HOW DOES KNOWLEDGE OF THE TUSKEGEE SYPHILIS STUDY AND BELIEFS IN HIV CONSPIRACY THEORIES AFFECT AFRICAN AMERICAN'S PERCEPTION OF MEDICAL RESEARCH?

by

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OBJECTIVES: The Tuskegee Syphilis Study and HIV conspiracy beliefs have continuing effects on perceptions of medical research in the African American community. This study was designed to explore how knowledge and beliefs concerning the Tuskegee Study and HIV impact African Americans' willingness to partake in medical research, how research incentives may influence that willingness and what level of importance they believe medical research has in their lives.

METHODS: Responses to medical research questionnaires were assessed for 100 participants. Outcome measures included accuracy of Tuskegee study knowledge, likelihood of participation in research based on incentives, level of importance of research and enrollment into a recruitment database. Data concerning knowledge and beliefs of the Tuskegee Study and HIV, likelihood of participation and level of importance were analyzed via two-way correlation tables and chi-square analysis.

RESULTS: Analysis revealed a relatively high level of inaccuracy of Tuskegee study knowledge and HIV. Influences of these topics in relation to willingness to participate in research and overall perceptions of medical research were minimal. However, there were associations indicating that individuals with moderate or greater knowledge of the Tuskegee Study were less likely to participate in research if free medical care was offered when compared to individuals who knew little or nothing regarding the study.

CONCLUSIONS: In order to improve the likelihood of minority participation, the medical research community should tailor their recruitment efforts to take into account common beliefs in the African American community concerning medical research.

PUBLIC HEALTH SIGNIFICANCE: The data have implications related to the ability to garner trust between the African American and medical research communities, with the ultimate goal to improve likelihood of minority participation in medical research. With a significant degree of misconceptions concerning both the Tuskegee Study and HIV being prevalent in the community, it is vital to take into account these beliefs in order to more effectively recruit African Americans. Outwardly dismissing these beliefs could result in further distrust between the scientific and African American community.

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1.0 INTRODUCTION

This research was conducted through the Center for Minority Health (CMH) located in the University of Pittsburgh's Graduate School of Public Health. The Center was established in 1994 with the purpose to improve and create community-based interventions through the use of evidence-based research. A major goal of this effort is to improve the overall health and well-being of minority populations in the Pittsburgh area by helping to eliminate health disparities as stated by the Center for Disease Control's Healthy People 2010 program. Health disparities can be defined as a difference in morbidity, mortality and disease burden between ethnic and socioeconomic groups. One approach developed by the Center to help eliminate these disparities was the creation of the Healthy Black Family Project.

The Healthy Black Family Project (HBFP) was established in 2004 and designed to promote the concepts of disease prevention and health improvement. Based on the Diabetes Prevention Program and located in two predominantly African American communities in Pittsburgh, the Kingsley Association in East Liberty and the Hosanna House in Wilkinsburg, the HBFP provides members the opportunity to take part in several classes and activities geared towards promoting health awareness. Samples of some of these activities include: health risk assessments, stress management, access to certified fitness trainers, nutrition assistance, smoking cessation, self-management classes on chronic diseases and evaluation of family health history.

Establishment of trust between the community and the HBFP is a critical component in order for the HBFP to be effective. Previous studies have shown that the African American community has a greater level of distrust regarding the medical community than other ethnic groups (Corbie-Smith, G et al. 2002; Braunstein, JB et al 2008; Rajakumar, K et al. 2009). This greater level of distrust has been implicated as a possible reason for the decreased willingness of African Americans to participate in medical research, which then translates into fewer studies having direct application (Corbie-Smith, G et al. 1997). Two possible factors contributing to this greater level of distrust are the awareness of this country's history involving African Americans in medical research, specifically the Tuskegee Syphilis Study, and current HIV conspiracy beliefs that persist throughout the African American community.

The objective of this study is to determine how knowledge and beliefs concerning the Tuskegee Syphilis Study and HIV influence an individual's perceptions and their willingness to take part in medical research. Specifically, the project examines perceptions concerning who benefits from medical research and the use of human subjects in research as well as assessed participation in previous research and interest in enrolling in a research recruitment database. It also focuses on the willingness to participate in research by examining the influences of research incentives (e.g. free medical care, medications, financial incentives), which are often used to encourage participation. The following is a review of literature that provides the rationale for the importance of this study. It includes information concerning the health disparities that exist in the African American community, the distrust that can be observed towards the medical community, the history and influence of the Tuskegee Syphilis Study and some of the noted HIV conspiracy theories.

2.0 BACKGROUND AND SIGNIFICANCE

2.1 HEALTH DISPARITIES IN THE UNITED STATES

Throughout the history of the United States, there has existed a clear disparity in overall health between African Americans and the Caucasian population (Kington et al 1997; Thomas et al. 2006; Thomas et al. 2008). Initially, this disparity was attributed to racist and absurd concepts such as racial inferiority of African Americans and other minorities. More recently, other causes have been suggested, such as socioeconomic factors due to the increased levels of poverty that are present in the African American population (Thomas et al 2006; Thomas et al 2008). As of 2006, nearly 24% of individuals living below the poverty line are African American, as compared to only 8% of the Caucasian population (DeNavas-Walt et al. 2007). Living at or below the poverty line can serve as a double burden to overall health as it often associates both with a lack of access to proper medical care and to a decreased ability to maintain proper nutrition, exercise and other factors that reduce the risk of many chronic conditions. However, even when these factors are taken into consideration, there still exists a greater burden of disease in the African American population (Nazroo 2003). Perhaps even more alarming, one study, which examined differences between the Caucasian and African American populations in regards to life expectancy and mortality rates between 1933 and 1999, showed that there has been no sustained decrease in the disparity of age-adjusted mortality since 1945 and that the disparity may in fact be increasing (Levine et al 2001). Further examination of the increased disease burden in the African American population paints a startling picture.

