20	0.45
	Anonymous	0.53	-0.67
8. Minimum dollar amount you would need to be paid to participate in the study described. (Min$)	Basic	19.13	389.96
	Identifiable	9.84	108.51
	Anonymous	9.42	95.50

Note. Skew Standard Error = 0.11, Kurtosis Standard Error = 0.21

Descriptive Statistics for Variables

Descriptive statistics (means and standard deviations) were examined for the items regarding perceptions of risk and enjoyment across the three vignettes of interest. Table 2 provides a summary of these statistics for the eight items asked in each vignette. Scale items were converted from a ten-point to a five-point Likert-type scale to ease comparison to the Main Study, with higher scores meaning more of the stated response (e.g., more willingness to participate, more concern). The final item was an open-response question ranging from $0-$10,000. A response of $0 indicates that the participant would not require compensation to participate. Scores above $10,000 and those including objects or services (e.g., pizza) were removed based on the exclusion criteria. Additionally, participants were allowed to indicate that they would not participate for any amount of money. Frequencies for this nominal variable are presented in Table 3. A Pearson's Chi-Square test of independence demonstrated that a higher proportion of individuals refused to participate for any amount of money (n = 148) in the identifiable vignette compared to any other risk level (n = 68 & 69 for Basic & Anonymous, respectively) $\chi^2(1, N = 522) = 54.23$, $p < .001$ $\varphi = 32$.

Risk Perceptions across Vignettes

Eight separate one-way ANOVAs, and post hoc tests, were run to determine if the three vignettes were discrete. Table 2 presents the initial F-statistics and p-values for these risk perception items. Statistically significant differences were present in all of the items except Min$, which has been analyzed with nonparametric analyses. Post hoc testing utilized the Scheffe method to examine pairwise comparisons. As all of the factors produced significantly different means in the ANOVA, post hoc analyses were performed (see Table 4).

Table 2

Descriptive Statistics and One-Way ANOVA for Items Used in Pilot Study Vignettes

(#) Item	Group	*M*	*SD*	Median	Mode	*F*	*p*
1. WTP	Basic	1.97	0.74	2	2	103.98	<.001
	Identifiable	1.52	0.66	1	1		
	Anonymous	2.03	0.73	2	2		
2. Others	Basic	1.87	0.62	2	2	155.48	<.001
	Identifiable	1.42	0.56	1	1		
	Anonymous	1.97	0.67	2	2		
3. Risk	Basic	1.21	0.46	1	1	164.38	<.001
	Identifiable	1.67	0.69	2	1		
	Anonymous	1.21	0.46	1	1		
4. PrivDNA	Basic	1.52	0.67	1	1	145.76	<.001
	Identifiable	1.89	0.75	2	2		
	Anonymous	1.28	0.51	1	1		
5. Prob	Basic	1.29	0.52	1	1	127.46	<.001
	Identifiable	1.67	0.68	2	1		
	Anonymous	1.2	0.44	1	1		
6. Serious	Basic	1.63	0.72	1	1	32.27	<.001
	Identifiable	1.85	0.76	2	2		
	Anonymous	1.52	0.69	1	1		
7. Enjoy	Basic	1.6	0.62	2	1	35.42	<.001
	Identifiable	1.37	0.55	1	1		
	Anonymous	1.63	0.65	2	1		
8. Min$	Basic	64.05	485.39	10	0	2.86	.06
	Identifiable	172.04	831.62	20	0		
	Anonymous	105.11	614.63	10	0		

Note. $N = 522$. WTP = Willingness to Participate; Others = Perceived willingness of others; Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation; Min$ = Minimum dollar amount to participate.

Table 3

Frequency Count for Non-Participation Regardless of Monetary Compensation

(#) Item	Group	*f*	% of Total
9. I would Not participate for any amount of money.	Basic	68	13.0
	Identifiable	148	28.4
	Anonymous	69	13.2

Note. $N = 522$

Table 4

Post Hoc Test (Scheffe) of Multiple Comparisons for Risk Perception Items

Variable	Group (I)	Group (J)	Mean Dif. (I-J)	*SE*	*p*	95% CI (I-J) Lower Bound	95% CI (I-J) Upper Bound
WTP	Basic	Ident.	1.99	0.17	.00	1.57	2.41
		Anon.	-0.28	0.17	.27	-0.70	0.14
	Ident.	Anon.	-2.27	0.17	.00	-2.69	-1.85
Others	Basic	Ident.	1.88	0.14	.00	1.54	2.22
		Anon.	-0.43	0.14	.01	-0.77	-0.09
	Ident.	Anon.	-2.31	0.14	.00	-2.65	-1.97
Risk	Basic	Ident.	-2.37	0.14	.00	-2.72	-2.02
		Anon.	-0.24	0.14	.25	-0.59	0.11
	Ident.	Anon.	2.13	0.14	.00	1.78	2.48
PrivDNA	Basic	Ident.	-1.71	0.16	.00	-2.12	-1.31
		Anon.	1.07	0.16	.00	0.67	1.48
	Ident.	Anon.	2.79	0.16	.00	2.38	3.19
Prob	Basic	Ident.	-1.75	0.14	.00	-2.10	-1.40
		Anon.	0.37	0.14	.03	0.02	0.72
	Ident.	Anon.	2.12	0.14	.00	1.77	2.47
Serious	Basic	Ident.	-0.88	0.18	.00	-1.31	-0.44
		Anon.	0.53	0.18	.01	0.10	0.97
	Ident.	Anon.	1.41	0.18	.00	0.98	1.85
Enjoy	Basic	Ident.	0.97	0.15	.00	0.59	1.34
		Anon.	-0.25	0.15	.26	-0.63	0.12
	Ident.	Anon.	-1.22	0.15	.00	-1.60	-0.85
Min$	Basic	Ident..	-107.99	45.29	.06	-218.99	3.01
		Anon.	-41.07	43.04	.63	-146.55	64.42
	Ident..	Anon.	66.92	45.41	.34	-44.36	178.20

Note. Ident. = Identifiable; Anon. = Anonymous; WTP = Willingness to Participate; Others = Perceived willingness of others; Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation; Min$ = Minimum dollar amount to participate.

A series of paired sample *t*-tests were conducted to examine differences across the three vignettes on each of the research perception items, with particular interest to those involving risk perceptions. In comparison to a baseline perception of risk, explored through the generic description of the research in the "Basic" group, both the "Anonymous" and "Identifiable" vignettes produced significantly different perceptions of risk and benefit (all $p < .001$). Of greatest interest for this study were the differences between the Identifiable and Anonymous conditions. Table 5 presents the findings from these analyses. All comparisons produced significantly different means, with higher ratings of risk perception in the Identifiable group, and higher ratings of enjoyment or benefit in the Anonymous condition.

Table 5

Paired t-Tests for Risk Perception Items

(#) Item	Group	*M*	*SD*	*t*	*p*
2. Others	Identifiable	1.42	0.56	-19.67	<.001
	Anonymous	1.97	0.67		
3. Risk	Identifiable	1.67	0.69	14.60	<.001
	Anonymous	1.21	0.49		
4. PrivDNA	Identifiable	1.89	0.75	18.98	<.001
	Anonymous	1.28	0.51		
5. Prob	Identifiable	1.67	0.68	15.54	<.001
	Anonymous	1.21	0.44		
6. Serious	Identifiable	1.85	0.76	11.65	<.001
	Anonymous	1.52	0.69		
7. Enjoy	Identifiable	1.37	0.55	-11.40	<.001
	Anonymous	1.63	0.65		

Note. *df* = 521. WTP = Willingness to Participate; Others = Perceived willingness of others; Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation; Min$ = Minimum dollar amount to participate.

Minimum Monetary Compensation across Vignettes

In order to examine differences in ratings of minimum monetary compensation across vignettes, we first had to address the issue that the ratings were not normally distributed. Examination of the variability in responses across vignettes suggested the use of nonparametric or "distribution-free" statistical analysis, that is, an analysis that does not rely on normal distributions. To examine these dependent samples, the Friedman Two Way Analysis of Variance Test was conducted across the three ratings of minimum monetary compensation. This nonparametric test is similar to a parametric repeated measure ANOVA in that it attempts to detect differences across cases, or in this case, across vignettes.

Because the Friedman Test should not be computed with missing data, individuals who would not participate for any amount of money (on any of the vignettes) were removed for analyses. This resulted in a sample of 361 individuals who were willing to participate for some amount of money, ranging from $0-$10,000. The initial Friedman Test, which included all three vignettes, resulted in detection of significant differences among at least one of the ratings ($p < .001$). The results of the Friedman Test are presented in Table 6. Note that the large standard deviations are due to the high degree of variability in responses to the minimum amount of money participants would require for participation (ranging from $0-$10,000). An additional analysis was conducted to determine if differences were present between the Anonymous and Identifiable vignettes. The Friedman Test produced significant differences Friedman $\chi^2(1, N = 361) = 124.46$, $p < .001$, $\varphi = .59$, indicating individuals required significantly higher amounts of compensation to be willing to participate in genetic research involving an identifiable repository. This evidence provided continued support that there were observable differences between the risk level groups used in the Main Study.

Table 6
Group Differences in Minimum Monetary Compensation (Min$)

					Friedman	
Group	*N*	*M*	*SD*	*Mdn*	χ^2	*p*
Basic	361	41.46	134.93	10.00		
Identifiable	361	147.31	663.03	20.00	219.47	<.001
Anonymous	361	91.46	578.04	10.00		

Note. Friedman Test *df* = 2

Differences in Willingness to Participate and Risk Perception across Vignettes

Willingness to participate was evaluated for all vignettes. Significant differences were present, with higher willingness to participate in the Anonymous group. This finding is presented in Table 7. In addition to differences in risk perception, this evidence provides additional support for the use of the Anonymous vignette as the "low risk" condition and the Identifiable vignette as the "high risk" condition.

Table 7
Paired t-Test for Willingness to Participate

(#) Item	Group	*M*	*SD*	*t*	*p*
1. WTP	Identifiable	1.52	0.67	-17.27	<.001
	Anonymous	2.03	0.73		

Note. df = 521. WTP = Willingness to Participate.

Gender Differences

As part of the examination of the pilot sample data, the possibility of gender differences among the variables of interest was considered. The results from this examination can be found in Table 8. No statistically significant differences were present in any of the items across groups.

Table 8
Gender Differences by Item Across Group

(#) Item	Group	Gender	*n*	*M*	*SD*	*t*	*p*
1. WTP	Identifiable	Male	205	1.56	0.69		
		Female	317	1.49	0.64	1.22	0.22
	Anonymous	Male	205	2.04	0.72		
		Female	317	2.03	0.74	0.21	0.83
2. Others	Identifiable	Male	205	1.44	0.57		
		Female	317	1.4	0.56	0.86	0.39
	Anonymous	Male	205	1.98	0.66		
		Female	317	1.97	0.67	0.2	0.84
3. Risk	Identifiable	Male	205	1.65	0.67		
		Female	317	1.68	0.71	-0.47	0.64
	Anonymous	Male	205	1.2	0.44		
		Female	317	1.21	0.47	-0.47	0.64
4. PrivDNA	Identifiable	Male	205	1.91	0.76		
		Female	317	1.88	0.74	0.52	0.60
	Anonymous	Male	205	1.29	0.54		
		Female	317	1.27	0.49	0.43	0.67
5. Prob	Identifiable	Male	205	1.66	0.64		
		Female	317	1.68	0.7	-0.38	0.71
	Anonymous	Male	205	1.23	0.47		
		Female	317	1.19	0.42	1.02	0.31
6. Serious	Identifiable	Male	205	1.87	0.74		
		Female	317	1.83	0.76	0.64	0.52
	Anonymous	Male	205	1.58	0.7		
		Female	317	1.48	0.68	1.58	0.11
7. Enjoy	Identifiable	Male	205	1.38	0.56		
		Female	317	1.36	0.55	0.48	0.63
	Anonymous	Male	205	1.64	0.66		
		Female	317	1.63	0.64	0.28	0.78
8. Min$	Identifiable	Male	157	229.69	939.51		
		Female	213	129.54	741.59	1.15	0.25
	Anonymous	Male	182	128.48	720.26		
		Female	267	89.19	531.61	0.66	0.51

Note. Items #1-7 *df* = 520; Min$ Identifiable *df* = 368; Min$ Anonymous *df* = 447. WTP = Willingness to Participate; Others = Perceived willingness of others; Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation; Min$ = Minimum dollar amount to participate.

Determination of Risk Levels

The results from the above studies support the use of the high and low risk levels of Identifiable and Anonymous, respectively. First, there was sufficient evidence that ratings of perceived risk across each condition were significantly different. As expected, individuals in the Identifiable condition perceived greater amounts of risk to privacy, probability and seriousness of harm, and had greater concern about the privacy of their DNA samples than when in the Anonymous condition. Significant differences, in the expected direction, were also found in the remaining items probing enjoyment and benefits from participation.

Second, there were significant differences in willingness to participate across conditions. Individuals in the Anonymous condition were more willing to participate than in the Identifiable condition. The difference between groups was significant; there was a 0.51 point (10.2%) difference when scored on a five-point Likert-type scale). Finally, there were significant differences in the minimum monetary compensation amounts across conditions, suggesting individuals would be less willing to participate in the Identifiable condition, compared to the Anonymous condition, without payment, or when payments were low. Taken together, these findings support the use of the Anonymous and Identifiable conditions in the Main Study.

Determination of Monetary Compensation Amounts

This study asked participants to rate the minimum amount of monetary compensation they would require to participate under several hypothetical privacy risk conditions. Across the two conditions of interest in this study, Anonymous and Identifiable, the modal response was $0.00, meaning most individuals would participate without monetary compensation. Interestingly, while most required no compensation, monetary values were as high as

$10,000 in the Identifiable condition and $8000 in the Anonymous condition. Exploration of the distributions of each condition showed non-normal distributions. Table 9 presents the 25th, 50th, and 75th percentiles for each condition. The values used in the Main Study, $10 & $100, were selected to approximate values used in existing genetic studies, while attending to the distributions presented by participants in this Pilot Study. The difference in monetary values was consistent with the proportions documented in the literature.

Table 9
Minimum Monetary Compensation Rating (Min$) By Percentile

	Percentiles		
Group	25th	50th	75th
Identifiable	5	20	70
Anonymous	0	10	30

Note. Amounts are expressed in U.S. dollars

Discussion

The objective of the pilot study was to explore the utility of two risk levels and develop two levels of monetary compensation for use in the Main Study. Additionally, the Pilot Study evaluated several aspects of perceived risk for each of the privacy risk vignettes developed by the researchers. Paired-sample *t*-tests were run for each question across the basic vignette and the two prospective risk variations, Anonymous and Identifible. The items assessing willingness to participate and the amount of perceived risk for a given scenario were of the greatest importance for the development of the Main Study. Statistically significant differences across ratings of the vignettes provided directional differences in perceived risk of participation and willingness to participate that suggested their use in the Main Study. Analysis of the minimum monetary compensation for participation included a nonparametric analysis of variance, frequency distributions, and descriptive statistics.

The risk levels and monetary compensation amounts were decided based on the statistical analyses and consultation between the primary researchers and a statistician. The high and low levels of risk were selected because they most closely mirrored real samples of genetic testing risks. The monetary amounts were decided based on conservative estimates from the distributions of "minimum amount for participation" and plausible amounts consistent with recorded monetary compensation amounts of active studies. The objective was to approximate moderately high and low monetary compensation amounts that would be within the scope of a research budget, but that could also be potentially coercive on the high end. Paired with the additional hypothetical question regarding willingness to participate without monetary compensation, the Main Study included three levels of compensation, two presented for each participant (i.e., the currency amount and the no payment hypothetical).

CHAPTER 3. MAIN STUDY

Materials & Methods

This study was conducted to investigate the effect of privacy risk and monetary compensation on participation in online university research involving the potential for genetic privacy loss. The objective of this examination was to illuminate the level of student concern for privacy of personal information and explore factors related to the presentation of the research in a consent document that may alter perception of this risk. To evaluate the research hypotheses, student-participants were asked to complete a two-stage experiment, with the first stage serving as a means to collect demographic and personality information and to disguise the experimental manipulation presented in the second stage.

Participants

Student-participants for the Main Study were recruited from the undergraduate participant pool at Iowa State University, a large Midwestern public university. All the volunteer-participants were enrolled in undergraduate psychology classes, signed up for participation in the study via the psychology department's online research system (see Appendix J), and received experimental credit in select psychology courses for their participation. Students were emailed a link to a secure external survey website to complete the study online.

The proposal for this research study was reviewed by the Iowa State University Institutional Review Board; approval was granted on April 9, 2009; IRB Identification Number 09-157. Please see Appendix K to examine the approval letter and Appendix L for the participant informed consent for participation.

A total of 305 electronic surveys were sent to potential participants via email. Of the surveys delivered, 236 (77.38%) were returned. After deletion criteria were applied to the responses, which was most commonly removal if ≥ 20% of any responses to a section were missing (see Appendix M for full deletion criteria), a total of 182 usable responses remained.

In relation to the total usable data sample (n = 182), there was an acceptable response rate and retention of 59.67% of participants from the surveys sent (N = 305), and 77.12% retention of participants among returned surveys (n = 236). The overall response rates for the returned (but not screened) surveys by treatment groups were 78.21%, 78.21%, 75.00%, & 78.08% (Risk-Money: Low-Low, Low-High High-Low, & High-High, respectively) (n = 236). The final usable sample (after application of deletion criteria) response rates by treatment group were 73.77%, 68.85%, 85.96%, & 80.70% (Risk-Money: Low-Low, Low-High High-Low, & High-High, respectively) (n = 182). In this final sample, the sample sizes by treatment groups were closely equal: (Risk-Money); Low-Low (n = 45); Low-High (n = 42); High-Low (n = 49); High-High (n = 46).

Demographic information was collected from participants at the beginning of the survey (see Appendix N). Frequencies and percentages for the demographic information can be found in Appendix O. The sample was largely comprised of Caucasian students, 167 individuals (91.8%), followed by six Asian/Pacific Islanders (3.3%), three African Americans (1.6%), three Latinos/as (1.6%), and three identifying as Other (1.6%); additionally, 10 participants identified as multiracial (5.5%). There were 100 (54.9%) female participants and 82 males (45.1%). Most participants were underclassmen (n = 141, 77.5%), with 103 freshmen (56.6%), 38 sophomores (20.9%), 27 juniors (14.8%), and 14 seniors

(7.7%). The median and modal age of participants was 19 years, with ages ranging from 18 to 45 years, and the largest number, 168 (92.3%), were between 18-21 years of age.

Most participants identified as single (n = 126, 69.2%), come from middle class (n = 93, 51.1%) or upper-middle class families (n = 70, 38.5%), and were decided on a major (n = 132, 72.5%). Nearly all participants had participated in previous psychological research at the university (n = 176, 96.7%), and while most had not participated in medical research at any location (n = 178, 97.8%); more than half of the individuals (n = 117, 64.3%) intend to participate in some kind of research in the future.

Procedures

Students recruited on the SONA online research system (IRB approval number 09-157; date 04/09/09), were emailed a link to the study survey. First, students were provided with the informed consent materials via the hyperlink (see Appendix L). Students were informed that this was a study investigating personality characteristics of undergraduate students. Students were also informed that participation was completely voluntary and they could withdraw their participation at any time without negative consequences. The prospective participant was asked to provide consent online by indicating "yes" or "no" to the question asking if she wished to participate after having read and understood what was being asked of her. For their participation, student-participants received experimental credit that could be applied toward designated psychology courses.

Upon completion of the initial informed consent procedure, students who elected to proceed participated in the first part of the study. In Stage I, participants were asked to complete demographic questions and series of questionnaires including scales of social

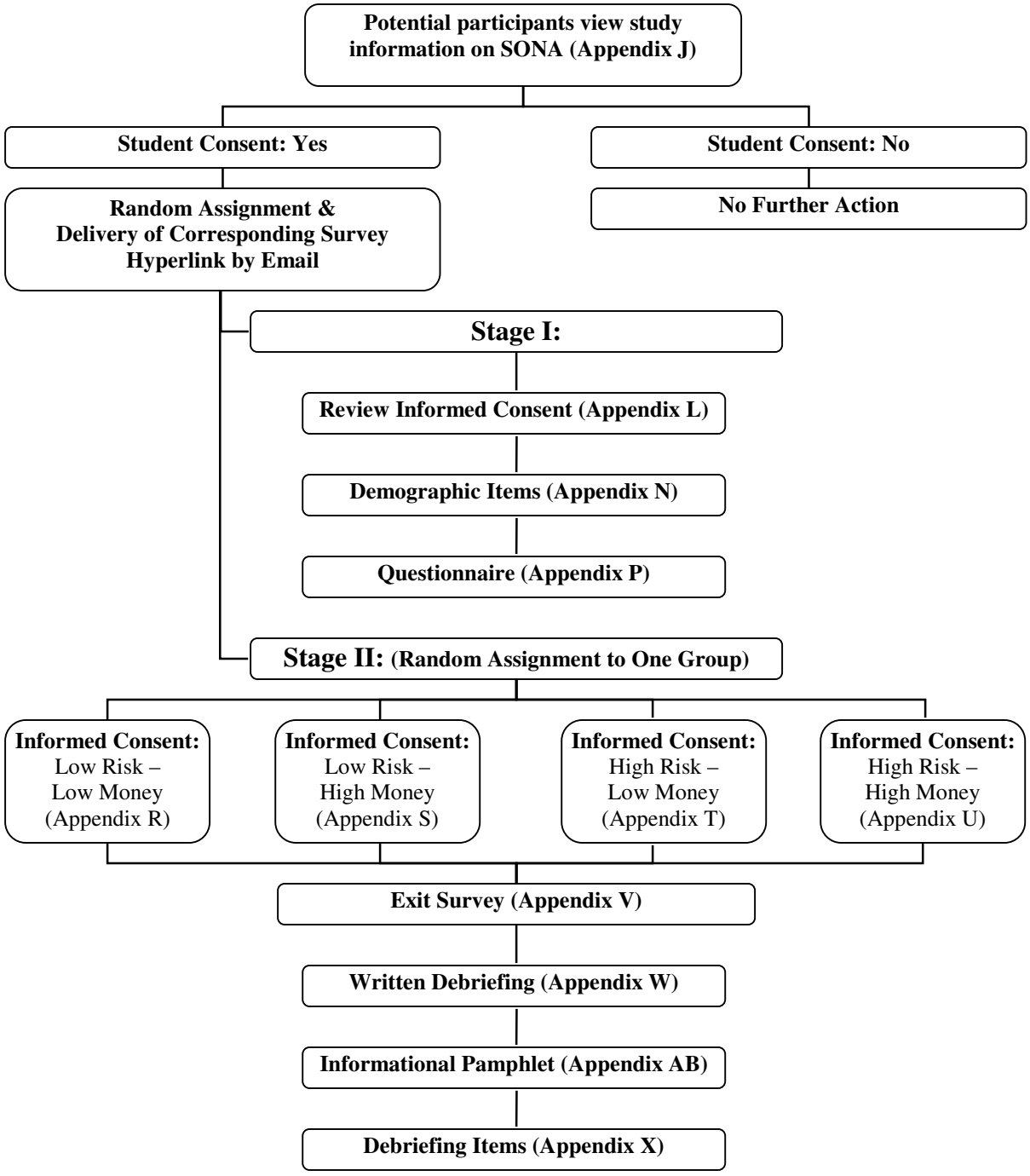
desirability, sensation seeking, and a five-factor model of personality (see Appendix N & P for demographic questions and the questionnaire, respectively).

At the conclusion of the questionnaire, Stage II asked students to view an "additional research opportunity" in the form of a faux consent form (see Appendix Q for the “additional research opportunity” page; see Appendixes R, S, T, & U for the experimental informed consents). The mock consent form was part of the experimental manipulation and represented a hypothetical research study that did not actually take place.

After reading the mock informed consent document, students were able to denote their consent or non-consent in a manner identical to the first informed consent. Regardless of interest in participation, all students were asked to complete a series of exit survey items (see Appendix V) including a rating of willingness to participate, perceived risk, and other items asking about behaviors and perceptions regarding genetic research. This section was followed by a written debriefing and several questions regarding participants’ reactions to participation in a deception study (see Appendix W for the debriefing; see Appendix X for the post-debriefing items). A flowchart of the study participation protocol can be found in Figure 2.