In the area of infant mortality (death of a child less than one year of age), the national average is approximately 6.9 deaths per 1,000 births (CDC 2007). In the African American population, this figure is double, with 14.1 deaths occurring with every 1,000 births (CDC 2007). Overall, African Americans have a lower life expectancy, with an average of 73.1 years when compared to 77.8 years for the general population (CDC 2009). This difference in mortality is interesting when one considers that the top three leading causes of death in the African American population (heart disease, cancer and stroke) are the same as in the general population (CDC 2009). However, further examination into these and other chronic conditions reveals a stark contrast in the number of people affected.

The death rate for heart disease is 29% higher in the African American population as compared to the Caucasian population and for stroke the difference is even greater, with a 40% increase (CDC 2009). Cancer rates and mortality are also increased, with the African American population having the highest level of mortality rate from cancer of any ethnic group in the United States (ACS 2008). Per 100,000 individuals, 321.8 African American males and 189.3 African American females have deaths attributed to cancer as compared to 234.7 males and 161.4 females in the Caucasian population (ACS 2008). Incidence rates of many types of cancer are also increased in the African American population.

For colorectal cancer, the incidence in African Americans is 72.6 in males and 55.0 in females per 100,000 individuals; the incidence in Caucasians is 60.4 and 44.0, respectively (ACS 2008). This increased rate is also observed in kidney and renal pelvic cancers (20.4 and 9.7 as compared to 18.3 and 9.1), liver and bile duct cancers (12.7 and 3.8 as compared to 7.9 and 2.9), lung and bronchial cancer (110.6 in African American males as compared to 81.0 in Caucasian males), prostate cancer (255.5 vs. 161.4), gastric cancers (17.5 and 9.1 as compared to 10.2 and 4.7) and endometrial cancers (11.4 vs. 8.5) (ACS 2008). Though the incidence rate of breast cancer is lower in African Americans as compared to Caucasians, the mortality rate of this cancer is markedly higher in African Americans, with 33.8 deaths attributed per 100,000 as compared to only 25.0 (ACS 2008).

In addition to the previously mentioned conditions, there is also a greater burden of disease in the African American population for other chronic conditions such as hypertension and diabetes. The prevalence of hypertension in the African American population is 41% when compared to only 28% in the Caucasian population (Ostchega 2008). Diabetes is diagnosed in nearly twice as many African Americans as compared to Caucasians (CDC 2007).

Another area that displays prominent health disparity is in regards to HIV and AIDS. African Americans comprise approximately 13% of the United States population; however, in the year 2005, they accounted for nearly 50% of all newly diagnosed cases of HIV/AIDS (CDC 2008). On average, African Americans are diagnosed with HIV/AIDS 10 times more frequently than Caucasians (CDC 2008). The greatest disparity is observed in women; African Americans are 23 times more likely be diagnosed than their Caucasian counterparts; in men, African Americans were 8 times more likely to be diagnosed (CDC 2008).

Some of the explanations for these disparities include socioeconomic factors, conscious or unconscious racial bias and discrimination, differences in preferences and perceptions of the medical community, differences in communication between patient and doctor and increased levels of distrust regarding the medical community. As mentioned previously, socioeconomic factors play a significant role in differences in health. According to the US Census Bureau in

1999, nearly 1 in 4 African Americans are living at or below the poverty line. Though this may explain some of the disparity that is observed, studies have shown that when taken into account, socioeconomic factors do not account for the entirety of the disparity picture (Nazroo 2003).

Another factor that may possibly contribute to health disparities is African Americans' distrust of the medical community (Corbie-Smith 2002; Braunstein 2008). Part of this distrust may stem from past abuses in medical studies that included African Americans. One of the most infamous examples is the Tuskegee Syphilis Study, which involved the recruitment of African American males diagnosed with syphilis (Jones 1981). Additionally, there is a significant level of concern in the African American community regarding the origin of HIV/AIDS (Corbie-Smith 1999; Klonoff 1999; Bogart 2005; Ross 2006). Both of these topics and the subject of distrust in general in the African American community are discussed in more detail in the following sections.

2.2 DISTRUST IN THE AFRICAN AMERICAN COMMUNITY

A common problem with many clinical research studies has been the lack of minority representation in the sample population (Moye 2001; Heiat 2002; King 2002). This under-representation leads to a decrease in the generalizability of findings to these groups, which possibly contributes to the health disparities observed in minority populations (Moye 2001; Heiat 2002; King 2002). Of particular note, is the lack of representation for the African American community in research (Moye 2001; King 2002). Several studies have shown that there appears to be a decreased willingness of African Americans to participate in research studies and that part of this may be caused by a lack of trust towards the medical community (Rajakumar 2009; Braunstein 2008; Corbie-Smith 2002; Corbie-Smith 1999).

Corbie-Smith et al 2002 revealed significant differences in trust between African American and Caucasian populations towards the medical and research community. In their study, it was shown that 41.7% of African Americans felt that they could not trust their physician to fully explain research participation. This differed significantly from the 23.4% reported from the Caucasian group (Corbie-Smith 2002). Additionally, there were differences regarding how comfortable patients felt they could talk with their doctor regarding health concerns. Approximately 15% of African American respondents stated they were less likely to believe that they could freely ask questions to their physicians, as compared to only 7.6% in the Caucasian group (Corbie-Smith 2002). Other significant differences included a greater likelihood to disagree that their physician would not ask them to participate in research if they felt it could do harm (37.2% vs. 19.7%), a greater belief that their physicians would expose them to unnecessary risks (45.5% vs. 34.8%), a higher likelihood to be used as "guinea pigs" in research studies (79.2% as compared to 51.9%), a greater likelihood of physicians prescribing medications as part of an experiment without the use of consent (62.8% vs. 38.4%) and a greater belief that their physicians administered treatment as part of a study without their consent (24.5% vs. 8.3%) (Corbie-Smith 2002). These levels of distrust remained significantly different even when socioeconomic factors were taken into account.

Data from a recent study in 2009 by Rajakumar et al also highlights distrust by focusing on the opinions of parents and their willingness to participate or have their children participate in studies. Two significant differences noted in this study between the African American and Caucasian participants were the belief that there is too much risk in research and that if their child was part of a study, they would not be fully informed of all the procedures. Approximately 47% of the African American respondents stated that there was too much risk involved in research, as compared to only 26% of the Caucasian respondents and nearly 25% believed they would not be fully informed of their child's role in research as opposed to 10% (Rajakumar 2009). This study also examined the effects that research incentives such as free medical care, financial compensation, free medications and free transportation may have on willingness to participate. There were slight increases in overall willingness to participate in research, but most interesting was a difference between the African American respondents and the Caucasian group. Though the Caucasian group showed no association with incentives in regards to distrust, there was an association showing that free medical care negatively influenced African American respondents (OR = 0.28) (Rajakumar 2009).

This statistical data are consistent with a previous study conducted by Corbie-Smith et al in 1999 that used focus groups of African Americans to explore reasons for the greater level of distrust. Several of the reasons cited by participants for their reluctance to participate in research included: too much risk involved for their own health, it was inconvenient to be part of a study, there was no need because they were already in good health, the belief that physicians would not fully inform them of the research and how as participants they would be involved and that they and the African American community would not see benefits arising from the research (Corbie-Smith 1999). Most interestingly were some of the personal comments given regarding the participants' thoughts on medical research.

With regards to informed consent, one participant stated, "Once you've given informed consent, you no longer have any legal rights. The consent is used to help protect themselves from being sued." (Corbie-Smith 1999) A similar sentiment is echoed by another participant concerning their legal rights, "…if you don't have any money, whatever happens to you, you can't prove it. You have to have a lawyer and that costs money. And some of them lawyers and doctors stick together anyway." (Corbie-Smith 1999) Comments concerning thoughts and fears regarding the Tuskegee Study and HIV were also expressed. When individuals were given accurate information concerning the Tuskegee Study, they disputed those facts; there were concerns that HIV was brought deliberately into specific communities, that the CIA introduced crack/cocaine into the inner city as a means to control the African American community and that the government and the medical community performs experiments on people without their consent (Corbie-Smith 1999). These sentiments highlight two important factors: (1) that there is a significant level of misinformation in the African American community and (2) that there has been a failure by the medical community to earn trust within that community and to accurately provide information. Given these levels of distrust, it is important to review two areas that may be acting as contributing sources to this distrust: knowledge regarding the Tuskegee Syphilis Study and HIV conspiracy theories.

2.3 THE TUSKEGEE SYPHILIS STUDY

From 1932 to 1972, the Tuskegee Syphilis Study was conducted as a joint venture between the United States Public Health Service (PHS) and the Tuskegee Institute. The purpose of the study was to examine the effects of untreated syphilis in the African American male. In total, 399 men, all of which already had syphilis, were enrolled in the study and were told that the purpose of the study was to help in the treatment of "bad blood." (Jones 1981) The study was conducted in Macon County, Alabama, an area that was home to a large number of poor, uneducated African American sharecroppers. The researchers in the study took advantage of these factors to help in recruitment (Jones 1981).

To encourage individuals to participate in the study, the workers at the PHS utilized African American physicians and nurses employed at the Tuskegee Institute, as well as prominent African American leaders in the local churches and elders in the community, as a means to garner trust during recruitment (Thomas 1991). In addition, researchers offered several incentives to individuals willing to participate in the study. These incentives included: free physical examinations, free food, free transportation and burial stipends for the families of volunteers (Rivers 1953). For a population of poor workers that had little or no access to medical care, these incentives acted as powerful influencers (Jones 1981).

Though the offering of incentives continues today and is not considered an unethical practice (unless used in a coercive manner), the misinformation given to participants and how they were "treated" during the study was appalling. Informed consent was not a concept at the time of this study, and researchers took advantage of the lack of education of the population they were studying. Instead of informing the participants that they had syphilis and educating them about the transmission, they simply told the participants they had "bad blood," a colloquial term used by African Americans at the time to describe a variety of conditions (Rivers 1953). Due to this deceptive practice, individuals in the study likely did not alter sexual practices, allowing for greater dissemination of the disease in the community. The most egregious aspects of the study were the denial and prevention of effective treatment for the men in the study.