This two-stage experiment involved four treatment conditions with a 2 x 2 design (high or low risk to privacy & high or low hypothetical monetary compensation). Each participant was exposed to only one treatment condition, either low money-low risk, low money-high risk, high risk-low money, or high risk-high money. There were four separate survey links corresponding to the four treatment conditions, conditions were randomly assigned to individuals in a given timeslot. Participants were not aware of the treatment

Figure 2
Experimental Participation Protocol



conditions or his/her group placement. Students who wished to cease participation were free to withdraw from the study at any point.

Stage I included demographic and questionnaire items (see Appendixes N and P, respectively), Stage II included the presentation of one of four mock experimental consent forms (see Appendixes R-U) and an exit survey (see Appendix V). These experimental informed consents were constructed manipulations of two independent variables, fictional risk to privacy and hypothetical monetary compensation. The first stage served as a means to collect questionnaire data and to disguise the experimental manipulation (i.e., the four experimental informed consent forms) presented in the second stage, which allowed collection of data regarding the behaviors and opinions of nonparticipants.

Independent Variable

This study had two independent variables with a 2 (level of privacy risk) by 2 (level of monetary payment), between-subjects, completely randomized design. Risk and monetary payment were manipulated using mock informed consent documents for a faux biomedical research project purporting to examine DNA and personality characteristics. The experimental informed consent forms (Appendixes R-U) were modeled after federal resources and examples of consent documents used in actual studies. Efforts were made to maintain consistent reading level and reading time for each of the experimental informed consent documents.

The high level of privacy risk included a statement that once the sample was used for the existing study it would be submitted to a repository in an identifiable format where a participant's DNA sample and associated information would be accessible for future use by

repository-approved researchers. This identifiable format represents a potential risk to privacy because the individual does not have control over the future use and dissemination of her personally identifying information. While uncommon, this data is susceptible to loss of privacy and misuse or sale of personal information.

The low level of privacy risk included a statement that once the sample was used for the existing study, it would be submitted to a repository anonymously. Participants in this group were also told that any code used to identify a sample would be stripped from his/her sample and data before submission so that there was no possibility of connecting the individual to his/her sample or data. This can be considered the safest option when a sample is to be put into a repository because personally identifiable data is not susceptible to intentional or unintentional privacy violation.

The level of payment, a high rate of $100 and low rate of $10, were estimated based on statistical analyses conducted on the pilot study data and guided by compensation rates recommended for a health system/university-run genetic repository by a large-scale university-based genetic research group (Partners Human Research Committee, *n*.d.). This study utilized a fictitious repository called the GENBEH (Genetic-Behavior) repository. A description of how the amount of compensation was calculated was not included in the informed consent to prevent the rationale from confounding the effect of the dollar amount. Each payment rate was described in the consent form under the heading "Costs and Compensation" and the amount was inserted in the following phrase:

> You will be compensated in the amount of $XX.$\underline{00}$ if your DNA sample is accepted to the GENBEH Repository, otherwise you will receive one credit for your participation. Compensation is contingent on the acceptance of a sample to the GENBEH Repository.

Dependent Variable

There were five dependent variables in this study: consent to participate, willingness to participate, willingness to participate without payment, willingness to participate with no repository, and a rating of the risks involved in this study.

Consent to Participate. Participants demonstrated their consent by marking yes to a question asking if they consent to participate in the stated study (see Appendixes R-U). While this did not serve as a behavioral measure of actual participation, the participant's consent was viewed in this sense as a behavioral variable because signing a consent form is a required step toward participation in any study and represents a commitment to act.

Willingness to participate. Willingness to participate was measured with a single item (Appendix V, item #141) rated on a 5-point scale with five being "very willing." This item asked the participant to rate her level of willingness to participate after reading the informed consent form. High scores indicate higher levels of willingness to participate.

Willingness to participate without payment. The effect on willingness to participate with a lack of monetary compensation was evaluated to separate the influence of money from the risk to privacy in the study. Item #150 (see Appendix V) asked participants to imagine they would not be paid to participate and asked how willing they would be to participate using a 5-point scale with five being "I would definitely participate even if I was not paid." The rating for the hypothetical items was similar to the measure of willingness to participate in that higher scores indicate higher willingness to participate.

Willingness to participate if there was not a repository. This item provided information about willingness to participate in a situation where samples would not be put into any form of repository. This was assessed with a single item (Appendix V, item #149)

using a 5-point scale, with five being "I would definitely participate even if the sample was not put in a repository."

Risk perception rating. A research participant's perception of risk is believed to be an important variable related to participation and willingness to participate. For this study, perceptions of risk were measured using four items (Appendix V, items #144-147), each on a 5-point scale; responses ranged from "Not at all" to "Very High" (coded values of 1 to 5 respectively). The items were presented following the administration of the experimental informed consent, open-response comprehension questions, and an item regarding willingness to participate in the aforementioned study.

The four risk items assessed perceptions of the amount of risk, concern for the privacy of their DNA sample, the probability of a negative consequence resulting from participation, and the severity of that consequence if it occurred. These items were adapted from Bentley & Thacker's study involving hypothetical informed consent documents (2004).

Using principal component analysis (PCA), they concluded that the summation of the items was appropriate. For this study, factor analysis was conducted on seven items to investigate the potential for multiple perceptive factors. An exploratory factor analysis, using principal axis factoring (PAF), was conducted to evaluate the suitability of two prospective factors, Risks and Enjoyment/Benefits. This analysis supported the factor structure of the Risks items; however, support for the second factor was limited. Details regarding the factor analysis process and outcomes are discussed in detail in the results section. Possible scores for the Risks scale ranged from 1 to 5 with higher scores indicating greater levels of risk perception.

Order of Variables

In an effort to disguise the true purpose of the study, an essential element needed to investigate this behavioral phenomenon, it was necessary to conduct the research in two segments. The initial segment of the study was presented under the guise of a survey on personality characteristics. This allowed for the collection of data on social desirability, sensation seeking, and the big five personality traits, that would act as covariates and additional variables of interest. The deception presented by the first study was needed for the second segment involving the experimental informed consent forms because there was no other feasible way to measure non-participant opinions, risk ratings, and level of willingness to participate. The current online research pool system used by the department is not equipped to track or survey individuals who do not consent to research studies. For this reason, it was necessary to first attract students who would normally enroll as participants, and subsequently observe their decisions regarding research participation.

To avoid biasing responses, the demographic and personality items were presented first, followed by the experimental informed consent, and finally, the exit survey and debriefing. The names of the instruments from which the items were drawn were not presented to participants, and some of the subscale items were shuffled to inter-mix items from different subscales within the instrument.

Measures

Social Desirability. As many of the items in this study were self-report, socially desirable responding was of concern. The Balanced Inventory of Desired Responding (BIDR), version 6 form 40A, was developed by Paulhus (1991) as a two-factor self-report measure of social desirability. Each of the two factors, Self Deceptive Enhancement (SDE)

and Impression Management (IM), consist of 20-items, making this version a 40-item measure. Self-deception is the unintentional propensity to portray oneself in a favorable light. Individuals have a positively biased, yet genuinely believed, sense of self. Individuals with high self-deception tend to have a high degree of confidence, they are well adjusted, and they ignore minor criticisms (Paulhus, 1991). In contrast, impression management is related to the intentional distortion of one's self-image to be seen in a more favorable manner by others..

Although the original scale utilizes a seven point Likert-type scale, for this study, responses were made in a five point Likert-type format from 1 (*Not True*) to 5 (*Very True*) due to limitations of the response forms. For each subscale, half of the items were reverse-scored. According to Paulhus (1991), two methods exist for calculating BIDR scores, dichotomous and continuous scoring. Due to the use of a five point Likert-type format, the dichotomous scoring method would not be possible. Using the continuous method, potential scores for each subscale range from 20-100, which were then divided by the number of items in the scale to maintain the original metric. High scores indicate socially desirable response patterns consistent with the subscale descriptor. A copy of the measure (using a five point Likert-type scale) can be found in Appendix Y. The items as presented in the questionnaire packet can be found in Appendix P (items #11-50).

Based on the body of literature, alpha coefficients for samples using the SDE range from .67 to .77, and .76 to .85 for samples using the IM subscale of the BIDR. In this study, the attained alpha coefficients were .61 for SDE and .74 for IM (n = 182). The Marlowe-Crowne, an established measure of social desirability, has been used to evaluate the concurrent validity of the BIDR subscales (Pauls & Crost, 2004). Correlations with the Marlowe-Crowne were .37 and .46 for the SDE and IM subscales, respectively.

Sensation Seeking. The Sensation Seeking Scale, Form V (SSS-V) (Zuckerman, Eysenck, & Eysenck, 1978) is a 40-item measure of individual differences in stimulation and arousal needs containing four subscales: Thrill and Adventure Seeking (TAS), Experience Seeking (ES), Disinhibition (Dis), and Boredom Susceptibility (BS). A copy of the original, unedited version, of this scale can be found in Appendix Z. For the present study, some of the item wordings or phrases were deemed outdated (e.g., jetsetters) and were substituted with modern phrases expressing similar surface content. The reworded item version can be found in the questionnaire packet (Appendix *P*, items #51-90).

The Sensation Seeking Scales are currently in a sixth revision; form five was selected for use in this study due to psychometric, as well as practical reasons (e.g., number of items, administration time). The SSS-V is composed of four subscales making up the SSS Total. The subscales are Thrill & Adventure Seeking (TAS), Experience Seeking (ES), Disinhibition (Dis), and Boredom Susceptibility (BS). Descriptions of each scale and their potential influence on participation in genetic research are presented below.

Thrill and Adventure Seeking (TAS). Items in this subscale are expressions of a desire to engage in physical activities that provide atypical sensations and experiences. These activities may include mountain climbing, skydiving, scuba diving, and other activities that involve sensations of speed or defiance of gravity. According to Zuckerman (2007a), the activities are commonly perceived as moderately risky, and therefore, deter low sensation seekers; however, is not the risk, but the rewarding sensations that entice high sensation seekers.

Based on the definition of this subscale, it appears to be unlikely that the activities proposed in this study would elicit evaluations similar to privacy risk. Therefore, while there

may be a general tendency to engage in risky behaviors among individuals scoring higher on this subscale, it is unlikely that the relationship between this scale and research participation would be as strong as with other subscales in the SSS-V.

Experience Seeking (ES). The Experience Seeking subscale describes sensations and new experiences involving the mind and the senses, such as art, music, and travel. This scale also included items related to "nonconforming general lifestyles with like-minded friends" (Zuckerman, 2007a, p. 13). An example of an item in this subscale includes willingness to try new foods, or meet new people.

In the history of the Sensation Seeking Scales, this subscale has received the most notable revision due to now-anachronistic terms such as *hippies*. In 1996, Zuckerman revised and added definitions to confusing terms and labels throughout the Sensation Seeking Scales; however, many items have again become outdated, and many have been revised for use in this study. Of all of the subscales, the Experience Seeking subscale appears to be the most likely to pick up an individual's willingness to participate in a novel research study, and for that reason, has been a target of close attention in this study.

Disinhibition (Dis). The items in this factor describe social sensation seeking, that is hedonistic activities such as "wild" parties, drinking to intoxication, and sexual promiscuity. Attitudes expressed in this subscale include enjoyment of activities regardless of convention or legality. Zuckerman (2007a) notes that the subscale is relatively unrelated to education, race, or class, and highly related to biological sensation seeking factors. Additionally, this scale has the potential to differentiate psychopathic personalities from non-psychopathic criminals and normals when paired with an aggression scale. Because no documented

biological influences have been noted regarding willingness to participate in research, it was unclear whether this subscale would be related to genetic research participation.

Boredom Susceptibility (BS). The fourth subscale is the weakest factor to emerge from factor analysis and has less internal reliability than the other three subscales. Boredom Susceptibility items represent restless aversion to monotonous or repetitive experiences and uninteresting people. Individuals high in Boredom Susceptibility are likely to prefer activities and friends that are exciting and unpredictable rather than reliable and predictable. This scale is closely related to the Disinhibition subscale, and it was therefore expected to have a similar relationship to genetic research participation.

Two types of items are presented in the SSS-V, the first type is stated as expressed desires to engage in activities; the second type of item is behaviorally oriented toward actual experiences. Many of the TAS items utilize the first type of statement, while the second type is found primarily in the Dis subscale. Many of the ES and BS items are phrased as preferences, but are not easily translatable into behavioral expressions (Zuckerman, 2007a).

Each item, regardless of the type of question or subscale, was presented in a forced-choice form with two phrases of which the participant was asked to select the one they most closely affiliate. The forced-choice format was originally developed to reduce social desirability and acquiescence response sets, although the influence of social desirability has not played as big a role as expected in later examinations (Zuckerman, 2007a). Newer versions of the SSS utilize true-false dichotomies; however, for research purposes, the SSS-V is still the preferred form (Zuckerman, 2007a).

The total score is calculated from the sum of the four ten-item subscales. Scores on the SSS-V can range from 0 to 40 for the Total score, and 0 to 10 for each of the four

subscales. One point per item was given for each response in the stated direction. Scored were summed for each subscale. All items in a subscale are independent of other subscales.

The SSS-V has reported internal reliabilities for the Total score between .83 and .86. Subscale reliability ranges reported in the literature were: TAS, .77-.82; ES, .61-.67; Dis., .74-.78; BS, .56-.65 (Zuckerman, 2006). In this study, the attained alphas were: TAS, .74; ES, .53; Dis, .71; BS, .49 (n = 182).The SSS-V has a three-week test-retest reliability of .94. The factor structure of the SSS-V subscales has been adequately replicated across a variety of western cultures, with more examination needed in other cultures (Ball, Farnill, & Wangeman, 1983; Birenbaum, 1986; Carton, Jouvent, & Widlocher, 1992).

Regarding the construct validity of the SSS-V, the use of subscales allowed examination of which of the scales were most related to specific phenomena. Consistent with the definitions of the subscales, the ES "Experience Seeking" subscale was highly related to art and design preference, while TAS "Thrill and Adventure Seeking" subscale was related to engagement in extreme sports. Of the subscales examined in this study, ES was seen as having the greatest conceptual relation to willingness to participate in novel or even risky research studies. Zuckerman (Zuckerman, 2007b) noted the lasting reliability of this measure and noted its good discriminate validity.

Five factor model of personality. The International Personality Item Pool representation of the NEO Personality Inventory Revised (IPIP-NEO) measures personality traits based on a five-factor model. The IPIP-NEO is framed after the NEO-PI-R, which was developed by Costa and McCrae (1992) using factor analytic methods. This taxonomy of personality traits is not the only model; however, a five-factor model has been found to have the greatest consistency across competing models and has broad support among researchers.

The IPIP-NEO was developed by Goldberg (1999; 2006) using a similar factor analytic process, using variations of the statements found in the NEO-PI-R, to provide a public-domain research item pool (see http://ipip.ori.org/ newScaleConstruction.html). The IPIP-NEO boasts a normative sample of over 20,000 individuals and has acceptable internal reliabilities. The IPIP-NEO has the same structure as Costa & McCrae's (1992) NEO-PI-R, that is, they both containing five domains: Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Openness to Experience.

Neuroticism (NEO-N). The first factor is Neuroticism. This factor contrasts emotional stability with negative emotionality. Individuals high in neuroticism may be more likely to experience feeling anxious, sad, or tense. Low neuroticism does not suggest an individual is happy, but that she is in greater control of her emotions. Sjöberg (2003) found a negative correlation with Neuroticism and risk perceptions across a variety of hazards.

Extroversion (NEO-E). The second factor, Extroversion, focuses on the direction of energy; that is, does the person focus inward on thoughts and ideas or outward on events and actions? Individuals high in extroversion are more likely to be assertive and poised and may be at ease even in difficult situations. These characteristics make extroverts particularly likely to engage in risky health behaviors (Vollrath & Torgersen, 2002). Chauvin et al. (2007) found high extroverts rated risky outdoor activities as less risky than individuals scoring lower on this trait. They deduced that because extroverts focus on action, they might not take time to intellectualize the risk.

Openness to Experience (NEO-O). The third factor of Openness to Experience (OE) is related to curiosity and an individual's approach toward novel stimuli. Individual's high in openness to experience are likely to see exposure to art, knowledge, sexual variety, and drug

use as less risky compared to individuals who are not open to experience. Barring drug use and sexual activity, the content of this scale appears to be the most similar trait congruent to the types of risks participants in the present study would be asked to complete. For this reason, it was expected that individuals high in openness to experience would also be most likely to provide lower risk ratings and be more willing to participate.

The Openness to Experience factor of the NEO-PI-R is similar to factors of the Sensation Seeking Scale, particularly the Experience Seeking subscale of the SSS-V. McCrae & Costa (1987) examined this relationship and found that Openness to Experience correlated moderately with the SSS Total (r = .45) and significantly with all other SSS subscales except Boredom Susceptibility. Not surprisingly, Openness to Experience and Experience Seeking, both measures of adventurousness, correlated higher than other scales (r = .51). In this study, Openness to Experience and Experience Seeking correlated significantly at r = .39, which was lower than the literature, but still comparatively higher than correlations between either scale with any other scales.

Agreeableness (NEO-A). The fourth factor is Agreeableness and is closely related to how individuals treat others. Individuals high in agreeableness are good natured and likely to cooperate with and trust others; agreeableness is contrasted with antagonism.

Conscientiousness (NEO-C). The final factor is Conscientiousness and describes a person who is responsible and dependable. By their nature, conscientious individuals are less likely to take risks due to precaution and foresight, a finding supported by the literature (Paunonen & Ashton, 2001; Vollrath et al., 1999).

For this study, five-factor traits were assessed, with each domain consisting of 10 items; some items within a scale were reverse scored. Respondents were asked to rate how

accurately various phrases, such as "(I) waste my time," describes them. Ratings were made on a 5-point scale, with five being "very accurate." Appendix AA shows the keying and alpha coefficients for each of the 10-item domain subscales. In the questionnaire packet (see Appendix P), the IPIP-NEO items were shuffled and are displayed in items #91-140 of the research questionnaire.

The average of the coefficient alpha values for the 50-item IPIP broad domain scales is 0.82. Goldberg (1999) reported the NEO-PI-R average coefficient alpha value at around 0.75. The average correlation between the IPIP-NEO and the NEO-PI-R is 0.77 (0.90 when correcting for attenuation due to unreliability), ranging from 0.82 (Neuroticism) to 0.70 (Agreeableness). (see http://ipip.ori.org/newNEO_DomainsTable.htm). In the present study, alphas for Agreeableness, Conscientiousness, Extraversion, Neuroticism, and Openness to Experience were .79, .80, .86, .86, & .77, respectively.

Stimulus Materials

Four experimental informed consent forms (see Appendixes R-U) have been created to match all combinations of levels of privacy risk and monetary compensation. All parts of the informed consent forms were identical except the description of how the samples would be submitted to the repository and the amount, in U.S. currency, participants would be paid as compensation.

For the two levels of privacy risk, one of the following statements was presented in the *Confidentiality* section. The variations between statements have been underlined in this presentation for the readers benefit; the passage was presented without this aid for the participant:

Low Privacy Risk:

> Samples submitted to the GENBEH Repository will be anonymous, that is, your personal identifier or code will be removed to your sample. No information will be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use anonymous study information to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.
>
> It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does, but because samples have been stripped of identifying data there is no way of matching you to your sample.

High Privacy Risk:

> Samples submitted to the GENBEH Repository will include identifying information, that is, your personal information will be attached to your sample. This information may be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use study information that identifies you to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.
>
> It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does and may disclose identifiable information to others.

The following statement, found in the *Cost and Compensation* section, was used to present one of the two possible levels of monetary compensation ($10 or $100):

> You will not have any costs from participating in this study. You will be compensated in the amount of $X.00 if your DNA sample is accepted to the GENBEH Repository, otherwise you will receive one credit for your participation. Compensation is contingent on the acceptance of a sample to the GENBEH Repository.

An effort was made to maintain approximately equal passage lengths and readability as measured using the Flesch-Kincaid Grade Level formula. This readability formula produced an approximate grade level of 11 across all forms of the mock consent. The format

for the final version of the informed consent forms mirrored the style and format of similar biomedical informed consent forms and was consistent with IRB regulations of the university where the research was conducted. The experimental informed consent forms were also evaluated by a member of the university IRB in order to judge the plausibility and realism of the experimental consent document.

Deception/confidentiality

The APA code of professional ethics requires that studies involving deception make every effort to ensure the safety and wellbeing of participants. This study involved a deceptive element in which participants were lead to believe that they would be engaged in research involving collection of a genetic sample and its submission to a genetic repository under various levels of anonymity and for various levels of monetary compensation.

The reality of the study's deception was that no samples were collected, analyzed, or submitted to repositories. This study did not involve the collection of a biological sample and did not actually connect the participant's name to her data, despite the appearance of the survey. The data collected from the participants utilizes a unique research ID assigned by the internet survey provider. This ID was not associated with the individual's name or other identifying information.

Debriefing

For studies involving deception or incomplete disclosure, it is recommended that a debriefing be used to fully inform participants. Because deception studies have the potential to lead to psychological stress, guilt, or embarrassment, debriefings allow researchers to assess and help participants cope with distressing elements, if present.

The debriefing for this study included a thorough written debriefing and extensive educational material regarding privacy, informed consent, and genetic studies (see Appendixes W & AB). The written debriefing included information about the true nature of the study, and included details regarding the procedures and treatment conditions, including rationale for the deception and for not providing monetary compensation. Participants were informed that their information was confidential and any personally identifiable information would be removed from their data. They were also reminded of their right to have their data stricken from the study if desired.

Educational elements of the debriefing included written statements about the importance of reading and comprehending an informed consent document. An educational pamphlet (see Appendix AB), created by the researchers, was also provided to participants. This pamphlet included basic information about genetic research studies, the Genetic Information Nondiscrimination Act (GINA), elements of an informed consent, and a bill of rights for research participants.

To assess the effect of the deception and subsequent debriefing, participants were asked to answer five post-debriefing questions (see Appendix X). The first questions assessed changes in awareness of privacy risks and participants' trust in psychological research as a result of participating in this study. This was followed by an item asking if a participant would have participated again, given what they know after participating in the study. The final two items assessed the participant's ability to maintain the secrecy of the deception and the truthfulness of her responses during the study. Of the final sample (n = 182), all but three participants reported that they would be able to maintain secrecy regarding the deceptive elements. The final item, assessing the truthfulness of responses, netted two

participants that admitted to untruthful responding; these participants' data were removed from the total sample as part of the exclusionary criteria.

Study Design

This attitudinal and behavioral study was developed as a 2 (level of privacy risk) by 2 (level of monetary payment), between-subjects, completely randomized design. Participants were randomly assigned to one of four conditions. The conditions were as follows: anonymous database entry of personal information (low risk) with $10 (low money), anonymous personal information (low risk) with $100 (high money), identifiable database entry of personal information (high risk) with $10 (low money), and identifiable personal information (high risk) with $100 (high money).

The primary dependent variables, consent to the experimental study and willingness to participate in the experimental study were analyzed separately using a variety of statistical analyses. Consent behavior, as a dichotomous "yes" or "no" decision, was analyzed using Pearson's Chi-Square test of independence. Willingness to participate, measured on a five-point Likert-type scale, was analyzed using independent *t*-tests, analyses of variance (ANOVAs), and analyses of covariance (ANCOVAs). Each ANCOVA examined the potential effect of a single covariate on each of the respective dependent variables. The prospective covariates were gender, the NEO-PI personality dimension of Openness to Experience (NEO-O), and the Sensation Seeking Scale-V (SSS-V) dimension of Experience Seeking (SSS-ES). The scales of the BIDR were also investigated as covariates.

Additional dependent variables were investigated. Perceptual factors of risks and benefits were evaluated by seven items probing elements that were believed to influence the likelihood of participation. These elements included the following: perceptions of others'

willingness to participate, anticipated enjoyment in the study, importance of monetary compensation, concern regarding the loss of the privacy of personal information as a result of participation, perceived risk to privacy from having a DNA sample put in a repository, the probability that the personal information would be used in an unethical manner or inconsistent with the wording of the informed consent, and the seriousness of the negative consequences related to loss of privacy if they occurred (see Appendix V for item wordings). Exploratory factor analysis was used to explore the potential factor structure underlying these items (discussed on page 92). The resulting factors were then used as variables of interest.