When the study began, there were no real effective treatments for syphilis. Practices included using arsenic-containing compounds such as Salvarsan for early stages and deliberate infection with malaria for tertiary stages of the disease; however, in the early 1940s the use of penicillin was started and then eventually instituted as standard care by 1952 for the treatment and cure of syphilis. At no point during the 40 years of the study, was penicillin ever administered to the participants. Worse yet, the PHS played an active role in ensuring that treatment was denied to the participants. At the onset of World War II, it was required by the military that all draftees receive penicillin treatment for syphilis. Approximately 50 of the individuals in the Tuskegee Study received notice form the local draft board ordering them to take treatment (Jones 1981). When the PHS became aware of the notices, they requested the draft board to exclude these men from getting treatment (Jones 1981). They stated that the importance of this study was critical because, with the advent of penicillin as a treatment, it could never be performed again (Jones 1981).

It was not until 1972, through the actions of whistle blower Peter Buxton and Associated Press reporter Jean Heller, that the public was informed of the Tuskegee Study. Shortly after the story received wide-spread attention, the study was officially ended. Congressional hearings and a civil rights class action lawsuit was filed, resulting in a $10 million dollar settlement that included free medical and burial services to the remaining surviving participants as well as health services for all family members that had been infected during the study (Carmack 2008). Though the study had been exposed, there was never any formal apology by the government agencies involved until former President Bill Clinton's apology in 1997. Due to this and other factors, the dissemination of information regarding the Tuskegee Study was spread primarily through word of mouth throughout the African American community and down through the generations. This has led to a perpetuation of inaccuracies concerning the study, many of which have added to the general distrust of the medical community, which in turn has been implicated as a reason for decreased African American participation in research studies (Clark 1995; Reverby 2001).

Multiple studies have been performed examining possible associations between knowledge of the Tuskegee Study and a decreased willingness to participate in medical research. A commonality observed in these studies has been that individuals familiar with Tuskegee did not necessarily have accurate knowledge (McCallum 2006; Freimuth 2001; Green 2000). Interestingly, contradictory results have been found regarding whether knowledge of the Tuskegee Study impacts willingness to participate in research. In multiple studies, the data indicated that there was no significant impact on willingness to participate (Green 2000; Katz 2008a; Katz 2008b). However, other studies indicate an association between knowledge of the Tuskegee Study and decreased willingness in African Americans to participate in research (Sengupta 2000; Shavers 2000; Freimuth 2001). The presence of such conflicting evidence indicates that the true effect of how the Tuskegee Study impacts willingness to participate in research is still undetermined. Additionally, many of these studies fail to account for the influence of specific research incentives. One of the most common misconceptions regarding the Tuskegee Study is that the men were deliberately infected with syphilis. Such misconceptions could impact how an individual responds to a research study that offers free medical care or medications. Should fear exist that the health care or medication offered is tainted, then a person's desire to enter the study will most likely be diminished. In fact, this sentiment has been observed in regards to participation in HIV/AIDS research (Sengupta 2000).

2.4 HIV CONSPIRACY THEORIES

Several studies have been conducted in the African American community that show significant levels of misinformation concerning HIV/AIDS (Klonoff 1999; Bogart 2005; Bogart 2006; Ross 2006). Some of the commonly held beliefs include: information concerning HIV/AIDS is being held back from the public, that a cure for AIDS exists, but that it is being deliberately kept from the poor, HIV was created by either the government or the CIA and that HIV/AIDS is being used to deliberately kill and control the African American population (Bogart 2005). Bogart et al's 2005 study showed that 48.2% of 500 surveyed African Americans believed that HIV is man-made, with 16.2% believing that is was made to help control the black population. Similar percentages were observed in a previous study by Klonoff et al 1999.

The 1999 Klonoff et al study showed that 50.8% of African Americans believed that HIV was a man-made virus being used to kill African Americans. Interestingly, it was noted that men were 3.5 times more likely to believe this statement than women (Klonoff 1999). Klonoff's study also took into account education as a factor that might influence one's belief regarding the origin of the AIDS virus. Their study revealed that college graduates were more likely to believe that HIV was man-made as compared to high school graduates, 28.1% vs. 18.7% (Klonoff 1999).

The significant percentage of individuals holding these beliefs presents a considerable obstacle when attempting to garner trust from the African American community. Though some of these beliefs may seem on the surface to be foolish and perhaps limited to those less educated about medical science, it should be noted that HIV conspiracy beliefs have been printed in the popular press and have received support from several scientists. The 2004 Nobel Peace Prize recipient, Wangari Maathai, stated that she believed HIV was created by the Western world to be used as a bioweapon against Africans (Steyn 2004). Though she later refuted in a *Time* magazine article (Oct, 10 2004) that she made this statement and that she does not believe that HIV is being used to kill Africans, the presence of that initial statement only added to the controversy. Additionally, articles have been printed in the *Los Angeles Sentinel*, the largest African American newspaper on the West Coast, and in *Essence*, a magazine predominantly geared towards African American women, that discuss the possibility of HIV being used to deliberately kill African Americans (Thomas 1991).

Even typing in the phrase “alternative origins of AIDS” into the online search engine, Google, or the online encyclopedia, Wikipedia, produces an extensive list of theories regarding HIV. With the easy accessibility to the internet, it is simple for individuals to be inundated with an overabundance of misinformation. This holds true not only in regards to HIV information, but with information concerning the Tuskegee Study as well.

With the ever growing accessibility to both accurate and inaccurate information concerning these topics and the already ingrained beliefs that have been passed down through family members, it is vitally important that the medical and scientific community more completely understand and appreciate the concerns that African Americans have with medical research. The ability to successfully recruit African Americans, and other minorities, into research studies is integral to developing and determining applicable medical health information and technologies. The purpose of this study is to help determine the level of knowledge and beliefs that the participants in the Healthy Black Family Project have regarding the Tuskegee Study and HIV and to see how these influence their perceptions about medical research. This study is composed of three specific aims, which are described in the next section.