Data Analysis

Demographic information was analyzed via SPSS 14 to provide descriptive statistics and measures of central tendency and standard deviations. Interscale correlations and scale reliabilities were also evaluated. Separate ANOVAs and *t*-tests were used to determine the presence of significant differences and interactions between monetary compensation and level of privacy risk in relation to each of five separate dependent variables. These dependent variables included a behavioral measure of consent to research, ratings of perceived privacy risk, and willingness to participate in the study under three conditions (as stated in the informed consent, hypothetically with no payment, hypothetically with no repository) (see Appendix P, items #141, #149, & #150 ,respectively). Measures of social desirability (Appendix P: items #11-50), sensation seeking (Appendix P: items #51-90), and the Big Five personality traits (Appendix P: items #91-140 were used as covariates and additional variables of interest.

Comprehension was assessed with five open-response items. Three raters, the primary researcher, and two independent raters who were unaware of the hypotheses, scored each

item using specific standards based on content presented in the experimental consent documents. Interrater reliability was assessed using intraclass correlation coefficients; a two-way mixed model was used. The results of these analyses are presented in the additional findings section (p. 118). Ratings were highly consistent across raters, and the convergence of at least two scores was used to determine the final rating of comprehension for each participant and item.

Where the hypotheses stated a difference in a continuous dependent variable between two levels of an independent variable, an independent *t*-test was used to investigate the presence of significant differences (Hypotheses 1a, 2a, 4 & 5). The hypothesis including an interaction among variables (Hypotheses 3) was examined using a two-way ANOVA. For the hypotheses including the dichotomous dependent variable of consent behavior (yes/no) (Hypotheses 1b, 2b, 6), a Pearson's Chi-Square test of independence was employed. Hypotheses 7 & 8 were analyzed using paired sample *t*-tests. These paired *t*-tests examined within-participant differences across a rating of willingness to participate under the presented conditions and willingness to participate under hypothetical conditions (i.e., no money, no repository). All analyses were evaluated using a 95% confidence level.

Power Analysis

An a priori data collection power analysis was completed using a needed power of 0.80 and a significance level of .05. In order to find medium main and interaction effects (d = 0.51) (as defined by Cohen, 1988), with four degrees of freedom, a total of 189 participants were needed (Murphy & Myors, 2004). The final sample closely approximates this number (n = 182) with roughly equal treatment group sample sizes.

Results for Main Study

Data Normality

Prior to an examination of the data, statistics of skew and kurtosis were computed to determine if an assumption of normality could be met. A series of histograms and scatterplots were also generated for this purpose. Table 10 presents skew and kurtosis values for all variables. While a number of the variables showed signs of skew or kurtosis, based on the sample size, it is unlikely that the distributions were amply nonparametric to impede standard statistical analyses. As a result of this examination, it was determined that no transformation of the data were necessary.

Descriptive Statistics for Measured Variables

Means and standard deviations for the independent and dependent variables were examined. Table 11 provides a summary of these statistics for each of the 13 independent variables and variables of interest measured. The means and standard deviations for the three continuous dependent variables measured are presented in Table 12.

Reliability

Statistics for internal consistency of this sample were computed for each of the 16 measured scales. The alpha coefficients for the 182 participants are presented on the diagonal axis in Appendix AC. The coefficients alpha were relatively consistent with those reported for each scale in the literature (see Table 13 for comparisons).

Interscale Correlations

Pearson product moment correlations were calculated as estimates of the correlations between the majority of the scales explored in this study. Due to the large number of comparisons, a Bonferroni correction was applied. Appendix AC presents the results of this

analysis. Among the significant correlations, the most noteworthy was the moderately strong positive correlation between the Sensation Seeking Scale – Experience Seeking and the IPIP-NEO's Openness to Experience. This finding provided some evidence that these were related concepts.

Table 10

Skew and Kurtosis Values for All Variables

Variable	Skew	Kurtosis
Independent Variables		
COMP-TOTAL	-0.17	-1.04
SDE	0.40	1.21
IM	0.17	0.23
BIDR-TOTAL	0.38	1.14
TAS	-0.79	-0.11
ES	-0.13	-0.25
DIS	-0.38	-0.47
BS	0.43	-0.20
SSS-TOTAL	-0.28	-0.30
NEO-A	-0.32	0.00
NEO-C	0.02	-0.15
NEO-E	-0.28	-0.18
NEO-*N*	0.36	-0.18
NEO-O	0.04	-0.70
Dependent Variables		
WTP	-0.28	-1.14
HYPO-NO REP	-0.01	-1.01
HYPO-NO MONEY	0.43	-1.04
RISKS	0.18	-0.73

Note. n = 182; skew standard error = .18; kurtosis standard error = .36. COMP-TOTAL = Comprehension Total; SDE = Self-Deception Enhancement; IM = Impression Management; BIDR-TOTAL = Balanced Inventory of Desired Responding; TAS = Thrill and Adventure Seeking; ES = Experience Seeking; Dis = Disinhibition; BS = Boredom Susceptibility; SSS-TOTAL = Sensation-Seeking Scale Total; NEO-A = Agreeableness; NEO-C = Conscientiousness; NEO-E = Extraversion; NEO-N = Neuroticism; NEO-O = Openness to Experience; WTP = Willingness to Participate; HYPO-NO REP = Hypothetical of No Repository; HYPO-NO MONEY = Hypothetical of No Money; RISKS = Risk Perceptions Scale.

Table 11
Descriptive Statistics for Independent Variables

Independent Variable	*n*	*M*	*SD*
COMP-TOTAL	182	2.58	1.55
SDE	182	2.93	0.29
IM	182	2.92	0.25
BIDR-TOTAL	182	2.92	0.20
TAS	182	7.18	2.41
ES	182	5.78	2.08
DIS	182	5.41	2.45
BS	182	2.80	1.84
SSS-TOTAL	182	21.16	5.76
NEO-A	182	36.73	5.39
NEO-C	182	33.21	5.95
NEO-E	182	33.74	6.69
NEO-*N*	182	25.55	7.12
NEO-O	182	36.08	6.25

Note. COMP-TOTAL = Comprehension Total; SDE = Self-Deception Enhancement; IM = Impression Management; BIDR-TOTAL = Balanced Inventory of Desired Responding; TAS = Thrill and Adventure Seeking; ES = Experience Seeking; Dis = Disinhibition; BS = Boredom Susceptibility; SSS-TOTAL = Sensation-Seeking Scale Total; NEO-A = Agreeableness; NEO-C = Conscientiousness; NEO-E = Extraversion; NEO-N = Neuroticism; NEO-O = Openness to Experience.

Table 12.
Descriptive Statistics for Dependent Variables

Dependent Variable	*n*	*M*	*SD*
WTP	182	3.26	1.37
HYPO-NO REP	182	2.90	1.30
HYPO-NO MONEY	182	2.47	1.35
RISKS	182	2.55	0.96

Note. WTP = Willingness to Participate; HYPO-NO REP = Hypothetical of No Repository; HYPO-NO MONEY = Hypothetical of No Money; RISKS = Risk Perceptions Scale.

Table 13

Comparison of Coefficients Alpha

Variable	Full Sample	Literature	Source
BIDR			
SDE	.61	.67-.77	Pauls & Crost, 2004
IM	.74	.76-.85	Pauls & Crost, 2004
SSS-V			
TAS	.74	.77-.82	Zuckerman, 2006
ES	.53	.61-.67	Zuckerman, 2006
DIS	.71	.74-.78	Zuckerman, 2006
BS	.49	.56-.65	Zuckerman, 2006
TOTAL	.77	.83-.86	Zuckerman, 2006
IPIP-NEO			
NEO-A	.79	.77	Goldberg, 2006
NEO-C	.80	.81	Goldberg, 2006
NEO-E	.86	.86	Goldberg, 2006
NEO-*N*	.86	.86	Goldberg, 2006
NEO-O	.77	.82	Goldberg, 2006
RISKS	(.80)	.96	Bentley & Thacker, 2004

Note. Item wordings for the Risk Perception Scale (RISKS), used in this study, are slightly different from the referenced literature. BIDR = Balanced Inventory of Desired Responding; SDE = Self-Deception Enhancement; IM = Impression Management; SSS-V = Sensation Seeking Scale (5th ed.); TAS = Thrill and Adventure Seeking; ES = Experience Seeking; Dis = Disinhibition; BS = Boredom Susceptibility; SSS-TOTAL = Sensation-Seeking Scale Total; IPIP-NEO = International Personality Item Pool representation of the NEO-PI-R; NEO-A = Agreeableness; NEO-C = Conscientiousness; NEO-E = Extraversion; NEO-N = Neuroticism; NEO-O = Openness to Experience; RISKS = Risk Perceptions Scale.

Factor Analysis of Research Risks/Benefits Perception Items

In an effort to determine how many latent factors were present among the research perception items used in this study, an exploratory factor analysis was conducted. In a study by Bentley & Thacker (2004), a five-item scale was created to assess the perceived likelihood and severity of negative consequences of research participation. Principal components analysis indicated a single factor that was subsequently used as a variable to

evaluate willingness to participate in research. The present study, which included modifications of Bentley & Thacker's items, sought to investigate the possibility of additional factors resulting from the introduction of additional items assessing participants' perceptions of others' willingness to participate, perceived enjoyment, and the importance of money in the decision to participate. A total of seven items were subjected to the factor analysis.

Data Screening

The sample for analysis included 182 undergraduate students from a large Midwestern university. Demographics for this group have been detailed earlier in this manuscript (see Appendix O). Prior to conducting the EFA, participant responses were screened for missing data, and, based on a maximum of three missing responses per individual, omitted responses were replaced with the whole number closest to the mean score of the sample's responses. Of the 182 participants, 96.70% of the respondents answered all of the questions. Of the remaining percent, only six substitutions were made; that is one per each individual with missing data. The data was screened for outliers. Two out-of-range outliers were present, one each for items 142 and 148. Inspection of these data points suggested they were within an acceptable distance from the mean for that item.

The factorability of the data for the items was supported by highly significant Bartlett's Test of Sphericity tests and Kaiser's (1970) measure of sampling adequacy (Kaiser-Meyer-Olkin MSA), as well as, suitable anti-image correlations. Bartlett's test of sphericity was significant (χ^2 (21, N = 182) = 305.97, $p < .001$). Bartlett's test indicates whether the correlation matrix is an identity matrix, which would indicate that the variables are unrelated. For this test, smaller significance levels support the assumption that there is a significant

relationship between the variables. The Kaiser-Meyer Olkin test of sampling adequacy value of .755 exceeded the minimum recommended value of .6 (Tabachnick & Fidell, 2007). This measure indicates the proportion of variance in the variables, which is common variance, potentially caused by the underlying factors. The diagonals of the anti-image correlation matrix were all over .5, supporting the inclusion of each item in the factor analysis. The anti-image matrices include the negative partial covariances and correlations and can indicate which correlations are not related to common factors. The diagonal of the anti-image correlation matrix is also known as the Measure of Sampling Adequacy (MSA), with values greater than .5 suggesting a good fit with the structure of the other variables. Item-to-item correlations can be found in Table 14.

Lastly, initial communalities were examined. Communalities are the variance in an item that is shared with at least one other item in the analysis. The initial unrotated communalities for this analysis ranged from .09-.57 (see Table 15). Kahn (2006) notes that communalities for this sample size should ideally be near .5, but may be as low as .3 if the purpose is to include the greatest number of items. Examination of the items in the above table shows that the items with insufficient communality include others' willingness to participate, importance of monetary compensation, and enjoyment of participation. Given the exploratory nature of this analysis and the other positive evidence for inclusion, factor analysis was conducted with all seven items.

Table 14

Correlations for Seven Items Entered Into Factor Analysis

Variable	1	2	3	4	5	6	7
1. Others	-						
2. Import$	.17*	-					
3. PrivDNA	-.24*	0.04	-				
4. Risk	-.16*	0.04	.68*	-			
5. Prob	-.19*	0.12	.55*	.59*	-		
6. Serious	-.15*	0.03	.39*	.48*	.41*	-	
7. Enjoyment	.35*	.24*	-.13*	-0.1	-0.12	-0.08	-

Note. * = $p < .01$; * = $p < .05$. Others = Perceived willingness of others; Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation.

Table 15

Factor Loadings Based on a Principal Axis Factor Analysis with Varimax Rotation for the Research Perception Items (n = 182)

			Communalities	
Item	**Factor 1**	**Factor 2**	**Initial**	**Extraction**
Risk	**.85**	-.02	.56	.73
PrivDNA	**.77**	-.11	.51	.60
Prob	**.72**	-.04	.42	.51
Serious	**.55**	-.05	.26	.30
Enjoy	-.10	**.63**	.16	.41
Other	-.22	**.52**	.18	.32
Import$	.11	**.39**	.09	.16

Note. Significant Varimax-rotated coeffiecients are those >.40 and appear in boldface. The two-factor rotated solution accounted for 43.3% of the variance. The two factors were correlated at r = -.11, p = .13. Risk = Perceived risk of study; PrivDNA = Concern about loss of genetic/personal information privacy; Prob = Perceived probability of unethical use of information; Serious = Perceived seriousness of loss of privacy; Enjoy = Perceived enjoyment of participation; Other = Perceived willingness of others; Import$ = Importance of monetary compensation.

Principal Axis Factoring

Items were subjected to an exploratory principal axis factoring method using SPSS 14. Principal axis factoring (PAF) was selected as the extraction method, over other methods

such as principal components analysis (PCA), due to PAF's purported increased accuracy. While PCA is found commonly in the literature, it is not a true factor analysis, and numerous authors have stressed that when the goal of analyses is to determine underlying latent factors in the data, PAF is preferable to PCA (Fabrigar, Wegener, MacCallum, & Strahan, 1999; D. W. Russell, 2002). The number of factors to be retained was guided by the following decision rules: inspection of the screeplot (Cattell, 1966), and the percentage of variance explained by each factor. The percentage of variance is valuable because it is a function of the strength of association between the factor and variables (Kahn, 2006).

Examination of a screeplot involves viewing the graph of the eigenvalues and looking for the natural bend or elbow in the data where the curve becomes asymptotic. Selecting a number of factors equal to the number of points above the "break," has been suggested as a reasonably reliable method of selecting the number of factors. In this dataset, the screeplot suggested a two-factor solution (see Figure 3). The initial eigenvalues (see Table 16) showed the first factor explained 38.60% of the variance, and the second factor 20.69% of the variance. The next three factors explained 11.38%, 9.33%, 9.19%, respectively. One, two, and three factor solutions were examined, using both Varimax and Promax (kappa = 4) rotations of the factor loading matrix.

The two-factor solution, which explained 59.29% of the variance, was preferred because of the good fit to the content and the "leveling off" of eigenvalues in the screeplot after two factors. Additionally, there were an insufficient number of primary loadings to interpret a third or subsequent factors. Examination of the items in each factor were suggestive of the following factor descriptors: Factor 1: Risks (4 items); Factor 2: Enjoyment/Benefits (3 items). Both Varimax and Promax solutions were examined and

found to be largely similar. Due to the relatively weak correlation among factors (r = -.11, p = .13), Varimax rotation was utilized for the final solution.

Figure 3
Scree Plot for Principal Axis Factoring

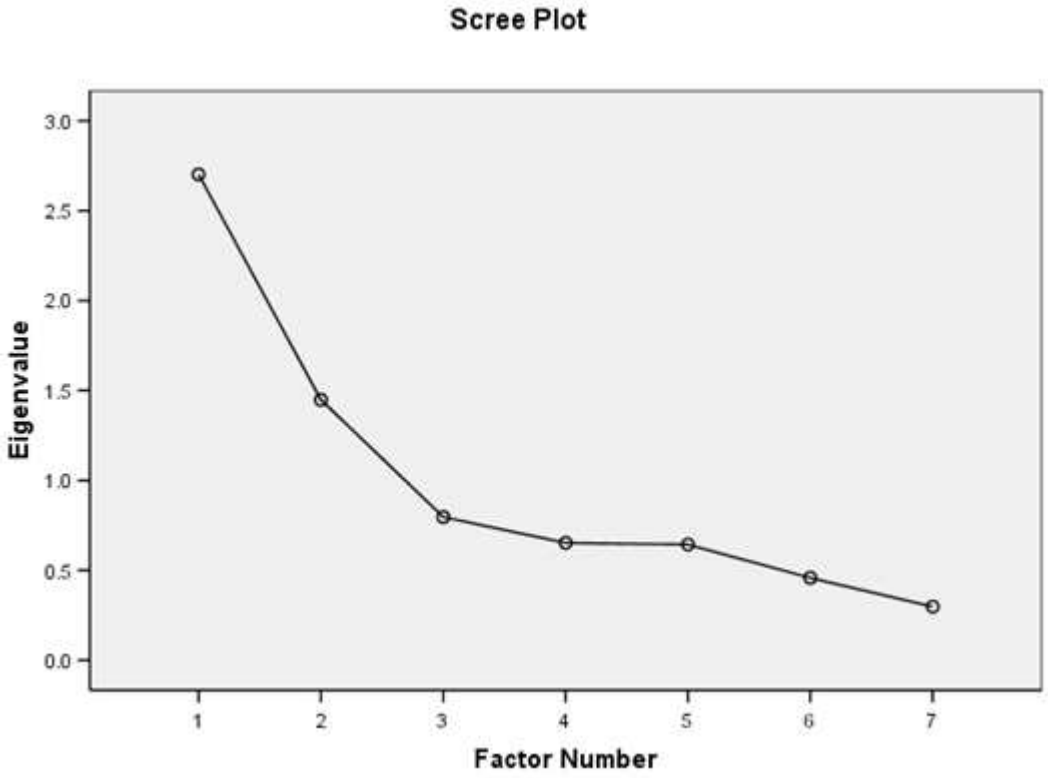


Table 16
Eigenvalues & Total Variance Explained

Factor	Initial Eigenvalues			Rotated Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	2.70	38.60	38.60	2.20	31.39	31.39
2	1.45	20.69	59.29	0.83	11.91	43.30
3	0.80	11.38	70.67			
4	0.65	9.33	80.00			
5	0.64	9.19	89.20			
6	0.46	6.55	95.74			
7	0.30	4.26	100.00			

Note. Extraction Method: Principal Axis Factoring.

One item was considered for elimination because it failed to meet a minimum criterion of having a factor loading of .40 or greater. The item "How important was the amount of compensation in your decision to participate?" loaded .389 on the second factor (Enjoyment/Benefits) and had a cross-loading of only .106 on the first factor (Risks). This factor was retained due to the close proximity of the "rule of thumb" factor loading criteria. In a sample with a greater degree of reading comprehension for the informed consent, it would be reasonably expected that this question might carry more weight in the factor loading. Examination of the distribution of scores for this item showed a slight bimodal distribution, with 26.9% reporting money was not at all important in their decision-making (i.e., the modal response of 1), while the median and mean(standard deviation) (3.00 and 2.86(1.44), respectively) suggested moderate importance of money.

The factor grouping proposed by Bentley and Thacker (2004) was supported by this principal axis factoring. Internal consistency for both scales was examined using Cronbach's alpha. Internal consistencies were $\alpha = .80$ for Risks (4 items) and $\alpha = .48$ for Enjoyment/Benefits (3 items). No substantial increases in alpha were possible through eliminating items from the Risks factor; however, removal of the item regarding the importance of monetary compensation would have increased the alpha to .52 for the Enjoyment/Benefits factor. Groups of items lacking adequate reliability are unlikely to form meaningful factors (Nunnally & Bernstein, 1994). Based on this consideration, the mediocre alphas for the second factor suggest the overall reliability of the combined items is lacking and that the items may be better viewed individually.

Composite scores were created for both factors using a summation of the items. To ease interpretation, the factor scores were divided by the number of items in that factor,

resulting in a range from 1 to 5 (with "5" being higher risk perception). This method was used over weighted scoring alternatives to avoid relying on the reproducibility of the weights derived from the factor analysis on this individual sample (Russell, 2002). For both factors, higher scores indicated greater perception of the factor label. Descriptive statistics for the factors are presented in Table 17. Skew and kurtosis were within a tolerable range for assuming a normal distribution. Examination of the histograms suggested that the distributions looked approximately normal (see Appendix AD).

Table 17
Descriptive Statistics for the Risks & Enjoyment/Benefits Factors

Factor	No. of items	*M* (*SD*)	Skew	Kurtosis	Alpha
Risks	4	2.91 (0.83)	0.10	-0.57	.80
Enjoyment/Benefits	3	2.55 (0.96)	0.18	-0.73	.48

Note. $n = 182$

Overall, these analyses indicated that two distinct factors were underlying the research perceptions responses and that at least one, namely the Risks factor, was moderately internally consistent. Given the poor communalities of all the Enjoyment/Benefits items and the mediocre factor loading of the item regarding the importance of monetary compensation, use of the individual items, rather than combined as a scale. Bentley and Thacker's (2004) risk rating factor was supported by the analysis and, for this study, was similarly named the Risks factor. Given this factor's adequate internal consistency, factor structure, and approximately normal distribution, the Risks factor data were well suited for subsequent parametric statistical analyses.

Comprehension

As part of this study's investigation of participants' reactions to informed consent documents, comprehension of the content of these documents was assessed. Following the administration of the experimental consent documents, all participants were asked to answer seven open-response questions. Of these items, five assessed comprehension by asking participants to recall specific information from the consent document (see Appendix V items C-G). In sum, these questions requested recall of information from the *Risks, Benefits, Costs and Compensation, and Confidentiality* sections of the consent document. Of greatest importance, students were asked to recall the amount of monetary compensation that was presented in the text and how participants' identifying information would be treated by the repository (i.e., risk level).

The percentage of individuals correctly responding across the comprehension questions ranged from 20% to 70%. A total of 128 participants (70.3%) recalled the basic physical risks from the consent document. Fewer participants, 86 (47.3%), were able to identify the stated benefits of the study. However, more than half of the individuals were able to recall the amount of monetary compensation and restate who would have access to the sample (n = 114 (62.6%) & n = 106 (58.2%), respectively). Interestingly, the final comprehension question, which assessed how the identifying information would be treated in the repository (i.e., anonymous or identifiable) produced the lowest number of correct responses, at 36 participants (19.8%). A breakdown of comprehension by item for each sample is presented in Table 18. The frequency counts and percentages by sample are included in Table 19.

Table 18
Number (Percentage) of Participants Correctly Recalling Informed Consent Information

Item	Full Sample	Comprehension Sample
C) Based on what you can remember, what were the risks of the SECOND study, as stated in the informed consent?	128 (70.3%)	25 (96.2%)
D) Based on what you can remember, what were the benefits of the SECOND study, as stated in the informed consent?	86 (47.3%)	22 (84.6%)
E) What is the monetary compensation in the SECOND study, as stated in the informed consent?	114 (62.6%)	26 (100%)
F) Who will have access to the repository, as stated in the informed consent?	106 (58.2%)	24 (92.3%)
G) How will your identifying information be treated by the repository?	36 (19.8%)	26 (100%)

Table 19
Frequency Count of Comprehension Items by Sample

Full Sample			Comprehension Sample		
Number Correct	*f*	% of Total	Number Correct	*f*	% of Total
0	23	12.6	0	0	0
1	27	14.8	1	0	0
2	33	18.1	2	0	0
3	39	21.4	3	1	3.8
4	40	22.0	4	5	19.2
5	20	11.0	5	20	76.9

Note. Full Sample n = 182; Comprehension Sample n = 26

It should be noted that from the original sample, the nonresponse rate increased in subsequent items, with the highest rate of nonresponse in the final item assessing the use of identifying information. For this reason, it is difficult to determine what amount of the lack of comprehension for later items was due to the effects of primacy and recency, and what was blinding, fatigue, or other factors. When attempting to define what warranted "comprehension," several formulas were considered including full comprehension (i.e., all items correct), a sum of the number of items correctly recalled, or a critical item comprehension approach (i.e., correct recall of money and risk level). The full comprehension formula appeared to be too stringent a method, although, 20 individuals (11% of the Full Sample) did recall all five items. The summing of comprehension items was not used because it appeared to capture individuals who comprehended many items, but not items critical to making judgments of risk or reward.