3.0 SPECIFIC AIMS

3.1 AIM 1

Previous research has indicated that distrust of the medical community persists in the African American community. Two commonly cited sources for this distrust lie in the knowledge of the Tuskegee Syphilis Study and its impact on the African American community and common misconceptions and beliefs held concerning HIV and AIDS.

The purpose of Aim 1 is to identify the level of knowledge concerning the Tuskegee Study and the perceptions concerning HIV and AIDS in participants from the Healthy Black Family Project. This knowledge will allow for a more robust understanding of possible concerns in the community regarding medical research and will allow future studies to tailor their research in reference to those concerns.

3.2 AIM 2

A common component of medical research involving human subjects is to offer incentives as a means to encourage participation. Some of the more common incentives offered include: financial compensation, access to free medical care and/or providing free medications. Despite these incentives, participation in medical research by the African American community remains comparatively low to the Caucasian population. Prior research has indicated that this difference may be in part due to the knowledge and beliefs in the African American community regarding the Tuskegee Study and HIV.

The purpose of Aim 2 is to identify how members of the Healthy Black Family Project respond to the incentives of free medical care, free medications and financial compensation as a means to encourage medical research participation. Their responses were analyzed to observe for possible influences due to differences in knowledge concerning the Tuskegee Study and beliefs concerning HIV. This knowledge could help determine better ways to improve African American participation in research studies.

3.3 AIM 3

Due in part to this country's history of mistreatment of African Americans and to some of the beliefs (accurate and inaccurate) held concerning the medical community, African Americans have been shown in previous studies to have not only higher levels of distrust towards the medical community, but also feelings that the research being conducted is of little to no value to themselves and their community.

The purpose of Aim 3 is to determine Healthy Black Family Project participants' beliefs concerning who benefits from medical research and what value medical research, particularly research using human subjects, has for society. Additionally, aim 3 examines individuals' prior research participation and their interest in joining a recruitment database geared towards improving minority participation in research studies. Their responses are then analyzed with respect to their knowledge of the Tuskegee Study and HIV beliefs to identify if these factors are influencing their perceptions on medical research.

4.0 MATERIALS AND METHODS

This study (IRB #0403125) was supported by the University of Pittsburgh's Institutional Review Board and approved on February 21, 2008. A copy of the letter approving the added questions relating to the Tuskegee Syphilis Study and HIV is found in Appendix A. These questions were approved on June 5, 2008.

4.1 THE HEALTHY BLACK FAMILY PROJECT

The Healthy Black Family Project (HBFP) is a program created by the University of Pittsburgh's Graduate School of Public Health's Center for Minority Health. The goal of the Center for Minority Health is to help eliminate the health disparities that currently exist in the African American population with the HBFP designed to specifically help individuals that live in predominantly African American neighborhoods in Pittsburgh. Based primarily at two sites, the Kingsley Association in East Liberty and the Hosanna House in Wilkinsburg, the HBFP offers members a variety of classes designed to promote health awareness and improve physical activity. A sample of some of these classes include: body toning, African dance, water aerobics, yoga, nutrition classes and family health history awareness.

All individuals included in this study are members of the Healthy Black Family Project. Individuals were contacted via a phone list generated from registration information and offered the opportunity to have a family health history assessment provided to them at no-cost as part of the Center's Family Health History Initiative.

4.2 FAMILY HEALTH HISTORY INITIATIVE

The Family Health History Initiative is a component of the HBFP. The primary goal of this initiative is to improve knowledge about the impact of family health history on disease risk. One element of this initiative is risk assessment for chronic disease in the family: diabetes, hypertension, cardiovascular disease, Alzheimer's disease and several types of cancer (breast, ovarian, prostate, colon and lung). Assessment of these risks is based on criteria developed by Scheuner et al 1997, which is shown in Table 1.

Table 1: Scheuner Risk Criteria

High Risk	Moderate Risk	Average Risk (general population risk)
1. Premature disease* in a 1st degree relatives 2. Premature disease in a 2nd degree relative (coronary artery disease only) 3. Two affected 1st degree relatives 4. A 1st degree relative with late/unknown onset of disease and an affected 2nd degree relative with premature disease from the same lineage 5. Two 2nd degree maternal or paternal relatives with at least one having premature onset of disease 6. Three or more affected maternal or paternal relatives 7. The presence of a "moderate risk" family history on both sides of the pedigree	1. A 1st degree relative with late or unknown disease onset 2. Two 2nd degree relatives from the same lineage with late or unknown disease onset.	1. No affected relatives 2. Only one affected 2nd degree relative from one or both sides of the pedigree 3. No known family history 4. Adopted individual with unknown family history.

* Premature disease:

- Coronary artery disease ≤ 55 years in males, ≤ 65 years in females
- Non-insulin dependent diabetes, hypertension, colon cancer, prostate cancer, breast cancer, ovarian cancer ≤ 50 years
- Alzheimer's disease ≤ 65 years

Members of the HBFP are contacted via phone by genetic counseling students employed by the Center for Minority Health. HBFP members are given a brief overview of a family health history session and those who are interested in the session are given an appointment to meet with the student at an agreed upon location. The majority of these sessions occur at either the Kingsley or Hosanna House.