Ultimately, the critical item comprehension approach was selected for additional analysis because it best captured the important elements examined in this study and represented the higher end of comprehension performance (96.1% of this sample of 26 participants correctly answered at least four of the five comprehension questions). This method was used to group individuals who correctly identified both the monetary compensation amount and the risk level presented in the informed consent (n = 26, 14.3% of the Full Sample). This analysis is highly limited due to the low number of participants in each treatment group (n = 6, 12, 7, & 1 for low risk-low money, low risk-high money, high risk-low money, & high risk-high money, respectively). Across risk level, there were 18 low risk and 8 high risk participants. For monetary compensation levels, 13 participants were present in each level. There were not any significant differences in the number of men or

women across risk or monetary compensation levels. This sample was included as an illustration of a high comprehension group and it should not be used to draw significant conclusions about the dataset. Future studies, with larger samples of comprehending individuals, will be needed to draw adequate conclusions using these variables. Given this limitation, the Comprehension Sample is provided to demonstrate difference between the "normal" participant pool and a select group of "high comprehension" participants.

Main Analyses

This section includes the results of the major analyses across a sample of 182 participants, which includes individuals of various levels of comprehension of the informed consent document. In the process of evaluating this group, it became clear that only a small subgroup actually demonstrated significant comprehension of both risk and monetary compensation levels. In order to draw a distinction between what might be considered the "normal" population of undergraduate online research participants at this university and those participants showing sufficient comprehension of research risks and benefits, two identical analyses were performed on each group.

What will be called the "Comprehension Sample" is a 26-participant subsample of the "Full Sample" consisting of the 182 participants. Selection for the Comprehension Sample was based on the correct identification of both the monetary amount to be paid, and the correct identification of whether the genetic sample would be stored anonymously or identifiably. Of this sample (n = 26), 20 participants (77.0%) demonstrated perfect comprehension on all five questions regarding the informed consent document. In addition to representing a high degree of comprehension, the Comprehension Sample contrasts the Full Sample in that perception of risk across treatment groups were statistically significantly

different in the former, but not the later (see next section for details). As would be expected, those who do not comprehend the risks or benefits of the study were unlikely to make judgments with regards these matters. The Full Sample is presented to represent an ecologically valid sample, while the Comprehension Sample is presented to demonstrate an ideal sample. The following results are presented with the Full Sample outcomes followed by those of the Comprehension Sample, where appropriate.

Effectiveness of the Manipulation of Risk Level

To evaluate if the manipulation of risk presented in the constructed informed consent forms was effective for individuals who appeared to comprehend aspects of the consent document, an analysis was run on those participants who were able to comprehend how their identifying information would be handled (i.e., anonymously or identifiably). As expected, these individuals' (n = 36) ratings of perceived risk were higher in the high risk treatment group (M = 2.89, SD = 0.91) when compared to the low risk treatment group (M = 2.11, SD = 0.87). The mean difference between ratings was 0.78, which was a significant difference, $t(34) = 2.30$, p = .02 (one-tailed) , d = .88). The 95% CI around the mean difference (CI-Mdif) was 0.09 to 1.47. Based on the results of this preliminary analysis, it appears that when sufficient comprehension for risk is present, the manipulations of high and low risk are seen as being significantly different in terms of perceived risk. Based on this evidence and the previous support of the Pilot Study's recommendations, we hypothesized that similar trends would be present in the Main Study samples; that is, we expected higher risk perceptions in the high risk treatment group.

In the Full Sample (n = 182), perception of risk, as measured by the four item Risks Scale, was compared across the high and low levels of risk using an independent-sample t-

test (Low Risk, $M = 2.50$, $SD = 0.97$; High Risk, $M = 2.61$, $SD = 0.96$). In contrast to expectations, the ratings of risk perception did not differ significantly ($t(180) = -0.76$, $p = .23$ (one-tailed), $d = 0.11$). Using 95% confidence, the interval around the mean difference was -0.39 to 0.17. This small effect size suggests there is a high degree of overlap in the distributions (approximately 8% nonoverlap), meaning the high and low risk groups are strongly similar in this sample. It should be noted that this sample included all individuals, regardless of level of comprehension of risk or money.

When this analysis was conducted on the Comprehension Sample, significant differences were present. Individuals in the low risk group ($M = 2.15$, $SD = .82$) perceived less risk than the high risk group ($M = 2.88$, $SD = .97$) ($t(24) = -1.96$, $p = .03$ (one-tailed), $d = .81$, CI-*M*dif -1.48 to 0.04. This strong effect size is an indicator that the distributions are largely dissimilar (approximately 47% nonoverlap). These results suggest, that compared to the Full Sample, individuals demonstrating higher levels of comprehension are more likely to perceive risk in a manner consistent with the theoretically and logically assumed directionality of the risks.

Impact of Social Desirability on Willingness to Participate

In an effort to evaluate the effect of social desirability on the self-report measures and willingness to participate, a series of ANCOVAs were conducted to determine the presence of any significant effect of social desirability on several key variables. The measures included in these analyses were willingness to participate, the Risk Perceptions Scale, and individual scales of the SSS-V and IPIP-NEO. Table 20 provides a summary of these analyses for the Full Sample and Comprehension Sample. This table indicates that Self Deceptive Enhancement (BIDR-SDE) of the BIDR (and also the BIDR-Total) was a

significant covariate the NEO–Agreeableness (NEO-A) in the Full Sample. Also, in the Full Sample, Impression Management was a significant covariate for the Sensation Seeking Scale–Disinhibition (SSS-Dis).

In the Comprehension Sample (n = 26), BIDR-SDE was significant for the Risks scale. No other significant findings were present in the Comprehension Sample. Increasing levels of self-deceptive enhancement was associated with lower levels of risk perception. For the main analyses, in the Comprehension Sample, when risk perception was utilized as a variable of interest in an analysis of variance, BIDR-SDE was considered as a covariate. The significant differences found in the Full Sample were not related to variables of interest in this study, and therefore, no modifications were made for these variables and analyses were conducted as planned.

Impact of Risk Level on Willingness to Participate & Consent Behavior (Tests of Hypotheses 1a & 1b)

We addressed several questions about the effects of risk level on participation and willingness to participate. First, we hypothesized that participants who were exposed to a higher risk to their personal and genetic privacy would be less willing to participate, as assessed by a self-rating of willingness on a 5-point Likert-type scale, compared to those exposed to less risky data handling methods. We also hypothesized that a similar effect would be present when assessing actual consent behaviors (i.e, whether or not someone consented to participate). These results would be consistent with previous literature suggesting higher levels of risk were associated with lower levels of willingness to participate (Bentley & Thacker, 2004; Halpern et al., 2004); actual participation behavior were not assessed in these studies.

Table 20
Balanced Inventory of Desired Responding as a Covariate for Full and Comprehension Samples

Variable	BIDR-Full Sample (N = 182)					
	SDE		IM		Total	
	F	*p*	*F*	*p*	*F*	*p*
WTP	0.80	.37	1.90	.17	0.05	.83
SSS-V						
TAS	1.85	.18	0.00	.97	1.00	.32
ES	0.42	.52	1.70	.19	1.65	.20
Dis	0.04	.83	4.69	.03*	1.42	.24
BS	0.81	.37	0.35	.55	1.05	.31
SSS-TOT	0.18	.67	1.46	.23	1.13	.29
IPIP-NEO						
NEO-A	9.42	.00*	0.86	.35	7.82	.01*
NEO-C	0.42	.52	0.23	.63	0.59	.44
NEO-E	0.07	.80	0.90	.35	0.60	.44
NEO-*N*	1.94	.17	1.04	.31	2.71	.10
NEO-O	0.02	.89	0.57	.45	0.32	.57
RISKS	0.01	.90	1.94	.17	0.91	.34

Variable	BIDR-Comprehension Sample (n = 26)					
	SDE		IM		Total	
	F	*p*	*F*	*p*	*F*	*p*
WTP	0.21	.89	0.44	.51	0.08	.78
SSS-V						
TAS	0.69	.42	2.07	.12	0.10	.76
ES	0.00	.99	0.19	.66	0.07	.80
Dis	1.13	.30	0.01	.91	0.68	.42
BS	0.80	.38	0.28	.60	0.12	.75
SSS-TOT	0.09	.76	0.56	.46	0.43	.52
IPIP-NEO						
NEO-A	2.75	.11	0.53	.47	0.51	.48
NEO-C	0.36	.55	0.10	.76	0.06	.81
NEO-E	0.03	.87	0.76	.39	0.15	.70
NEO-*N*	0.00	.99	3.72	.07	1.17	.29
NEO-O	0.40	.54	2.95	.10	0.25	.62
RISKS	5.29	.03*	0.81	.38	1.00	.33

Note. *p < .05. BIDR = Balanced Inventory of Desired Responding; SDE = Self-Deception Enhancement; IM = Impression Management; WTP = Willingness to participate; SSS-V = Sensation Seeking Scale (5th ed.); TAS = Thrill and Adventure Seeking; ES = Experience Seeking; Dis = Disinhibition; BS = Boredom Susceptibility; SSS-TOTAL = Sensation-Seeking Scale Total; IPIP-NEO = International Personality Item Pool representation of the NEO-PI-R; NEO-A = Agreeableness; NEO-C = Conscientiousness; NEO-E = Extraversion; NEO-N = Neuroticism; NEO-O = Openness to Experience; RISKS = Risk Perceptions Scale.

To address the questions of how risk to privacy would affect willingness to participate, an independent *t*-test was performed between high and low risk levels (i.e., identifiable and anonymous). For the Full Sample, there were no significant differences in willingness to participate across risk level treatment groups $t(180) = 0.11$, $p = .46$ (one-tailed), CI-*M*dif -0.38 to 0.43, $d = 0.02$, when willingness was assessed using a five point Likert-type scale. The respective means and standard deviations were $M = 3.25$, $SD = 1.36$ for the high condition and $M = 3.28$, $SD = 1.40$ for the low risk condition; higher scores on this measure indicate higher willingness to participate. The low effect size suggests that the nonsignificant findings are unlikely to be the result of an insufficient number of participants. However, the low effect size does not account for the potential influences of other variables such as comprehension levels.

A Pearson's Chi-Square test of independence was performed for the Full Sample to examine the impact of risk level on consent to participation, as assessed by a dichotomous response (yes/no). In contrast to willingness to participate, the relationship between risk level and consent was significant, $\chi^2(1, N = 182) = 4.93$, $p = .03$. Phi (φ) was .16, supporting that there was a significant, yet weak, relationship between risk and consent. In both high and low risk groups, the tendency was toward agreeing to participate; however, participants in the low risk group were more likely to consent to participation compared to participants in the high risk group (see Figure 4).

The likelihood of consenting to participate was not significantly different across individuals who did or did not comprehend the level of risk $\chi^2 (1, N = 182) = 0.35$, $p = .57$, $\varphi = .04$ (see Figure 5). In the Comprehension Sample ($n = 26$), no significant difference was found in willingness to participate across risk levels, high ($M = 3.38$, $SD = 1.30$) and low (*M*

= 2.67, *SD* = 1.61), *t*(24) = -1.09, *p* = .15 (one-tailed), -2.05 to 0.63, *d* = 0.49. A Pearson's Chi-Square test of independence was not run due to an insufficient cell count.

Figure 4
Risk x Consent (Full Sample)

		Consent		
		Yes	No	Total
Risk Level	Anonymous (Low)	64	23	87
		73.6%	26.4%	100%
	Identifiable (High)	55	40	95
		57.9%	42.1%	100%
	Total	119	63	182

Figure 5
Comprehension of Risk by Consent

		Consent		
		Yes	No	Total
Comprehension of Risk	Yes	25	11	36
		69.40	30.60	100%
	No	94	52	146
		64.40	35.6	100%
	Total	119	63	182

Impact of Monetary Compensation on Willingness to Participate & Consent Behavior (Tests of Hypotheses 2a & 2b)

We hypothesized that participants in the higher payment group ($100) would be more willing to participate compared to participants in the lower payment condition ($10). We hypothesized similar results regarding consent behavior. Previous studies found significant differences in willingness to participate using various payment levels (which also included different numbers of payment levels, types of tasks, lengths of participation, etc.). The amount of difference between high and low payment groups in these studies ranged from 5 to 20 times greater; the high payment in the present study is 10 times greater than that of the low payment condition.

In contrast to other literature, there were no significant differences in willingness to participate across monetary compensation groups in either group. In the Full Sample, the low payment level of $10 ($M$ = 3.16, SD = 1.35) was not associated with different ratings of willingness to participate when compared to the high payment level of $100 ($M$ = 3.38, SD = 1.39), $t(180) = -1.06$, $p = .15$ (one-tailed), -0.62 to 0.19, $d = 0.16$. The Comprehension Sample produced similar nonsignificant results across high (M = 3.08, SD = 1.66) and low (M = 2.69, SD = 1.44) monetary compensation levels $t(24) = -0.63$, $p = .27$ (one-tailed), -1.64 to 0.87, $d = 0.25$.

Although the ratio of consenting individuals varied significantly, depending on whether an individual comprehended the monetary value $\chi 2$ (1, N = 182) = 11.52, $p < .001$, $\varphi = .25$ (see Figure 6), the percentage of participants who consented did not differ by monetary compensation group assignment. In both the Full Sample $\chi 2$ (1, N = 182) = 0.59, p = .44, $\varphi = .06$, and the Comprehension Sample $\chi 2$ (1, n = 26) = 1.42, p = .23, $\varphi = .23$ monetary

compensation level was nonsignificant (see Figure 7). These results suggest that a monetary compensation level of $100 was not so large as to coerce individuals into participation. In fact, it appears that is was also not large enough to significantly sway individuals' willingness ratings. These findings were maintained even when accounting for risk level assignment.

Figure 6

Comprehension of Monetary Compensation Amount by Consent

Comprehension of Compensation		Consent: Yes	Consent: No	Total
	Yes	64	50	114
		56.1	43.9	100%
	No	55	13	68
		80.9	19.1	100%
	Total	119	63	182

Figure 7

Consent by Monetary Compensation (Full & Comprehension Samples)

Full Sample ($N = 182$)

Monetary Compensation		Consent: Yes	Consent: No	Total
	$10	59	35	94
		62.8	37.2	100%
	$100	60	28	88
		68.2	31.8	100%
	Total	119	63	182

Comprehension Sample ($n = 26$)

Monetary Compensation		Consent: Yes	Consent: No	Total
	$10	6	7	13
		46.2	53.8	100%
	$100	9	4	13
		69.2	30.8	100%
	Total	15	11	26

Interaction Effects of Risk & Monetary Compensation Levels on Willingness to Participate (Test of Hypothesis 3)

Although previous research studies have found significant effects for money and risk level, they have not found a significant interaction. Both Bentley & Thacker (2004) and Halpern et al. (2004) concluded that although higher monetary compensation levels acted as incentives, they were not enough to lead participants to ignore the research risks. We similarly hypothesized that there would be no significant interaction of Risk and Money; however, we did not postulate that this conclusion would suggest that individuals would not ignore risks; this issues was more directly examined by looking at differences in risk ratings across monetary compensation groups (please see the following section).

In the Full Sample, a two-way analysis of variance (risk x compensation) yielded nonsignificant main effects for risk level, $F_{(1,181)} = 0.01$, $p = .91$, $\eta 2 = .00$, and monetary compensation level $F_{(1,181)} = 1.10$, $p = .30$, $\eta 2 = .01$. As hypothesized, the interaction effect was nonsignificant, $F_{(1,181)} < 0.01$, $p = .95$, $\eta 2 = .00$. The calculated eta squared effect sizes suggest money accounts for only 1% of the variance in willingness to participate.

In the Comprehension Sample, nonsignificant main effects for risk level, $F_{(1, 26)} = 1.61$, $p = .22$, $\eta 2 = .07$, and monetary compensation level $F_{(1, 26)} = 0.90$, $p = .35$, $\eta 2 = .04$, were accompanied by a nonsignificant interaction $F_{(1, 26)} = 0.03$, $p = .88$, $\eta 2 = .00$. The lack of interaction is not surprising given the results presented in the two previous sections. It does not appear that research participants are differentially affected (in terms of willingness to participate or consent) by combinations of risk and monetary compensation. However, this does not imply that individuals do not alter perceptions of risk based on these variables.

Impact of Monetary Compensation Level on Risk Perception (Test of Hypothesis 4)

To examine the potential influence of monetary compensation on perception of risk, we conducted an independent *t*-test of risk rating, as measured by the four-item scale described earlier, between high and low monetary amounts. We hypothesized that there would not be a significant difference in risk perception across monetary level, consistent with previous findings.

Our hypothesis of no effect was not supported in the Full Sample; perception of risk varied statistically significantly by monetary compensation level. Lower perceived risk was present among individuals in the high monetary compensation ($100) group ($M$ = 2.38, SD = 0.95) compared to the low monetary compensation ($10) group ($M$ = 2.72, SD = 0.95), $t(180)$ = 2.38, $p < .01$ (one-tailed), 0.06 to 0.61, d = 0.36. When Self Deceptive Enhancement (SDE) was added as a covariate ($F_{(1, 182)}$ = .08, p = .78, η2 = .00., the effect of monetary compensation remained significant $F_{(1, 182)}$ = 5.70, p = .02, η2 = .03.

Similarly, for the Comprehension Sample, the higher monetary compensation level (M = 1.98, SD = 0.63) resulted in a significantly lower rating of risk perception than did the lower monetary compensation level (M = 2.77, SD = 1.00) $t(24)$ = 2.40, p = 01. (one-tailed), 0.11 to 1.47, d = 0.95. When SDE was added as a covariate in the Comprehension sample, monetary amount was not significant at $F_{(1, 26)}$ = 4.05, p = .06, η2 = .13. Based on the lack of significance of the covariate in this sample ($F_{(1, 26)}$ = 3.63, p = .07, η2 = .12), it is believed that the discrepancy is largely due to the small sample size and fewer degrees of freedom with the covariate (ANOVA without SDE as a covariate was ($F_{(1, 26)}$ = 5.75, p = .03, η2 = .19).

In both samples, the significant difference between monetary compensation levels in terms of risk ratings demonstrates that the proposed monetary compensation of $100 was enough to decrease a participant's perception of risk; however, as stated previously, this did not result in increased willingness to participate or actual changes in behavior (i.e., consent to participate).

Effects of Gender on Perceptions of Risk, Willingness to Participate (Test of Hypothesis 5)

We hypothesized that men would perceive lower levels of risk across treatment groups compared to women. There were no significant differences in the number of men and women in each treatment group or between risk or monetary compensation level individually. Thus, if significant differences in risk perception were present, they could be attributed to gender and not treatment condition assignment. This hypothesis was consistent with the postulations of Zuckerman and other risk-taking researchers, who found that men rated a variety of risky activities as less risky than did women. In the Full Sample of the present study, no significant differences were found between men (M = 2.59, SD = 0.98) and women (M = 2.52, SD = 0.95) in perceived risk, $t(180) = .48$, $p = .32$ (one-tailed), -0.21 to 0.35, d = -0.07.

Additionally, we examined gender differences in willingness to participate and consent behavior. There was a significant gender effect on willingness to participate, $t(180) = -2.15$, $p = .02$ (one-tailed) , $d = 0.32$, with women reporting higher willingness to participate (M = 3.46, SD = 1.34) compared to men (M = 3.02, SD = 1.38). This finding is consistent with the findings of Rosenthal and Rosnow (1975) and also Waite and Bowman (1999), both finding women to be more likely to volunteer for, and have positive views of psychological

research. McQuillan, Pan, and Porter (2006) found women were less likely to consent to research involving DNA sample storage compared to research that did not store samples. In contrast to previous findings, in this study, a higher proportion of women in the Full Sample elected to participate compared to men χ^2 (1, N = 182) = 4.29, p = .04, φ = .15 (see Figure 8). It should be noted that the effect for this finding is fairly weak.

Figure 8
Consent by Gender (Full & Comprehension Samples)

Full Sample (N = 182)

Gender		Consent: Yes	Consent: No	Total
Male		47	35	82
		57.3	42.7	100%
Female		72	28	100
		72.0	28.0	100%
Total		119	63	182

Comprehension Sample (n = 26)

Gender		Consent: Yes	Consent: No	Total
Male		4	7	11
		36.4	63.6	100%
Female		11	4	15
		73.3	26.7	100%
Total		15	11	26

Similar results were produced by the Comprehension Sample. There was not a significant difference in the number of men or women in any level of risk or monetary compensation. No significant differences in perception of risk were present across gender (Men, M = 2.55, SD = 0.91; Women, M = 2.25, SD = 0.93), t(24) = 0.81, p = .21 (one-tailed), -0.46 to 1.05, d = 0.33. Gender was a significant factor in willingness to participate, t(24) = -1.82, p = .04 (one-tailed), -2.26 to 0.14, d = 0.72, with women reporting higher willingness to participate (M = 3.33, SD = 1.45) than men (M = 2.27, SD = 1.49). In this sample, gender differences in consent were not significant, χ^2 (1, n = 26) = 3.55, p = .06, φ = .37, although

this finding should be considered with caution due to the extremely low cell count in two of the cells.

Visual inspection of the distributions in the Full Sample showed similar tendencies across genders to participate (72.0% & 57.3%, respectively for females and males); however, in the comprehension group, the tendency of women remains the same, while that of men seems to shift toward not providing consent (73.3% of females vs. 36.4% of males in the Comprehension Sample consented to participate). The small sample size limits our ability to draw any definitive conclusions, but it seems that there may be some unknown factor influencing consent among men who comprehend the risks and monetary compensation, but not women.

Influence of Experience Seeking & Openness to Experience Attitudes on Participation & Willingness to Participate (Test of Hypothesis 6)

In order to evaluate the influence of personality factors, using Zuckerman's Sensation Seeking Scale (SSS) and the International Personality Item Pool's version of the NEO-PI-R (IPIP-NEO), it was important to establish guidelines for what constituted a high score. The hypothesized facets of interest were the Experience Seeking subscale (SSS-ES) of the SSS, and the Openness to Experience (NEO-O) facet of the IPIP-NEO. To accomplish this goal, an arbitrary cutoff of one and a half standard deviations above the mean score was established to constitute a high score. To better represent the student population, the standard cutoff for both samples utilized the Full Sample means for each measure. Table 21 shows the means, standard deviations, and established cutoff scores denoting a high score for the respective measures.

Table 21
Means, Standard Deviations, and Scoring Cutoffs for the SSS-ES and NEO-O

Measure	*M*	*SD*	Cutoff (1.5 *SD*)
SSS-ES	5.78	2.08	8.90
NEO-O	36.08	6.25	45.46

Note. SSS-ES = Sensation Seeking Scale – Experience Seeking; NEO-O = International Personality Item Pool representation of NEO-PI-R facet Openness to Experience.

We hypothesized that individuals with higher scores in the SSS-ES and/or NEO-O would be more likely to participate compared to individuals with lower scores on these measures. Correlational research conducted by Marcus & Schutz (2005) found a significant difference between respondents and nonrespondents to research participation concerning Openness to Experience, with increased participation among individuals scoring high on openness to experience. Sensation seeking was also considered in this hypothesis to explore aspects of risk-taking behavior in addition to openness to experience. Analyses included examination of both willingness to participate and consent behavior.

Independent *t*-tests comparing five participants with both high SSS-ES and NEO-O scores to the rest of the sample (n = 177) did not produce significant differences in willingness to participate, $t(180) = 1.55$, $p = .06$ (one-tailed), -0.26 to 2.19, $d = 0.94$. The mean willingness to participate for individuals with high scores for both measures (M = 4.20, SD = 0.45) was approximate to those of participants with scores below 1.5 above the mean (M = 3.24, SD = 1.38). When examined individually, high SSS-ES scorers (n = 17) were no more willing to participate than those who were not high in SSS-ES $t(180) = 0.84$, $p = .20$ (one-tailed), -0.40 to 0.98, $d = 0.13$. Similarly, the high NEO-O participants (n = 14) did not differ in terms of willingness to participate when compared to other scorers $t(180) = 1.49$, p =

.07 (one-tailed), -0.19 to 1.32, d = 0.22. These scores were supported by serial ANOVAs arriving at the same conclusions of nonsignificance.

When the measures were evaluated against consent behavior, the analysis of the NEO-O included 14 individuals with high scores, of which, 13 (92.9%) consented to participate. For the SSS-ES, 17 individuals had high scores and 12 (70.6%) consented to participate. All five of the individuals scoring high in both the NEO-O and SSS-ES consented to participate. For comparison, of the Full Sample, 119 of the 182 participants (65.4%) consented to participate. Examination of the frequencies of consenting individuals across high and low levels of the NEO-O and SSS-ES show individuals with high openness to experience overwhelmingly consent, whereas a similar trend is not present between high and low SSS-ES scorers (see Figure 9). A Pearson's Chi-Square could not be performed for the combination of high NEO-O and SSS-ES because all of the individuals (n = 5) with high scores on both scales consented to participate, leaving an insufficient expected count in two cells. Also, analyses were not computed for the Comprehension Sample because there was an insufficient number of individuals in the high score groups. Three participants had either a high NEO-O or SSS-ES, with one individual having high scores in both scales. Two of the three participants consented to participate.

These findings suggest that there are relatively few differences across groups with regards to high SSS-ES or NEO-O scores. Within the Full Sample, there was an apparent difference in consent depending on if the NEO-O score was high or not, which showed that among high scorers, the overwhelming trend was participation. Greater numbers of participants with high scores on these measures will be needed in future studies to fully explore this hypothesis.

Figure 9
Consent across NEO-O & SSS-ES

Openness to Experience (NEO-O)

NEO-O		Consent		
		Yes	No	Total
	High	13	1	14
		92.9	7.10	100%
	Low	106	62	168
		63.10	36.9	100%
	Total	119	63	182

Experience Seeking (SSS-ES)

SSS-ES		Consent		
		Yes	No	Total
	High	12	5	17
		70.60	29.40	100%
	Low	107	58	165
		64.80	35.20	100%
	Total	119	63	182

Within-Subjects Differences between Actual & Hypothetical Scenarios (Tests of Hypotheses 7 & 8)

A final set of hypotheses sought to compare willingness to participate in two hypothetical situations, no monetary compensation, and no repository. To investigate the influence of such scenarios, two questions asked respondents to identify their willingness to participate under the given hypothetical situation. These responses were then compared to the base level of willingness to participate using separate paired *t*-tests. Comparison of the base willingness to participate and that of the no monetary compensation hypothetical resulted in significant differences $t(181) = 6.82$, $p < .01$ (one-tailed), 0.55 to 1.00. In this comparison, participants were more willing to participate when money was present ($M = 3.26$, $SD = 1.37$) than when under a hypothetical scenario of no monetary compensation ($M = 2.47$, $SD = 1.35$).

Significant differences were also found in the pairing of base willingness to participate and a no repository hypothetical $t(181) = 3.24$, $p < .01$ (one-tailed), 0.14 to 0.58.

Interestingly, individuals reported higher willingness under the base rating (M = 3.26, SD = 1.37) than under a no repository scenario (M = 2.90, SD = 1.30). One explanation for this unexpected result is that individuals deduced that the absence of a repository implied no monetary compensation; the informed consent document notes that monetary compensation is contingent on submission to the repository. Alternately, this could be a demonstration of participants' desire to have their samples used by a repository.

In contrast to the Full Sample, in the Comprehension Sample, no significant differences were present between the base willingness to participate and a rating in a hypothetical involving no payment, $t(25) = 1.25$, $p = .11$ (one-tailed), -0.27 to 1.12. Similarly, for the no repository hypothetical, no significant differences were present, $t(25) = -0.72$, $p = .22$ (one-tailed), -0.89 to 0.43.

Additional Findings

Comprehension Ratings. One of the most troubling findings of this study was the inconsistency between comprehension and non-comprehension groups. Based on the logic that individuals have a natural tendency toward consent or non-consent, we would expect that, all things equal, non-comprehending individuals would respond similarly across all treatment groups because they would be unaware of the variables believed to manipulate perception and behavior. Put simply, if participants didn't recall the risks or monetary compensation amounts, there should be no differences in willingness to participate or commitment to consent across high and low levels of risk or money. However, the results of analyses including non-comprehension are in contrast to that assumption; that is, they produced statistically significant differences.

In order to address this issue, the researchers attempted to rule out possible errors or confounds that could create these abnormal findings. The researchers rechecked the data for errors in coding, including returning to the original online database to ensure responses were coded appropriately and entered into SPSS consistent with the meaning of the numerical responses. After concluding that the data was entered without error, the methods of labeling and analyzing data in SPSS were reviewed. Again, no errors were present. Because the results in question included open response data scored by the researchers, issues with interrater reliability were addressed.

To address interrater reliability, the researchers recruited two additional raters with minimal awareness of the study and no knowledge of the hypotheses. Each rater was provided with the same specific coding standards used by the primary researcher to score responses and they were asked to rate the responses to all five items of the comprehension analysis. Both additional raters returned their ratings with no missing data points. The scored responses for each of the three raters were entered into SPSS and they were analyzed using an intraclass correlation coefficient. A two-way mixed model of consistency was used, where the rater effects were random and the measures effects were fixed. These rater reliability correlation coefficients can be found in Table 22. All values were high and within acceptable range for analysis. Finally, a response was coded as demonstrating adequate comprehension if at least two of the three raters agreed that it met the standards for comprehension. This final determination was used for all analyses including comprehension items.

Given that there was no error in collecting, calculating, entering, or scoring the data, one of the remaining sources of error includes the possibility that we have inadequately

Table 22
Intraclass Correlation Coefficients for Multiple Ratings of Comprehension

Scale	Intraclass Correlation Coefficient	Confidence Interval (95%)
General Risks	.96	.95 to .97
General Benefits	.95	.94 to .96
Monetary Compensation	1.00	.95 to 1.00
Access to Information	.88	.85 to .91
Identity Risk	.92	.90 to .94

Note. Each scale was rated independently by the same three raters

assessed for comprehension. It is possible that while individuals were unable to recall the details from the informed consent document, they in fact remembered elements of risk and compensation that influenced responses. While this issue cannot be directly addressed in the present study, future study using this paradigm should include measures of both recall and recognition. Additionally, pilot testing of recall questions could decrease confusion from ambiguously worded items.

Personality differences by comprehension level. Although it was possible to assess comprehension using a number of different calculations or methods, two comprehension levels were deemed of highest importance because they represented the extremes of comprehension for the critical conditions presented in the study. By looking at individuals who were able to recall both the risk level and monetary compensation level (n = 26), and comparing them to individuals who did not comprehend either risk or compensation level (n = 58), we hoped to learn more about why some individuals recalled important consent form data and others did not. Using a series of independent t-tests, we compared all personality factors from the SSS-V and IPIP-NEO across comprehension (both risk and money) and no comprehension (neither risk nor money) groups. Of these analyses, statistically significant

differences were found in SSS-V scales Thrill and Adventure Seeking (SSS-TAS) and Disinhibition (SSS-Dis).

For SSS-TAS, the no comprehension group scored higher (M = 7.41, SD = 2.10) than the comprehension group (M = 6.04, SD = 2.69), $t(82) = -2.54$, $p = .01$, -2.45 to -0.30, d = 0.57. Similar results were found in the SSS-Dis scale, although the assumption of equal variances was not met. With equal variances not assumed, the no comprehension group (M = 5.91, SD = 1.90) was higher than the comprehension group (M = 4.31, SD = 2.70), $t(37) = -3.13$, $p = .01$, -2.63 to -0.59, d = 0.69. Taken together, these results suggest that individuals with higher scores on SSS-TAS or SSS-Dis are less likely to recall the comprehension items regarding risk level or monetary compensation. Given that these are measures of sensation seeking and impulsivity, a possible explanation would be that individuals who are more uninhibited or willing to take physical risks are also more likely to not read an informed consent. It may also be possible that they read the consent document, but did not put forth sufficient effort in completing the open response items.

Comprehension of money & consent to participate. One interesting additional finding was that, in the Pearson's Chi-Square test between comprehension of monetary compensation amount and consent to the deception study, a greater percentage of individuals who comprehended the monetary amount declined participation (43.9% declined) compared to those who were not aware of the money (19.1% declined).

One possible explanation for this result is that individuals who do not closely attend to details presented in informed consent are also more likely to blindly sign a consent document. An alternate explanation would be that when individuals know a financial incentive is present, they become more cautious of the potential risks of the study. This could

be expressed in a statement like, "there must be something risky about the research if they think they have to pay $100 to get people to participate." Because this study did not probe the motivations and cautions of participants beyond initial participation, this interesting finding remains unclear. Future studies would benefit from interviewing participants (and nonparticipants) to assess the rationale they use in appraising the risks/rewards of a prospective study.

The influence of monetary compensation level on comprehension of risk level. Finally, the effects of lower comprehension of risk to privacy level compared to comprehension of other consent elements may be related to the biasing effect of monetary compensation. To explore this possibility, we ran Pearson's Chi-Square analyses on comprehension of the risk level by the monetary compensation level and risk level individually. For comprehension of risk by risk level, significant differences were observed with individuals in the high risk group being less likely to comprehend the risk level presented in the consent document $\chi^2(1, N = 182) = 13.30$, $p < .001$, $\varphi = .27$. The assigned monetary compensation value was not associated with any differences in comprehension of risk $\chi^2(1, N = 182) = 0.27$, $p = .60$, $\varphi = .04$ (see Figure 10).

When high and low monetary compensation levels were examined separately, a pattern was present where, with $100 and high risk, the relative frequency and percentage of correct recalls of risk level was lower than at $10 and high risk (see Figure 11). The Chi Square test was significant in the $100 group $\chi2(1, N = 88) = 16.60$, $p < .001$, $\varphi = .43$, but not in the $10 group $\chi2(1, N = 84) = 1.50$, $p = .22$, $\varphi = .13$. While we can only draw tentative conclusions given the small sample of individuals demonstrating comprehension of risk level, the data suggests the possibility that when risk to privacy is high, individuals may be

willing to ignore or "forget" the risks with sufficient monetary compensation. In this scenario, it may be possible that the high payment ($100) was large enough to be coercive.

Figure 10

Comprehension of Risk Level by Risk Level & Monetary Compensation

Risk Level

		Comprehension of Risk		
		Yes	No	Total
Risk Level	Anon.. (Low)	60	27	87
		69.00	31.00	100%
	Ident.. (High)	86	9	95
		90.50	9.50	100%
	Total	146	36	182

Monetary Compensation Level

		Comprehension of Risk		
		Yes	No	Total
Money	$10	74	20	94
		78.70	21.30	100%
	$100	72	16	88
		81.80	18.20	100%
	Total	146	36	182

Figure 11

Comprehension of Risk Level by Risk Level across Monetary Compensation Levels

$10 Monetary Compensation

		Comprehension of Risk		
		Yes	No	Total
Risk Level	Anon.. (Low)	33	12	45
		73.30	26.70	100%
	Ident.. (High)	41	8	49
		83.70	16.30	100%
	Total	74	20	94

$100 Monetary Compensation

		Comprehension of Risk		
		Yes	No	Total
Risk Level	Anon.. (Low)	27	15	42
		64.30	35.70	100%
	Ident.. (High)	45	1	46
		97.80	2.20	100%
	Total	72	16	88

Discussion

Review

Although a number of studies have examined informed consent, willingness to participate, the effects of risk and monetary compensation, and/or concern about privacy in research, few studies have utilized a behavioral measure of consent; and, no known studies have used an experimental deception design to evaluate these variables in the context of genetic storage. Though these numerous studies, individually, have affirmed that participants' willingness to participate can be swayed by hypothetical manipulations in risk and monetary compensation levels, remarkably little is known about how these phenomena occur in situations where participants are unaware of the purposes of the study. Based on the evidence collected through this study, the assumed relationship between willingness to participate, the perception of risks and rewards, and actual consent appears to be more complex than has been suggested by the previous literature, particularly for an online study.

This study included a number of objectives, of which, the guiding question was, "to what extent do student-participants demonstrate their concern for their genetic privacy through informed consent to research procedures?" The principle purposes of this study were to investigate the impact of risk to privacy and monetary compensation on perception of risk, willingness to participate, and ultimately consent to participation in research. The initial assumption was that the behavioral data would closely match that of hypothetical designs; however, this was largely not the case for the present study.

Another purpose of the study was to explore ways in which comprehension of informed consent documents altered the influence of the research variables. The informed consent literature continues to state that informed consent is a process not a piece of paper;

however, this is rarely the procedure in practice, particularly for online studies. In an effort to mimic a realistic study, this experiment did not include discussion or checks of comprehension prior to signing consent documents. The consequences of this practice are illustrated in the overall poor comprehension levels obtained in this study. As a result, one of the aims of this study is to expand the literature's understanding of issues involving informed consent by presenting a realistic assessment of comprehension in the context of online undergraduate studies and the growing field of genetic research.

To accomplish these goals, the study was designed using a deceptive element in which the participants were not made aware that faux informed consent documents were an experimental manipulation of two levels of risk to privacy and two levels of monetary compensation. As part of this deception, it was assumed that participants would respond in a manner consistent with the attitudes and behaviors they might have while undertaking similar studies. Additionally, the results of this study included assessments of both willingness to participate and consent behavior, allowing for an unprecedented examination of the relationship between these measures.

Findings

Comprehension

The general conclusions from this study regarding comprehension are that relatively few student-participants read or remember critical elements of informed consent documents (14.3% comprehension of risk level and monetary compensation). A larger number of participants were able to recall (or possibly guess) more general informed consent details (e.g., general risks and benefits), but fewer participants showed comprehension regarding how their identifying information would be handled.

In looking at the various aspects of comprehension, there are unanswered questions about whether the open-response recall questions truly captured individuals' abilities to remember important aspects of the consent documents. This concern was supported by results demonstrating significant differences across measures of the dependent variables (i.e., risk perception, willingness to participant, & consent to participate) that should have been consistent across groups of individuals labeled as failing to remember the independent variables of risk level and monetary compensation. While this possibility does not compromise the major findings of this study, it has increased the difficulty of interpreting the results from the Comprehension Sample.

The practical findings of this study regarding comprehension are troubling in light of the ethical obligation of researchers to ensure sufficiently informed consent. The Nuremburg Code states that participants "should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision" (Shuster, 1997). In contrast, the findings from the present study suggest this would not have been the case if this were a true genetic research study. The fact that the consent document was presented online, without any screening of understanding, demonstrates the concerns of willingness to participate and perception of risk. Had this study required participants to correctly identify critical components of the informed consent, or used another method for assessing comprehension, the quality of the data would have likely been improved and we may have found stronger effects for the risk and monetary compensation manipulations. While these scenarios represent ideals of research conduct, they are rarely followed.

The purpose of the present study was to examine the common practices, rather than the ideal practices. As such, we provided behavioral evidence in support of the postulations of previous researchers who have examined hypothetical consent preferences. Consistent with the principle arguments presented by Iltis (2006), we found the typical student has a limited capacity (also potentially effort) to understand and appreciate risk. Based on the findings of this study, we also concluded that risk is not a lay concept, and found that even when information was presented in a manner consistent with the potential participants' educational and reading level, individuals still failed to demonstrate an appreciation for risk to privacy.

Whereas Iltis argued that the standard of informed consent should be set to the ability of the "typical adult," we argue that the assessed level of understanding should be set apriori by the type of study and determinations of risk established by the researchers and institutional review board. The ethical principles of beneficence and nonmaleficence do not permit researchers to reduce the standards of informed consent; rather, these principles would suggest researchers should do more to increase participants' understanding of concepts like risk. We believe that this educational element is not present in the typical online consent procedures and should be included as a means to "do no harm" and "do good" through educating participants, particularly undergraduate research participants, of the concepts of risk, benefit, and potential influences of monetary or other forms of compensation.

Additionally, where Iltis (2006) stated, "we should neither expect nor require that subjects be highly sophisticated in processing information regarding risk and using it to make a decision" (p. 182), we disagree. We argue that the burden of protecting research participants is that of the researcher, and if we should not expect participants to be

"sophisticated in processing information regarding risk" than we should find alternative methods of providing adequate levels of information to allow them to make such decisions that would be in their best interest. The approval of research proposals by an IRB does not alleviate the researcher's obligation to continually address ethical issues during the course of research.

Risk to Privacy

This study utilized two levels of risk to privacy commonly found in genetic studies; participants were either told their personal and genetic data would be stored in a repository anonymously (low risk of privacy loss) or identifiably (high risk of privacy loss). These levels of risk were validated using a pilot study, which asked individuals to rate various scenarios involving genetic sampling using a set of risk perception questions. The Main Study utilized two scenarios that were rated, in the pilot study, as having significantly different levels of risk and were consistent with the types of risks that might be experienced in current studies of genetics involving repositories.

In the present study, risk level did not have the hypothesized effect on willingness to participate that had been found in previous studies involving hypothetical within-subjects designs (similar to that of the pilot study). Because no study is the final word on any issue and because this is the first known behavioral study incorporating these specific variables, our ability to draw definitive conclusions about the results of this study is limited. What can be said is that there is evidence suggesting the effects of risk on willingness to participate may be different across hypothetical and behavioral studies.

While there were not significant differences in willingness to participate there was a significant difference in actual consent behavior across risk levels. In the Full Sample, as

expected, a higher percentage of participants in the low risk group consented in comparison to the percentage of individuals consenting in the high risk group. In contrast to our expectations, this trend was not supported in a sample including only individuals demonstrating comprehension of risk level and monetary compensation. We believe this may be an artifact of the small sample size in the Comprehension Sample.

Taken together, the findings suggest the possibility of differences in the process and sequence of appraising risk, determining willingness to participate, and subsequent participant actions. If there were significant differences in willingness to participate by treatment group, but not differences in consent, we could reasonably conclude that the differences in ratings of willingness were statistically, but not functionally, significant. However, in this instance, the measure of willingness was not significant, while the differences in consent behavior were notably different. As a result, there is no clear explanation for this finding. It may be a statistical issue of the sensitivity differences between a Pearson's Chi-Square test and an independent *t*-test. Alternately, the differences could reflect real variation between concepts of willingness to participate and consent behavior that are yet unexplained.

Monetary Compensation

Monetary compensation amounts for this study were determined based on values from previous studies, real world compensation rates, and the reported minimum amounts for participation collected during the pilot study. The values defined for the present study were in line with the hourly rates paid by several genetic sampling research laboratories and consistent with the recommendations from the literature and federal sources. Additionally,

the difference ratio between the high and low amounts was within the range of differences used in previous literature.

In contrast to previous hypothetical studies and despite the similarities between the values used in this study and those utilized in other studies, there were not significant differences in willingness to participate or consent behavior across compensation levels. However, while the Comprehension Sample did not produce significant differences between monetary compensation group and consent, it appears that comprehension of the monetary amount had a significant effect on the likelihood of an individual consenting to participate. Individuals who were not aware of the monetary value consented at a higher rate than individuals who comprehended the monetary value.

While monetary levels of $10 and $100 had no influence on ratings of willingness to participate or consent behavior, willingness was higher when any amount of money was present compared to a "no monetary compensation" hypothetical. More importantly, while differences in $10 and $100 did not change willingness or behavior, they did alter perception of risk. The compensation value of $100 decreased ratings of risk when accounting for risk treatment. This finding is interesting in light of the debate concerning what constitutes a coercive or undue incentive for participation. In a strict interpretation, we could state that any incentive that has the capability of modifying a potential participant's perception, willingness, or behavior would be at under any circumstance be excessive and potentially coercive, particularly if the population highly valued money or was susceptible to omitting personal conditions that might otherwise exclude them from participation. However, incentives (including credit, money, etc.) are an important means of acquiring willing participants.

We believe that researchers need to be aware of their purposes for including monetary compensation as part of research. Researchers must compete with similar studies in participant collection. Popular or enjoyable studies often require no incentives; however, when studies require longer commitments, include tasks that are not enjoyable, or include uncomfortable physical or mental events incentives of some kind are often needed to encourage participation. It is critical that the value of compensation is respective of the time, effort, and discomfort of the participant, but also not so high as to make nonparticipation unlikely. A number of research participants use research compensation to supplement incomes, and when incentives are unrealistically high, many individuals may be prone to take risks they would otherwise not undertake. There is a fine line the researcher must balance between incentivizing participation while avoiding coercion.

In this instance, we hold that $100 may not have reached the point of coercion. Many students chose not to participate and given the finding that many individuals, without comprehension of monetary amounts, would still agree to participate, the general tendency to participate did not appear to be altered by the presence of money. We are concerned, however, about the influence of $100 on risk perception. This value's ability to decrease risk perceptions illustrates how logistic elements of a study can confound research. Two identical studies of genetic risk perception could result in divergent findings had one used $10 and the other $100 of monetary compensation.

From an economic point of view, this study also demonstrates why attending to the monetary amount could result in larger participant numbers. Given a $10,000 grant used solely for monetary compensation, a researcher could acquire ten times the participants at $10 with no loss in willingness to participate or consent likelihood. For this reason, when

monetary compensation is to be used, it would benefit researchers to pilot several values along with any perception variables to assess the impact and utility of different values. We believe that for studies more susceptible to participant risk, the IRB should require pilot studies to investigate this risk.

Risk Perception

In the Pilot Study, differences in individual measures of risk perception were used as a guide in choosing risk conditions for the Main Study. Significant differences between the anonymous and identifiable groups were present on all risk related items in the within-subjects pilot questionnaire.

In the Main Study, which utilized a between-subjects design, a risk rating scale was developed using exploratory factor analysis. The results of this factor analysis suggested a four-item scale, which was summed and divided by four to match the original metric of the items. This measure was significantly correlated with willingness to participate ($r = -.28$, $p < .001$), where higher risk perception is related to lower willingness to participate, and visa versa.

In the Full Sample, which included a range of comprehension levels, the manipulation of risk level was not effective, as measured by the Risks Scale. It is reasonable to assume that if individual were unaware of the risks (i.e., they do not comprehend or recall risks), they would not have a reason to perceive the presented high/low risks differently. To address this issue, a sample of individuals who comprehended both the risks and monetary compensation levels was included in the analyses. As expected, risk perceptions among participants in the high comprehension group were significantly higher for individuals in the high risk treatment group compared to risk ratings of those individuals in the low risk group.

As mentioned previously, risk perception varied significantly across monetary compensation levels. Lower perceived risk was observed among individuals in the high monetary compensation group across both comprehension samples. However, close examination of this finding suggests that the observed differences in risk ratings were small (i.e., an average difference of .63 on a 5-point Likert-type scale). When accounting for risk level, the effect was maintained in the Full Sample, but lost significance in the Comprehension Sample; however, this finding warrants further study due to the small sample size. Despite the relatively small functional difference in risk perception across monetary groups, we maintain that any significant alteration in risk perception merits concern.

With regard to desired responding (as measured by the Self Deceptive Enhancement & Impression Management scales of the BIDR) and ratings of risk perception, Self Deceptive Enhancement was found to have a significant, abet weak, effect on the Risks scale; however, its use as a covariate in subsequent analyses showed it inconsequential. In addition, other personality variables (e.g., Sensation Seeking, NEO domains) had no effect. Gender did not significantly influence risk perception. Age differences were not assessed due to the narrow range of participants' age.

A Final Word on Willingness to Participate & Consent

Although a number of the interesting findings regarding willingness to participate and its relationship with consent behavior have been presented in the previous sections, here we present some of the general findings regarding these variables. The results of this study demonstrated the interesting relationship between risk perception, willingness to participate and consent behavior. First, we found risk perception to be a significant factor for willingness to participate. We also found willingness to participate to be a significant factor for consent

behavior. However, we did not find risk perception to be a significant factor for consent. In fact, not only did we not find significant differences in risk perception across those who did or did not consent, but also the corollary relationship between the factors was quite weak. We found a rating of enjoyment to be a stronger corollary ($r = .21$, $p = .01$) of consent than risk perception. This study will require replication with additional measures of comprehension in order to more clearly understand these factors of interest.

Potential Strengths of the Present Study

All research requires a give and take between experimental rigor and external generalizability. Consistent with Gelso's (1979) "bubble hypothesis," we accept that all research is limited by this compromise. In this study, we attempted to balance threats to internal validity by random assignment to treatment in an experimental design while working to keep the external generalizability high by using a deception and realistic vignettes. Because there is no perfect balance, we opted to "move the bubble" in a direction that has not been thoroughly examined in the existing body of literature.

This experimental (quasi-)field study was designed to closely match the type of research study frequently experienced by undergraduate college students. Through the use of deception, the believability of this study's manipulations is thought to be high. As a result of the experimental design, we believe this study's results benefit from moderate internal and external validity and allow more meaningful interpretation than do either laboratory or descriptive field studies alone. While college students represent only a portion of the research participant population, the naturalistic design of this study should more readily lend itself to generalizations than would other designs.