During the session, the student constructs a three generation pedigree and records information about age, health status, causes of death and age of death. After completion of the family tree, the student ascertains and discusses the risks for several chronic diseases: heart disease, hypertension, diabetes, Alzheimer's disease and several types of cancer (breast, ovarian, prostate, colon and lung). Participants at risk for any of these diseases are then informed of possible ways to help reduce risks via exercise, diet or routine screening. At the completion of the session, a hand-drawn copy of the family tree is provided to the member.

The student then returns to the Center for Minority Health and uses the software program Progeny to create a computer-generated version of the family tree. This family tree, along with information pertaining to any conditions that are present in the participant's family history and ways to reduce risk for these conditions and a certificate of completion, is mailed to the participant in approximately 1-2 weeks time following the appointment session.

4.3 ASSESSMENT OF KNOWLEDGE AND BELIEFS OF THE TUSKEGEE STUDY AND HIV, MEDICAL RESEARCH PERCEPTIONS AND EFFECTS OF MEDICAL RESEARCH INCENTIVES

Each individual that chose to participate in the family health history initiative was given the option of taking two survey questionnaires during their appointment. Individuals that chose to take these surveys were administered the Pre-Survey Questionnaire prior to the family health history assessment and the Post-Survey Questionnaire after the family history was completed.

The Pre-Survey Questionnaire (Appendix B) gathers information concerning general demographics, body image perception, physical activity habits, risk perceptions and questions concerning a multidimensional health locus of control. Information utilized for this thesis project concentrated on the general demographics (gender, ethnicity, age, income, education and health insurance status).

The Post-Survey Questionnaire (Appendix C) gathers information concerning physical activity habits, risk perception, opinions on medical research, information seeking behavior and includes questions concerning beliefs and knowledge of the Tuskegee Syphilis Study and of HIV. This thesis project utilizes the collected information concerning beliefs and knowledge of the Tuskegee Study and HIV and the opinions regarding medical research. Specifically, questions 5 – 16 and 18 – 20 were used for analysis.

Information collected was entered into an online version of each respective survey. Retrieval of pertinent data was gathered through Perseus Survey Solutions Version 6, a database storage software program.

4.4 DATA ANALYSIS

Information gathered from Perseus Survey Solutions was exported into an Excel spreadsheet. This spreadsheet contained the general demographic data from the Pre-Survey Questionnaire and the data regarding medical research opinions and beliefs/knowledge about the Tuskegee Study and HIV from the Post-Survey Questionnaire. To assist with data analysis, answers to several questions were separated into distinct groups.

Age was stratified into decade groupings and also into two groups, individuals younger than 50 and individuals age 50 or older. Ethnicity was separated into those who either did or did not identify themselves as African American. Income data was grouped as those with income less than $50,000 and those with an income of $50,000 or more. Education status was separated into those with some college education and those with a high school degree or less. Answers concerning the amount of information individuals have heard or read about concerning the Tuskegee Study were broken down into those with moderate or better knowledge as compared to those with little or no knowledge. The answers for Question 18b were separated into individuals who either did or did not believe that the participants in the Tuskegee Study were deliberately infected with syphilis. Lastly, answers involving the beneficial quality of medical research were separated into groups who considered the benefit to be either moderate or better as compared to those who considered the benefit to be minimal, dependant on other factors or non-existent.

All data was then uploaded and analyzed using the SPSS 15.0 statistical software package. Analysis included determining frequencies of demographic information, knowledge and beliefs of the Tuskegee Study and HIV, likelihood of participating in medical research and perceptions of medical research and its importance in a sample population of 100 participants. Chi-square analysis using Fisher's exact test was then performed to determine the effects that knowledge and beliefs concerning the Tuskegee Study and HIV may have on willingness to participate in medical research, opinions about the degree of benefit resulting from research and perceptions on the importance of medical research.

Initial chi-square analysis involved comparing the level of knowledge an individual had on the Tuskegee Study to how research incentives of free medical care, free medicine and financial compensation would affect their willingness to participate in medical research. Following chi-square analyses examined if willingness to participate based on these incentives was influenced by belief of deliberate infection during the study, belief that HIV was man-made and belief that HIV was and is being used to deliberate kill African Americans. Analysis was performed by first comparing those who were more likely to participate in research due to incentives to those who were less likely and then comparing those who were more likely to participate in research to those who indicated that the incentives had no effect on willingness to participate. A p-value of 0.05 or less was considered statistically significant; values between 0.05 – 0.10 were considered indicative of a possible trend.

A second set of chi-square analyses was performed comparing the previously mentioned factors of Tuskegee knowledge, belief of deliberate infection and beliefs concerning HIV to the degree of benefit that the participants believed medical research has on themselves, their family and friends, their community and to the scientific community. The next set of chi-square analyses compared the factors concerning Tuskegee and HIV to the participants' perceptions on the overall importance of medical research, whether they have participated or declined to participate in research, their thoughts on the use of human subjects in medical research and whether they would or would not like to be enrolled in a minority recruitment database for medical research. As previously indicated, a p-value of 0.05 or lower was considered statistically significant and p-values between 0.05 – 1.00 were considered indicative of a possible trend.

The final set of chi-square analysis was used to determine any possible effects that demographic information may have on participants' responses. This analysis included the factors of age (separated into those under 50 vs. those 50 and older), gender, income (separated into two groups: income less than $50,000 versus an income of $50,000 or greater) and education (separated into those with at least some college education versus those without). Each factor was compared with all questions concerning the Tuskegee Study, HIV, research incentives, perceived degree of benefit and medical research perceptions. Ethnic differences were not examined as 95% of the sample population was African American and differences in health insurance status was not explored as 95% had some form of insurance. This made examining these differences within the groups impractical.