We believe that the use of careful deception in this study is among its most potent strengths. This study combined the rigors of experimental design with a realistic vignette in a way that was unlikely to artificially influence measured behavior. Unlike studies using known hypothetical vignettes, the use of a mock consent form to deliver the treatment conditions ensured a more authentic response from participants. This response included levels of social desirability and patterned responding that was likely consistent with participants' behaviors in studies similar to the deception. Put simply, the careful crafting of this deception prevented participants from altering their normal behaviors and allowed a more naturalistic observation.

Given the previous research involving informed consent, this study highlights the importance of methodological diversity. Traditionally, true experimental designs have been viewed as superior to other designs due to the ability to control relevant aspects of the study. It is now more widely accepted that researchers must select methods that fit the investigated phenomenon while also collecting the type of information needed to explain the phenomenon. Drew (1980) identified three categories of research questions. These categories include descriptive, difference, and relationship questions. The aims of the present study were to include a description of the phenomena regarding informed consent and concern for genetic privacy, examine differences across various types of risks, incentives, personalities, and demographics, and finally, explore the degree with which constructs were related and varied together.

The design of this study was developed so that it could be mirrored in an in-person study and/or a study with non-students. A major benefit of the current online study is that it provides a basis for which to compare potential studies noted above. With the addition of

demographic and personality measures, we can also begin to rule out issues within unique populations and more directly measure differences in the research format that may play a role in risk perception and consent behavior. Additional variables of interest have also been collected that may provide posthoc information valuable in later analyses of this data or in comparison to future data concerning genetic information.

The potential strengths of the design used in this study are complemented by the extent of statistical analysis used to interpret the data. The use of a within-subjects pilot study provided valuable data that was later analyzed using a between-subjects design. The use of multiple measures of risk perception was validated through exploratory factor analysis, showing a likely single risk perception factor.

Although somewhat unexpected, comprehension became a core component of the analyses. To address reliability issues with the open-response recall data, we implemented a coding system by which multiple raters assessed comprehension. While this did not provide any additional direction regarding the interpretation of the results, it bolstered the reliability and ruled out the much of the potential for rater error.

In a similar trend to rule out unwanted variance, analyses were run on both the Full Sample and Comprehension Sample. Had we ignored the influence of comprehension in our attempt to examine differences in risk perception, willingness to participate, and consent, we would have failed to find some of the most interesting, and perplexing, elements of this study. Finally, we hope that our inclusion of the appropriate statistics, primarily effect sizes and confidence intervals, will allow future research to more accurately compare the findings of this study to new works.

Limitations of the Present Study

As is true of all studies, ours is not without limitations. There are several areas in which we believe this study may be limited. The primary issues are concerning the narrow population and scope of the content. The remaining concerns are about item wording and placement. We acknowledge that many limitations are the result of decisions made in the design process that are inherent to the methods; however, we attempt to identify several limitations that can be better addressed by future research.

First, the findings of this study are currently limited to undergraduate students of a large Midwestern university, it is unclear what differences might be observed in diverse populations or non-university participants. Similarly, this study was conducted using online data collection, and there is inadequate information about how the variables used in this study might be influenced by an in-person administration of the study.

Given that this study was conducted as an online study, there are likely many random irrelevancies in the experimental setting. The fact that there are no controls over how, when, or where individuals complete online surveys (e.g., some may complete these studies in a library, dorm room, or bar, with or without onlookers, distractions, etc.) leaves many openings for variability in the experimental setting. This increased variability has the potential to increase error variance and obscure true relationships between variables of interest.

The present study made available preliminary findings on a voluntary online undergraduate research pool; this is clearly a unique population and the results of this study should be considered with awareness of the influence of age, race, and online administration. Given what is known about various groups, it is likely that older, non-Caucasian, and in-

person populations would have different, likely more cautious, views of the risks and monetary compensation in genetic studies. It is important to reiterate that student-volunteers self-select for participation in online studies, and for this reason, should be considered as a unique population with the student-participant pool. Online studies are generally shorter and require less effort than in-person studies. As a result, students in this group may be more inclined to rush through a consent form or respond in a less consistent manner than their in-person counterparts.

Second, the study utilized only two monetary values, and it found results in contrast to previous studies using different amounts. Because we only examined two monetary values, we cannot state with authority that higher values will always result in lower perceptions of risk. There may be a curvilinear relationship in which higher values may be seen by the participant as excessive and thus perceived as an attempt by researchers to reduce risk perception, resulting in higher risk ratings. What is known is that, despite this finding of lowered risk ratings at the $100 level, no differences in consent behavior were found. In other words, the $100 may have been enough to alter perceived risk, but not so strongly as to influence behavioral decision-making.

There are also concerns about the wording and placement of some of the items used in this examination. Specifically, an item referring to willingness to participate without a repository produced findings inconsistent with expectations and markedly similar to another question about no monetary compensation. One possible explanation for this may be that participants viewed no repository as meaning no monetary compensation (the consent document implies that the genetic sample must be submitted to the repository for compensation). After examination of this item, it is believed that if the matter were clarified,

there would be a change in the relationship between willingness with and without repository that is more consistent with hypotheses regarding perceptions of genetic storage.

Another procedural issue was in the assessment of comprehension of risk level, as assessed by the question, "How will your identifying information be treated by the repository?" This item resulted in less than optimal recall that is not directly explained by the current data. Of the 182 participants, only 36 participants (19.8%) were able to recall that their data would be held anonymously or identifiably under the present question format. After examining the recall rates of other comprehension items, several possible explanations are worth further discussion.

First, the wording of the item is somewhat vague and many respondents correctly noted that their information would be held with a degree of privacy or confidentiality, as stated in other parts of the informed consent form. In this case, the low comprehension may have been largely an artifact of a poorly worded question. Revising this item for clarity may alter the comprehension rate, as would adding a recognition task to the existing recall task.

Second, this particular comprehension question is the last in a series of seven open-response items. In examining the relative comprehension frequencies, a slight upward slope in missing and incorrect responses is present. The placement of the item later in the series of questions may have had an affect on the response rate and retention of the information. Future studies should consider rotation of these items to see if similar trends are present.

Third, the placement of the information and its relationship to other information may have had a real effect on the comprehension. As noted in the methods section of this manuscript, the terms of risk are presented both in the opening introduction and again in the *Confidentiality* section. However, the introduction simply states that the participant's sample

will be entered into a repository anonymously or identifiably, it does not suggest risk of privacy invasion. In contrast, the second statement is found in one of the last sections of the two-page document.

In the *Confidentiality* section of the consent document, there were four lengthy paragraphs, in which the risk level was presented in the third paragraph and additional risk related information in the final paragraph. These paragraphs were preceded by a relatively standard set of statements about confidentiality, access by regulatory auditors, and handling of the data. Participants may have viewed this information as standard research jargon and ignored it, decided to stop reading before completing the section, had blind trust in the Institutional Review Board's ability to weed out unsafe research, become bored, or any number of other scenarios that would result in not even reading this section. Additionally, student-participants may have become inoculated to the perception of risk by previous statements of privacy protection.

Practical Implications

This study has a host of practical implications, some of which can be implemented immediately and others that will require additional research. First, this study makes clear a lay-assumption that student-participants do not adequately read informed consent documents presented in online/text formats. With that information, researchers utilizing text or online consent documents should reassess their procedures for evaluating adequate comprehension. It is paramount that participants be informed of the potential risks and benefits of participation (and non-participation).

Review of responses to the consent comprehension items yielded some interesting anecdotal results. One surprising finding was that, of those who did not demonstrate

comprehension of monetary compensation (nearly 40%), a majority of individuals were unaware that any amount was being offered. Also, in response to the item asking why the individual choose to participate, several students answered that they wanted to know more about their personality despite the clear statement in the form that the participants' results would not be released. These findings demonstrate a need to be explicit and reiterate important elements when communicating with research participants.

Among the responses to open-ended items, the most startling was the apparent lack of awareness or concern about risks among those who choose to participate. Students who consented to participate regularly reported that they were not concerned about or aware of the risks of the study, with common responses being "probably none" or "I don't remember." Several participants made comments best characterized by the following response, "I didn't really pay attention that closely, I figured that the statements were the same for every study." These statements are disturbing in light of the fact that had this study included an actual genetic repository collection or had involved potential physical, mental, financial, or privacy risks, many students would have been ill prepared to make judgments needed to act in their best interest.

We hope that these findings serve as a warning to researchers that many student-participants are naïve to the potential risks of research and have a false sense of security through their belief that Institutional Review Boards will protect them from harm. While we complement IRB's for their efforts to ensure research is safe, we urge researchers to ensure the research is safe for each individual by confirming each element of consent is understood. We do not believe that researchers should make decisions for individuals regarding the

balance of risk and benefit; however, we must do all that we can to allow participants to make that decision in an informed way.

Another area of practical implication is that this study raises additional concerns about the congruence between hypothetical and real studies. While many aspects of out pilot study (a known within-subjects hypothetical design) were consistent with the Main Study, appraisals of risk seem to be artificially influenced by the participant's knowledge that he or she will not actually be required to participate in the hypothetical study. For this reason, we suggest researchers consider possible influences on risk perception and social desirability when reviewing literature with hypothetical designs. Continued use of carefully developed deceptions will be useful in demonstrating the most significant areas of incongruence.

Finally, like obtaining an informed consent, assessing comprehension is a process. Through review of the comprehension literature, we have come to the realization that both recall and recognition are likely valuable tools in the assessment of comprehension. While it is widely accepted that recall requires greater levels of cognitive resources, many individuals may have adequate comprehension when assessed with recognition tasks. Researchers should use both methods until more information is available about what constitutes adequate comprehension

Directions for Future Research

Despite being an often-overlooked element of research, informed consent provides countless avenues for research. Among these areas, the line of research pursued by these authors would be best directed in several key areas. Future research should address ways to broaden the sample to include novel populations; it should seek ways to increase

measurement accuracy; and, new and revised variables and designs should be considered to fill gaps in the existing literature.

The easiest of the above recommendations for future research is to replicate this and other studies using unique and diverse populations or study settings. Differences across online and in-person samples may provide useful information to universities that host research pools. Additionally, this information would be relevant to any researcher, doctor, or practitioner required to obtain an informed consent because empirically supported practices may be limited to the setting utilized in the research.

The effects on comprehension and differences in personality measures across online and in-person samples would be of specific interest. While there is no known data to support this hypothesis, we believe that in-person studies may produce higher ratings of risk, lower willingness, lower consent, and better comprehension rates compared to online studies.

Another possible direction for research is conducting the research with populations other than college students. Students may possess less concern about their privacy than would community participants. Age, personal history, socialization, and acceptance of being identified in online settings may all contribute to greater willingness to participate. Additionally, students in university settings may overly trust researchers and the Institutional Review Board. Preliminary hypotheses regarding this line of research are that community populations would have higher ratings of risk, lower willingness, lower consent, and higher comprehension rates compared to college student populations.

In order to advance research on informed consent, better measurement tools need to be developed for assessing comprehension. In the interim, researchers need to ensure that they conduct a power analysis and collect an appropriate number of participants. An

increased sample size will be critical for researchers that may wish to compare comprehension across groups (the present study demonstrates the need for more participants with adequate comprehension).

In addition to the directions stated previously, there may be merit in tracking assessments of willingness at various times. It is possible that the act of recalling or identifying important elements of the consent document may cause participants to reevaluate their willingness to participate. By asking participants to rate willingness before the consent is made, after comprehension questions and the rating of risks, and at the end of the study researchers can determine if this reevaluation is present and consider ways to utilize it for improving consent understanding.

In addition to the influence of monetary compensation, future research would benefit from evaluating the influence of course credit or other forms of compensation. In the present study, the IRB requested that the researchers add "or 1 credit" after the monetary compensation described in the experimental consent form. While this was undoubtedly intended to avoid harm due to the deception, it may have inadvertently introduced another element in the risk assessment. It is possible that, for students, money as an incentive is secondary to credit. Students may have discounted concerns about the repository if they knew they would get the research credit regardless of how they responded to the consent request.

Researchers are cautioned to avoid including potential confounds that could inhibit the understanding of monetary compensation while being aware of the need to keep participants safe from harmful deception. We believe that if the changes mentioned above are

implemented, they will produce a greater percentage of comprehending participants, result in stronger effect sizes, and reduce no comprehension effects.

Finally, there are a number of possible modifications and additions to the variable list and design that could offer improved data collection and clarify findings. Among these recommendations, increasing the number of risk and monetary compensation levels from two to three would allow researchers to explore potential interaction effects. While this may be beneficial, it also requires increasing the sample size substantially. Alternately, in a manner similar to items used in this study to evaluate willingness to participant under a no repository and no monetary hypothetical, researchers may choose to include additional hypothetical items regarding variables such as credit instead of money, higher monetary amounts (e.g., $1000), different risks (e.g., more serious physical or emotional risks). Researchers may even ask how much money would be required to get a person to change their mind (this would clearly represent an undue inducement). These hypothetical items would lack the benefits of experiemental control and may suffer from comparison to previous responses; however, they would be easy ways to explore additional factors without being forced to increase sample size.

This is not an exhaustive list of potential modifications or directions for future research. Likewise, it is impractical to expect all, or even a majority, of these recommendations to be followed in a single study. In fact, it may be more beneficial to reduce the number of variables and only assess differences in risk levels before pursuing various monetary compensation levels. It is essential that we first understand how decisions regarding research participation are made before we jump to modify the consent system. Recent research funding has been focused on improving consent comprehension without an

understanding of how to assess comprehension. The result of this body of research has been inconsistent results flawed by varied and limited assessment tools. We ought not to put the cart before the horse concerning understanding and improving comprehension, while at the same time avoiding becoming mired in theoretical discussions that have limited practical utility.

Conclusions

Informed consent is a fundamental element to all research studies. Participants regularly engage in all forms of research, from the most benign to those that are complex and potentially risky for the participant. The increasing examination of the human genome and the need to retain genetic samples and information in repositories and data banks has fostered new debate regarding consent practices and ethics. This study aimed to describe current beliefs and behaviors concerning genetic research risks and monetary compensation by exposing participants to a deception involving experimental informed consent documents. Our aim was to document student-participants' concerns about their genetic privacy and examine the related influence of monetary compensation on risk perceptions, willingness to participate, and consent behavior.

This study resulted in a number of interesting findings despite producing largely statistically insignificant findings. Most notably, we demonstrated that attention to and comprehension of elements of consent documents is poor among college online research participants. While, empirically, this study was limited in its analysis of the variables due to an insufficient number of comprehending individuals, this sample provided an authentic assessment of participants' beliefs and behaviors that have been unexamined in previous hypothetical designs. Through continued research of factors influencing risk assessments and

consent behaviors, we seek to improve our understanding of the decision making process and ensure that research participants are treated in accordance with our fundamental ethical principles.

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APPENDIX A: Pilot Study IRB Approval Letter 09-009

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office of Research Assurances
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

DATE: 13 January 2009

TO: Paul L. Ascheman
W112 Lagomarcino

CC: Norman Scott
W271 Lagomarcino

FROM: Jan Canny, IRB Administrator
Office of Research Assurances

TITLE: **Risk-Monetary Compensation Calibration**

IRB ID: **09-009**

Approval Date: 13 January 2009
Date for Continuing Review: 12 January 2010

The Chair of the Institutional Review Board of Iowa State University has reviewed and approved this project. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- **Use the documents with the IRB approval stamp** in your research.
- **Obtain IRB approval prior to implementing any changes** to the study by completing the "Continuing Review and/or Modification" form.
- **Immediately inform the IRB of** (1) **all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.
- **Stop all research activity if IRB approval lapses**, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- **Complete a new continuing review form** at least three to four weeks prior to the **date for continuing review** as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office of Research Assurances website [www.compliance.iastate.edu] or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office of Research Assurances, 1138 Pearson Hall, to officially close the project.

APPENDIX B: Pilot Study Informed Consent

ISU IRB # 1	08-063
Approved Date:	12 November 2008
Expiration Date:	19 February 2009
Initial by:	jlc

MASS TESTING INFORMED CONSENT
9/26/2008

This research project is being conducted by the Iowa State University Psychology Department. If your are under 18 years of age, you are not eligible to participate unless you have submitted a signed written parental consent form to the course information office, as explained to you by your course instructor. If you are under 18 and have not yet obtained written parental consent, please log out now and contact your instructor about procedures necessary to become eligible.

Sometimes in Psychology research, it is necessary to select participants based on certain criteria. The purpose of this session is to gather information on a number of different criteria that will help researchers know whom to contact for their specific projects.

If you decide to participate in this mass testing session there may be no direct benefit to you other than the opportunity to learn from a participant's perspective about current psychology research projects. It is hoped that information gained from this session will benefit society by selecting the appropriate study population for future studies, and thus produce scientifically valid results. By participating in this session you may be eligible for participation in future research. This questionnaire session is expected to take you 50 minutes or less to complete. You will receive **one research credit** for your participation. If you are eligible for a specific future research project based on your questionnaire responses, the researcher will contact you, and you may decide at that time whether to participate in that project. Because researchers need to be able to contact you, you will be asked your name, e-mail address, and phone number. As noted on your course syllabus, mass testing is one option for acquiring research credits. The other options include participating in experiments or reading research articles and then taking a short quiz about them.

Several researchers have developed the questionnaires and ratings posed during this testing session. Your responses will be assembled in an electronic date file that pairs your responses with your name and student identification number. However, only the research investigators with current IRB approved research studies for mass testing will have access to your responses. The data will be stored in a locked facility and will not be stored with the codebook. Moreover, all information collected will be kept confidential to the extent permitted by applicable laws and regulations, and will be available only for use by psychology department researchers in approved projects. However, federal government regulatory agencies, including the IRB, may inspect and/or copy records for quality assurance and data analysis. At the end of the semester, all files linking names and student identification numbers to questionnaire responses will be deleted. If you would like your questionnaire file deleted before the end of the semester, contact the Chair of the Psychology Department Research Participant Pool Committee (see below).

By confirming your acceptance of this consent form, you are indicating your voluntary participation in the project. We do not anticipate any risk from participation in this mass-testing session. However, some of the questions may be sensitive in nature, and you may feel uncomfortable in responding to them. You may skip any questions you are not comfortable answering or decline to participate at any time without receiving any penalty or loss of benefits

APPENDIX C: Pilot Study Demographic Information

Pilot Study Demographic Information

Variable	Level	*n*	(%)
Gender			
	Male	221	(40.6)
	Female	324	(59.4)
Age			
	17*	4	(0.7)
	18	162	(29.7)
	19	200	(36.7)
	20	94	(17.2)
	21	45	(8.3)
	22	19	(3.5)
	23	7	(1.3)
	24	3	(0.6)
	25	1	(0.2)
	26-35	7	(1.4)
	36-45	3	(0.6)
Primary Race/Ethnicity			
	African American	4	(0.8)
	Asian American	14	(2.6)
	Caucasian	489	(89.7)
	International Student	16	(2.9)
	Latina/o American	11	(2.0)
	Multiracial	6	(1.1)
	Native American	2	(0.4)
	Other	3	(0.6)
Education Level			
	First Year	307	(56.3)
	Sophomore	133	(24.4)
	Junior	72	(13.2)
	Senior	33	(6.1)
Marital Status			
	Single	399	(73.2)
	Married	5	(0.9)
	Divorced/Separated	3	(0.6)
	In a Committed Relationship	137	(25.1)
	Other	1	(0.2)

Note. * Four participants under the age of 18 participated with written assent and written parental consent as part of mass testing procedures.

APPENDIX D: Pilot Study Basic Vignette

Risk-Compensation Calibration

A) Please read the following passage from an informed consent form describing a research opportunity. We are interested in your willingness to participate in this study and variations of the study. Please respond truthfully and in a manner that represents your actual willingness to participate and not the expectations of others.

PURPOSE
The purpose of this study is to examine genetic markers that relate to personality characteristics in undergraduate students. As part of this study, you will be asked to provide a cheek tissue sample that will be used to explore genetic components to personality.

DESCRIPTION OF PROCEDURES
During the study, you will be asked to provide a DNA sample using a cheek (buccal) swab method. For this procedure, you will be asked to gently rub a sterile cotton swab along the inside of your cheek to collect a buccal tissue sample.

You should not provide a sample if you have:
(a) allergies to cotton or latex;
(b) a communicable disease or open sore in or around your mouth;
(c) mouth sensitivity that might produce pain as a result of participation.

RISKS
There are no foreseeable physical risks at this time from participating in this study.

Genetic information that results from this study does not have medical or treatment importance at this time. However, information about taking part in a genetic study may influence insurance and/or employers regarding your health status.

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 genetic personality traits.

APPENDIX E: Pilot Study Items

1 2 3 4 5 6 7 8 9 10
Not at all Very High

1. Based on the description of the study, how willing would you be to participate in this study?

2. How likely do you think other students like you would be to participate in this study?

3. How risky do you think it would be to participate in this study?

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

5. What is the probability that your personal information would be used unethically or in a way inconsistent with the wording of the description?

6. How serious would the negative consequences related to loss of privacy be if they occurred?

7. How much would you enjoy participating in this research study?

8. Please read and select one of the options below. Enter the MINIMUM dollar amount you would need to be paid to participate in the study described. If you would participate for no money, please enter $0. If you would not participate for any amount of money skip this item and mark item 9.

   I would participate in this study for a <u>minimum</u> of $_____.<u>00</u>.

9. Mark this item Only if you would Not participate for any amount of money
   ___ **I would Not participate for any amount of money.**

B) We would now like you to imagine that the following descriptions are included in the original study description. Please try to respond to each scenario independently. Work quickly, but accurately.

APPENDIX F: Pilot Vignette (High Risk - Identifiable)

Scenario A

At the conclusion of this research project, genetic samples will be entered into the GENBEH Repository, a large university-based Repository that exists for the study of genetic markers for personality, temperament, and behavior.

Samples submitted to the GENBEH Repository will include identifying information, that is, your personal information will be attached to your sample. This information may be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use study information that identifies you to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.

It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does and may disclose identifiable information to others.

APPENDIX G: Pilot Vignette (Low Risk - Anonymous)

Scenario B

At the conclusion of this research project, genetic samples will be entered into the GENBEH Repository, a large university-based Repository that exists for the study of genetic markers for personality, temperament, and behavior.

Samples submitted to the GENBEH Repository will be anonymous, that is, your personal identifier or code will be removed to your sample. No information will be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use anonymous study information to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.

It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does, but because samples have been stripped of identifying data there is no way of matching you to your sample.

APPENDIX H: Pilot Vignette (Very Low Risk – No Repository)

Scenario C

At the conclusion of this research project, genetic samples will be destroyed. Your sample will be anonymous, that means, there is no way for researchers to connect you to your sample or data. Your sample will not be used in any way other than specified above. It will not be entered into your health record or submitted to a genetic repository for future use.

APPENDIX I: Pilot Vignette (Very High Risk – Government Access)

Scenario D

At the conclusion of this research project, genetic samples will be entered into the GENBEH Repository, a large university-based Repository that exists for the study of genetic markers for personality, temperament, and behavior.

Samples submitted to the GENBEH Repository will include identifying information, that is, your personal information will be attached to your sample. This information may be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use study information that identifies you to do research in a variety of areas and may create cell lines from your sample. It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does and may disclose identifiable information to others.

This information will also be entered into a government database. Local and federal law enforcement agencies, including The Department of Homeland Security, will have open access to this data. Samples will be stored indefinitely.

APPENDIX J: SONA Posting Form for Main Study

STUDY POSTING FORM

Ann Schmidt MUST receive a copy of this form before you send an activation request.

PRINCIPAL INVESTIGATOR (*Faculty Supervisor*): Norman Scott, Ph.D.

RESEARCHERS: Paul Ascheman, B.S.

STUDY NAME & NUMBER: Personality Characteristics of Undergraduate Students

BRIEF ABSTRACT:

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

The purpose of this study is to examine unique personality characteristics of undergraduate students. The study will include completing a series of three personality questionnaires as well as demographic questions. You would complete these paper and pencil personality questionnaires in a university classroom.

This is a two-credit experiment that will take 90 minutes or less to complete. Participation in this study is voluntary and if you decide not to participate, it will not affect your grade or evaluation in your psychology class.

ELIGIBILITY REQUIREMENTS: You must be 18 years old to participate in this study.

DURATION (*Minimum 50min.):* 90 Minutes

CREDITS: 2 Credit

PREPARATION:

IRB APPROVAL CODE:

IRB APPROVAL EXPIRATION:

IS THIS AN ONLINE STUDY? NO

ATTENTION RESEARCHER:

THE STUDY DESCRIPTION POSTED ON SONA MUST BE IDENTICAL TO THAT APPROVED BY IRB. IF YOU NEED TO MODIFY THE DESCRIPTION OF A STUDY, YOU MUST PROVIDE ANN WITH THE NEW IRB-APPROVED DESCRIPTION.

Participants under 18 years of age are not eligible to participate in research studies unless they have written parental consent.

Field	Explanation
Study Name	A short name for the study. This is how the study is identified throughout the system. Studies are shown in a random order to participants, so there is no advantage in choosing a study name that might put it at the top of an alphabetical list. Study names must be unique, and you will be prevented from adding a study if there is already another study in the system with the same name.
Brief Abstract	This is a short one or two line description of the study. This short description will be displayed to participants when they view the entire list of studies, so you may want to list the most pertinent details here.
Detailed Description	This is your IRB-approved description of the study, and it will show if a participants clicks on the study to get more information, before they sign up. You may include basic HTML in this area, but please be sure you know what you are doing.
Eligibility Requirements	If there are any restrictions on who may participate (for instance, only those who are left-handed), list them here. Otherwise, leave the field as-is. If you list any restrictions, these will be displayed on the list of studies, when participants view a list of all available studies. Note the system does not enforce these restrictions, but it is expected a participant will only sign up for a study in which they are qualified, since they would otherwise fail to receive credit. In most cases, you will leave this field as-is and set pretest participation restrictions, which you can do after you add the study.
Duration	The amount of time, in minutes, that each study session will take. If you are setting up a 2-part study, then this setting applies to the first part of the study.
Preparation	Enter any advanced preparation a participant must do here (e.g. “do not eat 2 hours before session”). If there are no preparation requirements, leave this field as-is.
IRB Approval Expiration Date	The date when IRB approval expires. You must provide a valid expiration date. The system will prevent you from adding new timeslots to take place after this date, and your study will become inactive (not visible to participants) after this date. You may not make a study active if the IRB approval has expired. Only the administrator can change the IRB approval expiration date, once it has been entered.

This page was extracted from the experiment management system documentation (v2.63), further was modified with permission of Sona Systems to meet Iowa State Department of Psychology’s specific program needs

APPENDIX K: Main Study IRB Approval Letter 09-157

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office of Research Assurances
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

DATE: 9 April 2009

TO: Paul L. Ascheman
W112 Lagomarcino

CC: Norman Scott
W271 Lagomarcino

FROM: Jan Canny, IRB Administrator
Office of Research Assurances

TITLE: **Online Informed Consent to Genetic Research**

IRB ID: **09-157**

Approval Date: 9 April 2009
Date for Continuing Review: 6 April 2010

The Institutional Review Board of Iowa State University has reviewed and approved this project. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- **Use the documents with the IRB approval stamp** in your research
- **Obtain IRB approval prior to implementing any changes** to the study by completing the "Continuing Review and/or Modification" form.
- **Immediately inform the IRB of** (1) **all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.
- **Stop all research activity if IRB approval lapses**, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- **Complete a new continuing review form** at least three to four weeks prior to the **date for continuing review** as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office of Research Assurances website [www.compliance.iastate.edu] or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office of Research Assurances, 1138 Pearson Hall, to officially close the project.

APPENDIX L: Main Study Informed Consent

INFORMED CONSENT DOCUMENT

Title of Study: **Personality Characteristics of Undergraduate Students**
Investigators: **Paul L. Ascheman, B.S.**
Norman Scott, Ph.D.

This is a two credit research study that will take approximately 90 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 unique personality characteristics of undergraduate students. 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 one hour. During the study, you may expect the following study procedures to be followed: You will be asked to complete an online survey about your attitudes and personal beliefs. 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 behavior. 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 self-perceptions, personality, and behavior among college students.

COSTS AND COMPENSATION
You will not have any costs from participating in this study. You will be compensated for participating in this study (approx. 90 minutes) with research credit toward your Psych 101, Psych 230, or Psych 280 class(es) consistent with the Psychology Department guidelines. You will receive two research credits for your full participation in the study.

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: Subjects will be assigned a unique code that will be used on forms instead of their name. The key for this unique code and the questionnaires will be kept separate locked filing cabinets. These 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, your identity will remain confidential.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study. For further information about the study contact Paul Ascheman: ascheman@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 Research Assurances, Iowa State University, Ames, Iowa 50011.

****

PARTICIPANT SIGNATURE

Your digital confirmation 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.

APPENDIX M: Deletion Criteria

Deletion Criteria for Main Study

	Deletion Criterion	Criteria Met	*N* Deleted	Progressive *N* Deleted
A	Did not consent to the initial study	2	2	*2*
B	Demographics Non-Response (≥1)	13	11	*13*
C	BIDR Non-Response ≥ 20% (≥8)	8	2	*15*
D	SSS Non-Response ≥ 20% (≥8)	9	1	*16*
E	NEO-PI Non-Response ≥ 20% (≥10)	12	3	*19*
F	Comprehension Open-Ended Responses Non-Response (≥3)	41	30	*49*
G	Hypotheticals (any missing) (≥2)	21	3	*52*
H	Debriefing Item D5 "Truthful responses" (Response=No)	2	2	*54*
		108	54	

Note. Initial *N* = 236, Final sample after deletions *n* = 182; "Criteria Meet" includes samples where multiple deletion criteria were satisfied; "*N* Deleted" represents the number of samples removed for meeting one or more criteria.

APPENDIX N: Demographic Items

SECTION 1 DIRECTIONS:
You are now ready to begin filling out the answer sheet. Answer honestly and do not discuss your answers with others.

Answer the following questions beginning with question #1

1. What is your sex?
- A. Male
- B. Female
- C. Transgender

2. What year are you in college?
- A. Freshman
- B. Sophomore
- C. Junior
- D. Senior
- E. Grad

3. Do you consider yourself multiethnic or multiracial?
- A. No
- B. Yes

4. To which racial or ethnic group(s) do you most identify?
- A. African-American (Non-Hispanic)
- B. Asian/Pacific Islanders
- C. Caucasian (non Hispanic)
- D. Latino or Hispanic
- E. Other

5. In terms of income, would you say your parents are:
- A. Upper class
- B. Upper-middle class
- C. Middle class
- D. Lower-middle class
- E. Working class

6. Your marital status
- A. Single
- B. Dating (Living Separately)
- C. Dating (Cohabitating)
- D. Married
- E. Divorced/Separated

7. Major choice status
   A. I am undecided about a major
   B. I am tentatively decided about a major
   C. I have decided on a major.

8. Have you participated in other psychology research studies while at ISU?
   A. Yes
   B. No

9. Have you ever participated in medical research (i.e. drug trials, provide cell sample)?
   A. Yes
   B. No

10. Do you intend to participate in research of any kind in the future?
   A. Yes
   B. No

(Continue to the next section)

APPENDIX O: Main Study Demographic Information

Main Study Demographic Information

Variable	Level	*n*	(%)
Gender			
	Male	82	(45.1)
	Female	100	(54.9)
Age			
	18	56	(30.8)
	19	62	(34.1)
	20	35	(19.2)
	21	15	(8.2)
	22	7	(3.8)
	23	2	(1.1)
	24	0	(0)
	25	1	(0.5)
	26-35	3	(1.5)
	36-45	1	(0.5)
Identify as Multiracial			
	Yes	10	(5.5)
	No	172	(94.5)
Primary Race/Ethnicity			
	African American	3	(1.6)
	Asian American	6	(3.3)
	Caucasian	167	(91.8)
	Latina/o American	3	(1.6)
	Native American	0	(0)
	Other	3	(1.6)
Education Level			
	First Year	103	(56.6)
	Sophomore	38	(20.9)
	Junior	27	(14.8)
	Senior	14	(7.7)
Marital Status			
	Single	126	(69.2)
	Married	1	(0.5)
	Divorced/Separated	0	(0)
	Dating (Living Separately)	44	(24.2)
	Dating (Cohabitating)	11	(6.0)
Major Choice			
	Undecided	13	(7.1)
	Tentatively Decided	37	(20.3)
	Decided	132	(72.5)

APPENDIX O (continued)

Variable	Level	*n*	(%)
Family Income			
	Upper Class	3	(1.6)
	Upper-Middle Class	70	(38.5)
	Middle Class	93	(51.1)
	Lower-Middle Class	12	(6.6)
	Working Class	4	(2.2)

APPENDIX P: Questionnaire Packets

SECTION 2 DIRECTIONS:
Using the scale below as a guide, select a number for each statement to indicate how true it is. For each item, enter the corresponding number on the scantron card.

1	2	3	4	5
Not True		Somewhat True		Very True

11. My first impressions of people usually turn out to be right.

12. It would be hard for me to break any of my bad habits.

13. I don't care to know what other people really think of me.

14. I have not always been honest with myself.

15. I always know why I like things.

16. When my emotions are aroused, it biases my thinking.

17. Once I've made up my mind, other people can seldom change my opinion.

18. I am not a safe driver when I exceed the speed limit.

19. I am fully in control of my own fate.

20. It's hard for me to shut off a disturbing thought.

21. I never regret my decisions.

22. I sometimes lose out on things because I can't make up my mind soon enough.

23. The reason I vote is because my vote can make a difference.

24. My parents were not always fair when they punished me.

25. I am a completely rational person.

26. I rarely appreciate criticism.

27. I am very confident of my judgments.

28. I have sometimes doubted my ability as a lover.

29. It's all right with me if some people happen to dislike me.

30. I don't always know the reasons why I do the things I do.

31. I sometimes tell lies if I have to.

32. I never cover up my mistakes.

33. There have been occasions when I have taken advantage of someone.

1	2	3	4	5
Not True		Somewhat True		Very True

34. I never swear.

35. I sometimes try to get even rather than forgive and forget.

36. I always obey laws, even if I'm unlikely to get caught.

37. I have said something bad about a friend behind his/her back.

38. When I hear people talking privately, I avoid listening.

39. I have received too much change from a salesperson without telling him or her.

40. I always declare everything at customs when I travel abroad.

41. When I was young, I sometimes stole things.

42. I have never dropped litter on the street.

43. I sometimes drive faster than the speed limit.

44. I never read sexy books or magazines.

45. I have done things that I don't tell other people about.

46. I never take things that don't belong to me.

47. I have taken sick-leave from work or school even though I wasn't really sick.

48. I have never damaged a library book or store merchandise without reporting it.

49. I have some pretty awful habits.

50. I don't gossip about other peoples' business.

(Continue to the next section)

SECTION 3 DIRECTIONS:

Each of the items below contains two choices A and B. Please indicate which of the choices most describes your likes or the way you feel.

In some cases, you may find items in which both choices describe your likes or feelings. Please choose the one that better describes your likes or feelings. In some cases, you may find items in which you do not like either choice. In these cases marked the choice you dislike the least.

We are interested only in your likes or feelings, not in how others feel about these things or how one is supposed to feel. There are no correct or incorrect answers. Work quickly and give an honest appraisal of yourself.

51. A. I like “wild” uninhibited parties.
B. I prefer quiet parties with good conversation.

52. A. There are some movies I enjoy seeing a second or even third time.
B. I can’t stand watching a movie that I've seen before.

53. A. I often wish I could be a mountain climber.
B. I can't understand people who risk their lives climbing mountains.

54. A. I dislike all body smells.
B. I like some body smells.

55. A. I get bored seeing the same old faces.
B. I like the comfortable familiarity of everyday friends.

56. A. I would like to explore a strange city by myself, even if it means getting lost.
B. I prefer a guide when I am in a place I don't know well.

57. A. I dislike people who do or say things just to shock or upset others.
B. When you can predict almost everything a person will do and say he or she must be a boring person.

58. A. I usually don't enjoy a movie or play where I can predict what will happen in advance.
B. I don't mind watching a movie or play where I can predict what will happen in advance.

59. A. I would like to or have smoked marijuana.
B. I would never smoke marijuana.

60. A. I would not like to try any drug that might produce hallucinations.
B. I would like to try some of the drugs that produce hallucinations.

61. A. A sensible person avoids activities that are dangerous.
B. I sometimes like to do things that are a little frightening.

62. A. I dislike people who are uninhibited and free about sex.
B. I enjoy the company of people who are uninhibited and free about sex.

63. A. I am uncomfortable with drug use.
B. I am comfortable with drug use.

64. A. I like to try new foods that I have never tasted before.
B. I order familiar dishes to avoid disappointment and unpleasantness.

65. A. I enjoy looking at others' home movies, videos, or travel photos.
B. Looking at someone's home movies, videos, or travel photos bores me tremendously.

66. A. I would like to take up the sport of water skiing.
B. I would not like to take up water skiing.

67. A. I would like to try surfboarding.
B. I would not like to try surfboarding.

68. A. I would like to take off on a trip with no preplanned or definite routes or timetables.
B. When I go on a trip, I like to plan my route and timetable carefully.

69. A. I prefer "down to earth" and conventional kinds of people as friends.
B. I would like to make friends with "dreamers" or creative individuals.

70. A. I would not like to learn to fly an airplane.
B. I would like to learn to fly an airplane.

71. A. I prefer the surface of the water to the depths.
B. I would like to go scuba diving.

72. A. I would like to meet some persons who live unusual or alternative lifestyles.
B. I stay away from anyone I suspect of being odd or eccentric.

73. A. I would like to try parachute jumping.
B. I would never want to jump out of a plane even with a parachute.

74. A. I prefer friends who are excitingly unpredictable.
B. I prefer friends who are reliable and dependable.

75. A. I am not interested in experience for its own sake.
B. I like to have new and exciting experiences and sensations even if they are a little frightening, unconventional, or illegal.

76. A. The essence of good art is in its clarity, symmetry of form, and harmony of colors.
B. I often find beauty in the "clashing" colors and irregular forms of modern paintings.

77. A. I enjoy spending time in the familiar surroundings of home.
B. I get very restless if I have to stay around home for any length of time.

78. A. I like to dive off the high board at the pool.
B. I don't like the feeling I get standing on the high board (or I don't go near it).

79. A. I like to date persons who are physically exciting.
B. I like to date persons who share my values.

80. A. Heavy drinking usually ruins a party because some people get loud and annoying.
B. Keeping the drinks full is the key to a good party.

81. A. The worst social sin is to be rude.
B. The worst social sin is to be boring.

82. A. A person should have considerable sexual experiences before marriage.
B. It's better if two married persons begin their sexual experience with each other.

83. A. Even if I had the money, I would not care to associate with celebrities or elitists.
B. If I had the money, I would associate with celebrities and elitists.

84. A. I like people who are sharp and witty even if they sometimes insult others.
B. I dislike people who have their fun at the expense of hurting the feelings of others.

85. A. There is altogether too much portrayal of sex in movies.
B. I enjoy watching of the sexy scenes in movies.

86. A. I feel best after taking a couple of drinks.
B. Something is wrong with people who need alcohol to feel good.

87. A. People should dress according to some standard of taste, neatness, and style.
B. People should dress in individual ways even if they are seen as different.

88. A. Sailing long distances in a small boat is foolish.
B. I would be interested in sailing in a small boat over a long distance.

89. A. I have no patience with dull or boring persons.
B. I find something interesting in almost every person with whom I talk.

90. A. Skiing down a high mountain slope is a good way to end up on crutches.
B. I think I would enjoy the sensation of skiing very fast down a high mountain slope.

(Continue to the next section)

SECTION 4 DIRECTIONS:

On the following pages, 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.

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

Answer the following questions beginning with question #91

91. Feel comfortable around people.

92. Have frequent mood swings.

93. Believe that others have good intentions.

94. Don't see things through.

95. Tend to vote for conservative political candidates.

96. Waste my time.

97. Suspect hidden motives in others.

98. Carry out my plans.

99. Am always prepared.

100. Respect others.

101. Am very pleased with myself.

102. Tend to vote for liberal political candidates.

103. Am skilled in handling social situations.

104. Don't like to draw attention to myself.

105. Feel comfortable with myself.

106. Am the life of the party.

107. Seldom feel blue.

108. Find it difficult to get down to work.

109. Insult people.

110. Don't talk a lot.

111. Panic easily.

112. Have a good word for everyone.

113. Am not easily bothered by things.

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

114. Do just enough work to get by.

115. Get back at others.

116. Have little to say.

117. Have a sharp tongue.

118. Make plans and stick to them.

119. Rarely get irritated.

120. Keep in the background.

121. Carry the conversation to a higher level.

122. Do not like art.

123. Accept people as they are.

124. Enjoy hearing new ideas.

125. Would describe my experiences as somewhat dull.

126. Believe in the importance of art.

127. Am often down in the dumps.

128. Avoid my duties.

129. Make people feel at ease.

130. Get chores done right away.

131. Avoid philosophical discussions.

132. Often feel blue.

133. Make friends easily.

134. Have a vivid imagination.

135. Pay attention to details.

136. Cut others to pieces.

137. Know how to captivate people.

138. Dislike myself.

139. Am not interested in abstract ideas.

140. Do not enjoy going to art museums.

APPENDIX Q: Additional Research Opportunity Page

Thank you for your participation

Invitation

We would like to invite you to participate in an additional study that can be completed during the remaining time.

Please read the following informed consent and consider carefully if you would like to participate.

Your decision to participate or decline will not alter the credit earned for the study you have just completed (1Credit). One additional research credit will be provided for time spent reading a consent form for an additional study and completing an exit survey. You are not required to participate in the additional study to complete the exit survey.

(Attach Experimental Informed Consent)

APPENDIX R: Experimental Informed Consents 11 (Low Risk – Low Money)

INFORMED CONSENT DOCUMENT (Form 11)

Title of Study: Genetic Markers for Personality Characteristics of Undergraduate Students

Investigators: Paul L Ascheman (ascheman@iastate.edu)
Norman Scott (nascott@iastate.edu)

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to examine genetic markers that relate to personality characteristics in undergraduate students. This study has a potential monetary compensation of $10.00. As part of this study, you will be asked to sign up for a time to provide a cheek tissue sample that will be used to explore genetic components to personality. At the conclusion of this research project, anonymous genetic samples will be entered into the GENBEH Repository, a large university-based repository that exists for the study of genetic markers for personality, temperament, and behavior.

Please read this document and ask any questions you may have before agreeing to be in the study. You are being invited to participate in this study because you are a student in a designated psychology class and are age 18 years or older.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, you will be asked to sign up for a collection time to be conducted in the next week.
During the study, you may expect the following:

(1) Provide an anonymous DNA sample using a cheek (buccal) swab method (see confidentiality section for more detail). For this procedure, you will be asked to gently rub a sterile cotton swab along the inside of your cheek to collect a buccal tissue sample. You will then place the swab into a collection tube and label it with your ID number.

You should not provide a sample if you have:
(a) allergies to cotton or latex;
(b) a communicable disease or open sore in or around your mouth;
(c) mouth sensitivity that might produce pain as a result of participation.

You are free to decline to answer any question or to stop participation at any time without penalty.

RISKS
There are no foreseeable physical risks at this time from participating in this study.

Genetic information that results from this study does not have medical or treatment importance at this time. However, information about taking part in a genetic study may influence insurance and/or employers regarding your health status.

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 genetic personality traits.

COSTS AND COMPENSATION
You will not have any costs from participating in this study. You will be compensated in the amount of $10.00 if your DNA sample is accepted to the GENBEH Repository, otherwise you will receive one credit for your participation. Compensation is contingent on the acceptance of a sample to the GENBEH Repository.

PARTICIPANT RIGHTS
Your participation in this study is 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
Sample identification and records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and they 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: Subjects will be assigned a unique code that will be used on forms instead of their name. The key for this unique code and the questionnaires will be kept separate locked filing cabinets. These 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.

Samples submitted to the GENBEH Repository will be anonymous, that is, your personal identifier or code will be removed to your sample. No information will be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use anonymous study information to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.

It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does, but because samples have been stripped of identifying data there is no way of matching you to your sample.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

- For further information about the study contact Paul Ascheman: ascheman@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 Research Assurances, Iowa State University, Ames, Iowa 50011.

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PARTICIPANT CONFIRMATION

READ THIS: Your digital confirmation 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. By selecting the "I agree to participate" button on this form, you agree to submit a genetic sample and allow it to be submitted to the GENBEH Repository. Please print a copy of this informed consent document for you records.

APPENDIX S: Experimental Informed Consents 15 (Low Risk – High Money)

INFORMED CONSENT DOCUMENT (Form 15)

Title of Study: Genetic Markers for Personality Characteristics of Undergraduate Students

Investigators: Paul L Ascheman (ascheman@iastate.edu)
Norman Scott (nascott@iastate.edu)

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to examine genetic markers that relate to personality characteristics in undergraduate students. This study has a potential monetary compensation of $100.00. As part of this study, you will be asked to sign up for a time to provide a cheek tissue sample that will be used to explore genetic components to personality. At the conclusion of this research project, anonymous genetic samples will be entered into the GENBEH Repository, a large university-based repository that exists for the study of genetic markers for personality, temperament, and behavior.

Please read this document and ask any questions you may have before agreeing to be in the study. You are being invited to participate in this study because you are a student in a designated psychology class and are age 18 years or older.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, you will be asked to sign up for a collection time to be conducted in the next week.
During the study, you may expect the following:

(1) Provide an anonymous DNA sample using a cheek (buccal) swab method (see confidentiality section for more detail). For this procedure, you will be asked to gently rub a sterile cotton swab along the inside of your cheek to collect a buccal tissue sample. You will then place the swab into a collection tube and label it with your ID number.

You should not provide a sample if you have:
(a) allergies to cotton or latex;
(b) a communicable disease or open sore in or around your mouth;
(c) mouth sensitivity that might produce pain as a result of participation.

You are free to decline to answer any question or to stop participation at any time without penalty.

RISKS
There are no foreseeable physical risks at this time from participating in this study.

Genetic information that results from this study does not have medical or treatment importance at this time. However, information about taking part in a genetic study may influence insurance and/or employers regarding your health status.

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 genetic personality traits.

COSTS AND COMPENSATION
You will not have any costs from participating in this study. You will be compensated in the amount of $100.00 if your DNA sample is accepted to the GENBEH Repository, otherwise you will receive one credit for your participation. Compensation is contingent on the acceptance of a sample to the GENBEH Repository.

PARTICIPANT RIGHTS
Your participation in this study is 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
Sample identification and records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and they 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: Subjects will be assigned a unique code that will be used on forms instead of their name. The key for this unique code and the questionnaires will be kept separate locked filing cabinets. These 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.

Samples submitted to the GENBEH Repository will be anonymous, that is, your personal identifier or code will be removed to your sample. No information will be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use anonymous study information to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.

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QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

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APPENDIX T: Experimental Informed Consents 51 (High Risk – Low Money)

INFORMED CONSENT DOCUMENT (Form 51)

Title of Study: Genetic Markers for Personality Characteristics of Undergraduate Students

Investigators: Paul L Ascheman (ascheman@iastate.edu)
Norman Scott (nascott@iastate.edu)

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to examine genetic markers that relate to personality characteristics in undergraduate students. This study has a potential monetary compensation of $10.00. As part of this study, you will be asked to sign up for a time to provide a cheek tissue sample that will be used to explore genetic components to personality. At the conclusion of this research project, identifiable genetic samples will be entered into the GENBEH Repository, a large university-based repository that exists for the study of genetic markers for personality, temperament, and behavior.

Please read this document and ask any questions you may have before agreeing to be in the study. You are being invited to participate in this study because you are a student in a designated psychology class and are age 18 years or older.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, you will be asked to sign up for a collection time to be conducted in the next week.
During the study, you may expect the following:

(1) Provide a personally identifiable DNA sample using a cheek (buccal) swab method (see confidentiality section for more detail). For this procedure, you will be asked to gently rub a sterile cotton swab along the inside of your cheek to collect a buccal tissue sample. You will then place the swab into a collection tube and label it with your ID number.

You should not provide a sample if you have:
(a) allergies to cotton or latex;
(b) a communicable disease or open sore in or around your mouth;
(c) mouth sensitivity that might produce pain as a result of participation.

You are free to decline to answer any question or to stop participation at any time without penalty.