5.0 RESULTS

5.1 DEMOGRAPHIC DATA

General demographic data of the participants are summarized in Table 2. A total of 100 individuals had completed the optional survey questions concerning their opinions on the Tuskegee Syphilis Study and HIV conspiracy beliefs as well as questions concerning their opinions on medical research and research incentives.

In brief, the population consisted of a majority of women (88%) and African Americans (95%). Additionally, 65% of the population consisted of individuals age 50 or older. Income level varied throughout the population, with the majority of individuals making between $20,001 and $35,000 (30%). Nearly 80% of the population reported at least some college education and almost all individuals (95%) reported some form of health insurance.

Table 2: Demographic Data of Study Participants

Participant Characteristics (n=100)	N
Gender	
Male	11
Female	88
Unknown	1
Ethnicity	
African American	95
Other	4
Unknown	1
Age	
10-19	1
20-29	7
30-39	9
40-49	17
50-59	27
60-69	24
70-79	13
80+	1
Unknown	1
Income	
Less than $10,000	8
Between $10,000 and $20,000	14
Between $20,001 and $35,000	30
Between $35,001 and $50,000	19
Between $50,001 and $75,000	11
Greater than $75,000	9
Unknown	9
Education	
Grades 9 through 11 (some high school)	3
Grade 12 or GED (high school graduate)	14
College 1 to 3 years (some college)	48
College 4+ years (college graduate)	18
Graduate level (MS, PhD)	13
Unknown	4
Health Insurance	
Yes	95
No	4
Unknown	1

5.2 AIM 1

The purpose of Aim 1 was to examine participants' beliefs with regards to the Tuskegee Syphilis Study and current HIV conspiracy theories. This data is summarized in Table 3.

Table 3: Knowledge and Beliefs Concerning the Tuskegee Syphilis Study and AIDS

Participant Beliefs (n=100)	n
Tuskegee Syphilis Study Knowledge	
A great deal	30
A moderate amount	31
A little amount	18
None at all	21
Tuskegee Study Beliefs*	
Men deliberately infected	48
Men denied treatment	17
Men given the wrong treatment	3
Men believed they were getting effective treatment	18
No strong beliefs	20
Unknown	8
Belief HIV is man-made	
Yes	30
No	42
Don't know	28
Belief HIV Used to Kill African Americans	
Yes	14
No	69
Don't know	16
Unknown	1

* Numbers add greater to 100 due to multiple answers by individuals

Nearly all individuals (79%) stated they had at least heard some information concerning the Tuskegee Study, with the majority of those individuals (61%) indicating that they had at least moderate or better knowledge. Only 21% indicated they had no knowledge or had not heard of the study. Examination of the participants' beliefs concerning the study revealed a large degree of misinformation. Nearly half of the individuals believed that the men were deliberated infected with syphilis during their time in the study. In comparison, only 17% of individuals correctly identified that the men in the study were specifically denied effective treatment.

Examination of current beliefs concerning HIV also revealed a large degree of inaccuracies. The majority of participants (58%) did not accurately identify that HIV is of natural origin, with nearly one-third of individuals believing that the virus is man-made. While nearly 70% of participants did not believe the virus had been deliberately used to kill African Americans, a significant percentage (14%) claimed otherwise and 16% were unsure.

Table 4 displays associations between the different belief responses and knowledge of the Tuskegee Study and HIV. As shown, individuals who stated they had moderate or greater knowledge were more likely to indicate that the participants in the Tuskegee Study were deliberately infected with syphilis, $p < 0.001$. Additionally, individuals who believe that HIV is a man-made virus were more likely to believe that the virus is being used to deliberately kill African Americans, $p < 0.001$.

Table 4: Interactive Effect of Belief Responses

Belief Response	**Tuskegee Knowledge (Moderate +) (n)**			**p-value**
	Unknown	**No**	**Yes**	
Deliberate Infection				
Yes		11	37	
No		20	24	
Unknown		8	0	**$p < 0.001$**
HIV Man-Made				
Yes		10	20	
No		16	26	
Unknown		13	15	$p = 0.593$
HIV Used to Kill				
Yes		4	10	
No		28	41	
Unknown		7	10	$p = 0.776$
Belief Response	**HIV as a Man-Made Virus (n)**			**p-value**
	Unknown	**No**	**Yes**	
Deliberate Infection				
Yes	10	20	18	
No	15	19	10	
Unknown	3	3	2	$p = 0.465$
HIV Used to Kill				
Yes	2	2	10	
No	16	39	14	
Unknown	10	1	6	**$p < 0.001$**
Belief Response	**HIV Used to Kill African Americans (n)**			**p-value**
	Unknown	**No**	**Yes**	
Deliberate Infection				
Yes	2	6	0	
No	7	32	5	
Unknown	8	31	9	$p = 0.669$

5.3 AIM 2

To examine the effects that knowledge of the Tuskegee Study and HIV conspiracy beliefs may have on individuals' likelihood to participate in medical research, cross tabulation tables were constructed to compare responses concerning knowledge and beliefs against three incentives often offered for participation in research trials: free medical care, free medicine and financial compensation. Table 5 presents the overall responses research incentives had on an individual's decision to participate in medical research.