RISKS
There are no foreseeable physical risks at this time from participating in this study.

Genetic information that results from this study does not have medical or treatment importance at this time. However, information about taking part in a genetic study may influence insurance and/or employers regarding your health status.

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 genetic personality traits.

COSTS AND COMPENSATION
You will not have any costs from participating in this study. You will be compensated in the amount of $10.00 if your DNA sample is accepted to the GENBEH Repository, otherwise you will receive one credit for your participation. Compensation is contingent on the acceptance of a sample to the GENBEH Repository.

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Samples submitted to the GENBEH Repository will include identifying information, that is, your personal information will be attached to your sample. This information may be shared with other researchers who have access to the GENBEH Repository. Partners of the GENBEH Repository may use study information that identifies you to do research similar to that described in this study and to do related research. Samples will be stored indefinitely.

It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does and may disclose identifiable information to others.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

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APPENDIX U: Experimental Informed Consents 55 (High Risk – High Money)

INFORMED CONSENT DOCUMENT (Form 55)

Title of Study: Genetic Markers for Personality Characteristics of Undergraduate Students

Investigators: Paul L Ascheman (ascheman@iastate.edu)
Norman Scott (nascott@iastate.edu)

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to examine genetic markers that relate to personality characteristics in undergraduate students. This study has a potential monetary compensation of $100.00. As part of this study, you will be asked to sign up for a time to provide a cheek tissue sample that will be used to explore genetic components to personality. At the conclusion of this research project, identifiable genetic samples will be entered into the GENBEH Repository, a large university-based repository that exists for the study of genetic markers for personality, temperament, and behavior.

Please read this document and ask any questions you may have before agreeing to be in the study. You are being invited to participate in this study because you are a student in a designated psychology class and are age 18 years or older.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, you will be asked to sign up for a collection time to be conducted in the next week.
During the study, you may expect the following:

(1) Provide a personally identifiable DNA sample using a cheek (buccal) swab method (see confidentiality section for more detail). For this procedure, you will be asked to gently rub a sterile cotton swab along the inside of your cheek to collect a buccal tissue sample. You will then place the swab into a collection tube and label it with your ID number.

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(a) allergies to cotton or latex;
(b) a communicable disease or open sore in or around your mouth;
(c) mouth sensitivity that might produce pain as a result of participation.

You are free to decline to answer any question or to stop participation at any time without penalty.

RISKS
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It is possible that other researchers who may apply for access to the GENBEH Repository may not have to meet the same privacy requirements that GENBEH Repository does and may disclose identifiable information to others.

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READ THIS: Your digital confirmation 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. By selecting the "I agree to participate" button on this form, you agree to submit a genetic sample and allow it to be submitted to the GENBEH Repository. Please print a copy of this informed consent document for you records.

APPENDIX V: Exit Survey

EXIT SURVEY

DIRECTIONS:

- Regardless of whether or not you decided to participate in the research study, we would like you to complete an exit survey for the online portion of this study.

- You will be awarded one research credit for time spent completing the exit survey.

DIRECTIONS: Please briefly answer the following questions in the space provided.

A) Why did you participate in the FIRST research study regarding personality characteristics?

_____

_____

B) Why did you participate in the SECOND research study?

_____

_____

C) Based on what you can remember, what were the risks of the SECOND study, as stated in the informed consent?

_____

_____

D) Based on what you can remember, what were the benefits of the SECOND study, as stated in the informed consent?

_____

_____

E) What is the monetary compensation in the SECOND study, as stated in the informed consent?

_____

F) Who will have access to the repository, as stated in the informed consent?

_____

_____

G) How will your identifying information be treated by the repository?

_____

_____

Please answer the following questions

DIRECTIONS:
Please answer the following questions regarding your beliefs about the additional study opportunity. Please answer honestly.

1	2	3	4	5
Not at All				Very High

141. After reading the informed consent, but before participating, how willing were you to participate in this study?

142. How likely would other students like you be to participate in this study?

143. How important was the amount of compensation in your decision to participate?

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

145. How much risk to your privacy do you feel it is to have your DNA sample put in a repository?

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?

147. How serious would the negative consequences related to loss of privacy be if they occurred?

148. How much did you enjoy participating in this research study?

DIRECTIONS:
These items include hypothetical scenarios regarding this study. Regardless of your decision to participate in the additional study opportunity, please answer the following questions.

149. Imagine that you would be asked to provide a DNA sample but the sample would NOT be put into a repository. Given this, how willing would you be to participate in the research study?

I would definitely NOT participate if the sample was not put in a repository	**1**	**2**	**3**	**4**	**5**	**I would definitely participate even if the sample was not put in a repository**

150. Imagine that you would NOT be paid any money to participate in the study. Given this, how willing would you be to participate in the research study?

I would definitely NOT participate if I was not paid	**1**	**2**	**3**	**4**	**5**	**I would definitely participate even if I was not paid**

(Continue to the next section)

DIRECTIONS:
Please answer the following questions regarding your opinion of genetic testing, repositories, and databanking. Using the scale below as a guide, select a number for each statement to indicate how true it is.

1	**2**	**3**	**4**	**5**
Strongly Disagree	Disagree	Indifferent	Agree	Strongly Agree

151. I am comfortable contributing information to medical researchers.

152. I am comfortable contributing information to healthcare companies.

153. Genetic information submitted to a repository is the property of that institution

154. Genetic repositories have the right to sell genetic information to researchers.

155. Private companies should not be able to purchase genetic information.

156. There are more benefits than drawbacks to knowing more about our genetic information.

157. I have moral objections to genetic testing that would lead me to decline participation.

158. It should be each person's right to determine whether or not they will have a genetic test, even in the case of a court order.

159. I am concerned about the privacy of my financial information.

160. I am concerned about the privacy of my medical information.

161. I am concerned about the privacy of my mental health information.

162. I am concerned about the privacy of my academic records.

163. I am concerned about the privacy of my online information.

164. Genetic information should be treated the same as medical information.

165. Insurance companies should have the same access to genetic information as they do to medical health information.

166. Genetic information should be more strictly regulated than medical health information.

167. Genetic information should be more strictly regulated than mental health information.

168. I am the owner of genetic information provided voluntarily to the repository.

169. My financial information is safe.

170. My medical health information is safe.

171. My mental health information is safe.

172. My personal genetic information is safe.

173. My online information is safe.

174. I am willing to contribute personally identifiable information from a genetic test to a repository that would be used for research.

175. I am willing to contribute personally identifiable information from a genetic test to a repository that would be used commercially (sold to pharmaceutical or other companies).

176. I am willing to contribute information from a genetic test results to a repository when identifying information has been stripped from the results.

DIRECTIONS:
Answer the following questions using YES=1 & NO=2.

177. Have you ever provided a genetic sample to a genetic repository prior to this experiment? (YES=1; NO=2)

178. Have you ever provided a genetic sample for research purposes, but NOT to a genetic repository, prior to this experiment? (YES=1; NO=2)

179. Have you ever been genetically screened for a disease or health condition? (YES=1; NO=2)

180. Do you have family members who have been genetically screened for a disease or health condition? (YES=1; NO=2)

APPENDIX W: Written Debriefing

Debriefing Statement

Thank you for your participation. I reassure you that all your responses are confidential and will be combined with the responses of other participants to protect your identity. Now that your participation is complete, 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 study you participated in was not designed to investigate genetic markers for personality. Rather, it was designed to evaluate undergraduate students' concern about their genetic privacy and the influence of money on the decision to participate in research that includes a risk to privacy. In order to accurately evaluate students' level of concern, it was necessary to disguise the true purpose of the study. The second informed consent was created by the experimenter's for the purpose of this research and was the same for each participant with the exception of what would happen to the sample and how much money would be paid if the sample were submitted to a genetic repository.

Because the studies purpose was not to evaluate genetic markers for personality, no samples will be collected and your personal information will not be entered into a repository databank. The purpose of the consent form was to allow a behavioral measure of participation related to level of monetary compensation to evaluate if higher levels of payment would be coercive or be an undue inducement. For this reason, it would be unreasonable to include the monetary compensation. If we were to find that monetary compensation unduly influenced participation, it would be represent an unethical loop. Additionally, it would be unfair to pay individuals different rates.

You will recall that this is a two-credit study. You have participated for the allotted time, and therefore, it is reasonable to compensate you with credit you would normally be entitled to for this study's duration. The first study was worth one credit, and regardless of whether you consented to the second study, the second credit is awarded for the time you spent completing the exit survey and reading to this debriefing.

All students participated by filling out questionnaires at the beginning of the study. Information gathered from these studies is confidential and is used to look at trends between responses and willingness to participate in genetic studies with risk to privacy.

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.

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 (Ascheman@iastate.edu). However, due to the anonymous nature of your responses, you must make this request immediately following the debriefing. Once you are awarded credit, the researchers will remove your name from your data and will no longer be able to identify data belonging to you.

We have provided a short digital brochure as educational material to help you understand the importance of protecting your privacy while participating in research, particularly genetic research. The most important message is that providing consent to research is more than signing a piece of paper. It is called and "informed" consent because its purpose is to inform you of what will take place during a study.

Informed consent is not a piece of paper, rather it is a process in which researchers inform you of the aspects of the study, assess your comprehension of the information, and remind you that your participation is completely voluntary. By blindly signing an informed consent, you may put yourself at physical, psychological, or economic risk. As this study shows, risk may also include risk to your privacy in putting your identifiable data in a relatively public domain. The reason this is risky is that individuals may use this information in a way that is not in your best interest.

While under the Genetic Information Nondiscrimination Act of 2008 (GINA), your genetic information cannot be used against you by an insurance company or employer, it can still be used to discriminate eligibility for life insurance and long term disability insurance. Additionally, even though the law protects your privacy on paper, unscrupulous individuals may still attempt to use this for other purposes, such as identity theft. For these reasons, it is critical that you pay close attention to privacy protections in research and read all documents carefully, asking questions before you consent to participate.

In closing, I would like to thank you for volunteering to be in the study. Your participation today has been very valuable because it will further the field's understanding of circumstances that can influence how people's behavior is shaped by elements of risk and reward.

Again, for the integrity of this study, we ask that you not discuss these elements with other students. If asked about your participation, you may wish to simply reply that you were asked to participate in a similar study, without divulging that it involved specific risks or monetary compensation. It is critical that other students participate with the same lack of information about the study that you have today.

I am glad that you had the opportunity to participate in a deception study, as they are a valuable methodology in psychological research and allow researchers to look at unfiltered behavior that hypothetical or survey data does not.

Again, thank you for your participation and commitment to maintain the mystery of this experiment for others. There are several final items regarding this debriefing that we would like you to answer before your close your browser by clicking the "X" in top corner of your browsing window.

APPENDIX X: Post-Debriefing Items

Items to be completed following debriefing information

181. As a result of participating in this research project, how has your awareness of the need to protect your privacy changed?

Less aware now	**1**	**2**	**3**	**4**	**5**	**More aware now**

182. As a result of participating in this research project, has your view or opinion, confidence, and trust in psychological research increased or decreased?

Decreased	**1**	**2**	**3**	**4**	**5**	**Increased**

183. How likely would you be to participate in this research study again?

Would definitely not participate	**1**	**2**	**3**	**4**	**5**	**Would definitely participate**

184. I will be able to keep elements of this study a secret from my friends or others who might participate in the future to prevent biasing their responses.

I will not be able to keep this a secret	**1**	**2**	**3**	**4**	**5**	**I have some self control and can keep a secret**

185. Have you answered truthfully to all parts of this questionnaire?

I have Not answered truthfully	**1**	**-**	**-**	**-**	**5**	**I have answered truthfully**

APPENDIX Y: Balanced Inventory of Desired Responding (BIDR) (Unmodified)

BIDR

1. My first impressions of people usually turn out to be right.
2. It would be hard for me to break any of my bad habits.
3. I don't care to know what other people really think of me.
4. I have not always been honest with myself.
5. I always know why I like things.
6. When my emotions are aroused, it biases my thinking.
7. Once I've made up my mind, other people can seldom change my opinion.
8. I am not a safe driver when I exceed the speed limit
9. I am fully in control of my own fate.
10. It's hard for me to shut off a disturbing thought.
11. I never regret my decisions.
12. I sometimes lose out on things because I can't make up my mind soon enough.
13. The reason I vote is because my vote can make a difference.
14. My parents were not always fair when they punished me.
15. I am a completely rational person.
16. I rarely appreciate criticism.
17. I am very confident of my judgments.
18. I have sometimes doubted my ability as a lover.
19. It's all right with me if some people happen to dislike me.
20. I don't always know the reasons why I do the things I do.
21. I sometimes tell lies if I have to.
22. I never cover up my mistakes.
23. There have been occasions when I have taken advantage of someone.
24. I never swear.
25. I sometimes try to get even rather than forgive and forget.
26. I always obey laws, even if I'm unlikely to get caught.
27. I have said something bad about a friend behind his/her back.
28. When I hear people talking privately, I avoid listening.
29. I have received too much change from a salesperson without telling him or her.
30. I always declare everything at customs.
31. When I was young I sometimes stole things.
32. I have never dropped litter on the street
33. I sometimes drive faster than the speed limit.
34. I never read sexy books or magazines.
35. I have done things that I don't tell other people about.
36. I never take things that don't belong to me.
37. I have taken sick-leave from work or school even though I wasn't really sick.
38. I have never damaged a library book or store merchandise without reporting it.
39. I have some pretty awful habits.
40. I don't gossip about other people's business.

APPENDIX Z: Sensation Seeking Scale (SSS-V) (Unmodified)

Zuckerman's (1994; 1996) Sensation Seeking Scale – V

Directions: Each of the items below contains two choices A and B. Please indicate which of the choices most describes your likes or the way you feel. In some cases, you may find items in which both choices describe your likes or feelings. Please choose the one that better describes your likes or feelings. In some cases, you may find items in which you do not like either choice. In these cases marked the choice you dislike the least. Do not leave any items blank. It is important you respond to all items with only one choice, A or B. we are interested only in your likes or feelings, not in how others feel about these things or how one is supposed to feel. There are no correct or incorrect answers as in other kinds of tests. Work quickly and give an honest appraisal of yourself.

1) A. I like "wild" uninhibited parties.
   B. I prefer quiet parties with good conversation.
2) A. There are some movies I enjoy seeing a second or even third time.
   B. I can't stand watching a movie that I've seen before.
3) A. I often wish I could be a mountain climber.
   B. I can't understand people who risk their necks climbing mountains.
4) A. I dislike all body odors.
   B. I like some of the earthy body smells.
5) A. I get bored seeing the same old faces.
   B. I like the comfortable familiarity of everyday friends.
6) A. I like to explore a strange city or section of town by myself, even if it means getting lost.
   B. I prefer a guide when I am in a place I don't know well.
7) A. I dislike people who do or say things just to shock or upset others.
   B. When you can predict almost everything a person will do and say he or she must be a bore.
8) A. I usually don't enjoy a movie or play where I can predict what will happen in advance.
   B. I don't mind watching a movie or play where I can predict what will happen in advance.
9) A. I have tried marijuana or would like to.
   B. I would never smoke marijuana.
10) A. I would not like to try any drug which might produce strange and dangerous effects on me.
   B. I would like to try some of the drugs that produce hallucinations.
11) A. A sensible person avoids activities that are dangerous.
   B. I sometimes like to do things that are a little frightening.
12) A. I dislike "swingers" (people who are uninhibited and free about sex).
   B. I enjoy the company of real "swingers."
13) A. I find that stimulants make me uncomfortable.
   B. I often like to get high (drinking liquor or smoking marijuana).

14) A. I like to try new foods that I have never tasted before.
    B. I order the dishes with which I am familiar so as to avoid disappointment and unpleasantness.
15) A. I enjoy looking at home movies, videos, or travel slides.
    B. Looking at someone's home movies, videos, or travel slides bores me tremendously.
16) A. I would like to take up the sport of water skiing.
    B. I would not like to take up water skiing.
17) A. I would like to try surfboard riding.
    B. I would not like to try surfboard riding.
18) A. I would like to take off on a trip with no preplanned or definite routes, or timetables.
    B. When I go on a trip I like to plan my route and timetable fairly carefully.
19) A. I prefer the "down to earth" kinds of people as friends.
    B. I would like to make friends in some of the "far-out" groups like artists or "punks."
20) A. I would not like to learn to fly an airplane.
    B. I would like to learn to fly an airplane.
21) A. I prefer the surface of the water to the depths.
    B. I would like to go scuba diving.
22) A. I would like to meet some persons who are homosexual (men or women).
    B. I stay away from anyone I suspect of being "gay" or "lesbian."
23) A. I would like to try parachute jumping.
    B. I would never want to try jumping out of a plane, with or without a parachute.
24) A. I prefer friends who are excitingly unpredictable.
    B. I prefer friends who are reliable and predictable.
25) A. I am not interested in experience for its own sake.
    B. I like to have new and exciting experiences and sensations even if they are a little frightening, unconventional, or illegal.
26) A. The essence of good art is in its clarity, symmetry of form, and harmony of colors.
    B. I often find beauty in the "clashing" colors and irregular forms of modern paintings.
27) A. I enjoy spending time in the familiar surroundings of home.
    B. I get very restless if I have to stay around home for any length of time.
28) A. I like to dive off the high board.
    B. I don't like the feeling I get standing on the high board (or I don't go near it at all).
29) A. I like to date persons who are physically exciting.
    B. I like to date persons who share my values.
30) A. Heavy drinking usually ruins a party because some people get loud and boisterous.
    B. Keeping the drinks full is the key to a good party.
31) A. The worst social sin is to be rude.
    B. The worst social sin is to be a bore.
32) A. A person should have considerable sexual experiences before marriage.
    B. It's better if two married persons begin their sexual experience with each other.
33) A. Even if I had the money, I would not care to associate with flighty rich persons in the "jet set."
    B. I could conceive of myself seeking pleasures around the world with the "jet set."
34) A. I like people who are sharp and witty even if they do sometimes insult others.
    B. I dislike people who have their fun at the expense of hurting the feelings of others.

35) A. There is altogether too much portrayal of sex in movies.
B. I enjoy watching many of the "sexy" scenes in movies.
36) A. I feel best after taking a couple of drinks.
B. Something is wrong with people who need liquor to feel good.
37) A. People should dress according to some standard of taste, neatness, and style.
B. People should dress in individual ways even if the effects are sometimes strange.
38) A. Sailing long distances in small sailing crafts is foolhardy.
B. I would like to sail a long distance in a small but seaworthy sailing craft.
39) A. I have no patience with dull or boring persons.
B. I find something interesting in almost every person I talk to.
40) A. Skiing down a high mountain slope is a good way to end up on crutches.
B. I think I would enjoy the sensation of skiing very fast down a high mountain slope.

APPENDIX AA: International Personality Item Pool Version of NEO-PI-R

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 AB: 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.

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 AC: Correlation Matrix for Scale Variables

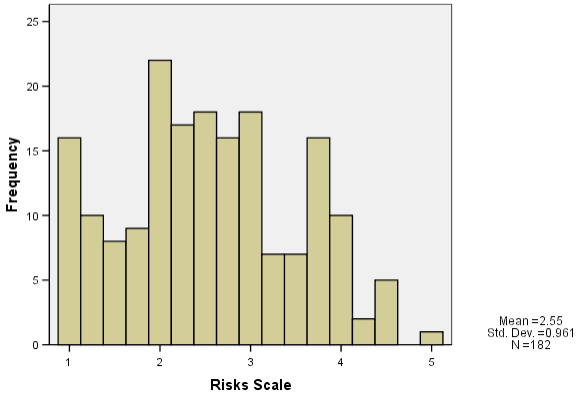
Correlation matrix for scale variables (Coefficients Alpha displayed in bold along the diagonal)

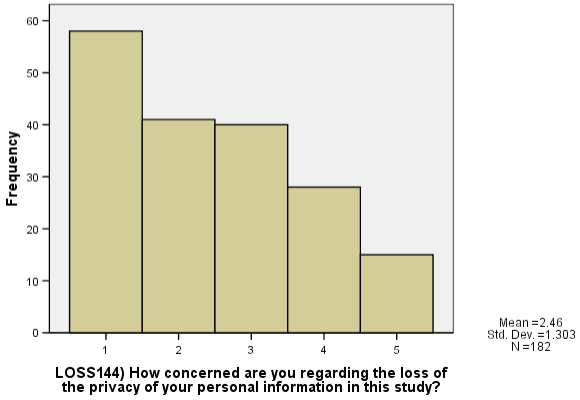
	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.	SDE	**.61**													
2.	IM	.10	**.74**												
3.	BIDR	.78**	.70**	**.77**											
4.	TAS	-.10	.00	-.07	**.74**										
5.	ES	-.05	-.10	-.10	.27**	**.53**									
6.	DIS	.02	-.16*	-.09	.22*	.31**	**.71**								
7.	BS	.07	.04	.08	.07	.16*	.38**	**.49**							
8.	SSS-TOT	-.03	-.09	-.08	.63**	.66**	.75**	.57**	**.77**						
9.	NEO-A	-.22*	-.07	-.20*	.06	-.01	-.34**	-.40**	-.25*	**.79**					
10.	NEO-C	-.05	-.04	-.06	-.04	-.24*	-.22*	-.42**	-.33**	.40**	**.80**				
11.	NEO-E	-.02	-.07	-.06	.13	.12	.22*	.06	.21*	.05	.23*	**.86**			
12.	NEO-N	.10	.08	.12	-.14	.03	.13	.14	.05	-.38**	-.30**	-.39**	**.86**		
13.	NEO-O	-.01	-.06	-.04	.12	.39**	.04	-.06	.19	.33**	.13	.19*	-.13	**.77**	
14.	RISKS	.01	.10	.07	.07	-.02	.00	.04	.04	-.07	.01	.01	.11	-.04	**.88**

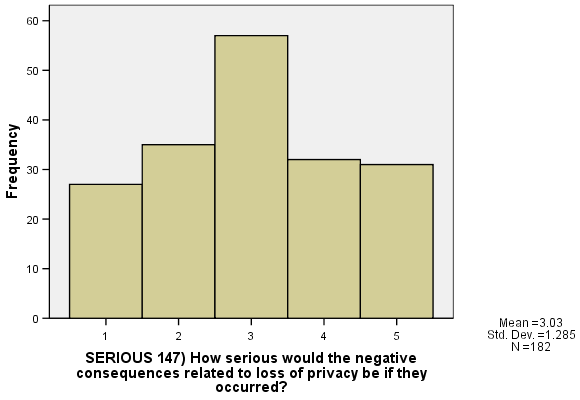
Note. * $p < .05$; ** Bonferroni Correction $p < .0003$; Scale coefficient alphas in bold along the diagonal

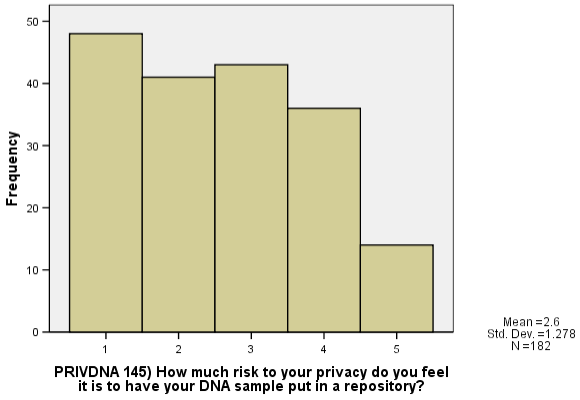
APPENDIX AD: Histograms for Risks Scale & Enjoyment/Benefits Scale

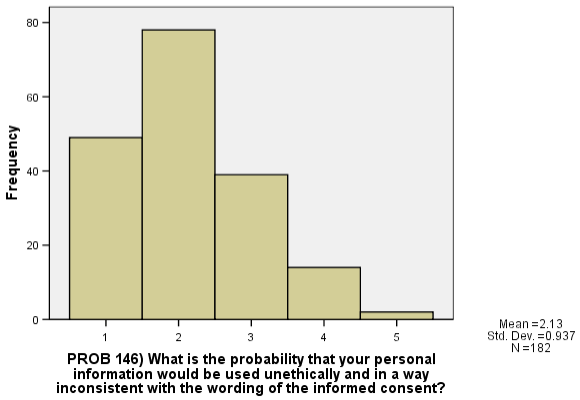
Risks Scale & Items











Enjoyment/Benefits Scale & Items