Table 5: Likelihood of Participation in Medical Research Based on Incentives

Participant Response (n=100)	n (% of participants)
Offer of Free Medical Care	
More likely	46
Less likely	4
No effect	39
Don't know	9
Unknown	2
Offer of Free Medicine	
More likely	40
Less likely	8
No effect	38
Don't know	13
Unknown	1
Offer of $500	
More likely	59
Less likely	2
No effect	27
Don't know	12

In each instance, the majority of individuals responded favorably to the offer of research incentives: 59% of individuals were more likely to participate in medical research if offered $500, 46% of individuals were more likely if free medical care was offered and 40% of individuals were more likely if free medicine was offered. Intuitively, the percentage of individuals who answered they were less likely to participate if these incentives were offered increases in reverse order. Only 2% of individuals were less likely to participate if $500 dollars was offered, while 4% and 8% were less likely to participate given the incentives of free medical care and medicine, respectively. There were also a large percentage of individuals that stated the incentives of financial compensation, free medical care and free medicine would have no effect on their decision to participate in research: 27%, 39% and 38%, respectively.

Table 6 examines the effects that knowledge of the Tuskegee Study has on individuals' willingness to participate in medical research. Included in the analysis are individuals who responded to their level of knowledge of Tuskegee and also to their likelihood of participating in medical research based on incentives. Knowledge of Tuskegee was broken down into two groups: those with moderate or better knowledge compared to those with little or no knowledge. Chi-squared analysis was utilized to compare the groups that stated they were more likely to participate to those who stated they would be less likely to participate or to those who stated the incentive would have no effect. Statistically significant results are listed in bold.

Table 6: Effect of Tuskegee Knowledge on Likelihood of Research Participation

Incentive	Tuskegee Knowledge (Moderate +) (n)			p-value (More vs. Less likely) (More vs. No effect)
	Unknown	No	Yes	
Free Medical Care				
More likely		26	20	
Less likely		0	4	**p = 0.046**
No effect		8	31	**p = 0.001**
Free Medicine				
More likely		15	25	
Less likely		3	5	p = 0.662
No effect		15	23	p = 0.521
$500				
More likely		20	39	
Less likely		2	0	p = 0.126
No effect		11	16	p = 0.353

Our results indicate that individuals who have little or no knowledge of Tuskegee are more likely to be positively influenced by free medical care to participate in medical research. Individuals who stated they had moderate or better knowledge of Tuskegee were more inclined to state that free medical care would make them either less likely (p=0.046) or have no effect (p=0.001) to participate in research when compared to the group that had little or no knowledge of the Tuskegee Study.

The effects of free medicine and financial incentive were not influenced by knowledge concerning the Tuskegee Study.

Table 7 examines the influence that believing that the men who participated in the Tuskegee Study were deliberately infected may have on willingness to participate in medical research based on research incentives.

Table 7: Effect of Belief of Deliberate Infection on Likelihood of Research Participation

Incentive	**Belief of Deliberate Infection (n)**			**p-value (More vs. Less likely) (More vs. No effect)**
	Unknown	**No**	**Yes**	
Free Medical Care				
More likely	3	20	23	
Less likely	0	2	2	p = 1.000
No effect	2	19	18	p = 0.939
Free Medicine				
More likely	3	18	19	
Less likely	0	4	4	p = 1.000
No effect	2	17	19	p = 1.000
$500				
More likely	2	26	31	
Less likely	0	2	0	p = 0.272
No effect	3	11	13	p = 0.450

There are no statistically significant differences between individuals who believe men were deliberately infected in the Tuskegee Study compared to those who did not when examining research incentives.

The effects that the belief that HIV is of man-made origin has on willingness to participate in medical research is listed in Table 8.

Table 8: Effect of Belief of HIV as Man-made on Likelihood of Research Participation

Incentive	**Belief of HIV as Man-made (n)**			**p-value (More vs. Less likely) (More vs. No effect)**
	Unknown	**No**	**Yes**	
Free Medical Care				
More likely	9	20	17	
Less likely	0	2	2	p = 1.000
No effect	15	15	9	p = 0.129
Free Medicine				
More likely	6	20	14	
Less likely	0	5	3	p = 0.748
No effect	13	15	10	p = 0.152
$500				
More likely	8	34	17	
Less likely	0	1	1	p = 1.000
No effect	13	6	8	**p = 0.001**

The majority of comparisons did not show any statistically significant differences between the groups of individuals who believed that HIV is man-made versus those who did not. However, there were significant differences when examining the influence that financial compensation had on willingness to participate. Specifically, there was a significant difference (p=0.001) found for the impact of the $500 incentive on willingness to participate in research. This difference was most notable in the group who was unsure if HIV was man-made, with the majority of individuals stating that the financial incentive would not alter their decision to participate in research. This differs from both those who stated HIV was man-made and those who stated it was not man-made; each of these groups were more likely to participate in research given financial offers.

Finally, it was examined whether willingness to participate in research is influenced by the belief that HIV is being used to kill African Americans (Table 9).

Table 9: Effect of Belief That HIV is Being Used to Kill African Americans on Likelihood of Research Participation

Incentive	Belief That HIV is Used to Kill African Americans (n)			p-value (More vs. Less likely) (More vs. No effect)
	Unknown	No	Yes	
Free Medical Care				
More likely	6	33	7	
Less likely	0	3	1	p = 0.744
No effect	7	26	6	p = 0.846
Free Medicine				
More likely	8	27	5	
Less likely	0	7	1	p = 0.403
No effect	1	30	7	p = 0.057
$500				
More likely	6	47	6	
Less likely	0	2	0	p = 1.000
No effect	5	16	6	p = 0.134

As with the beliefs concerning deliberate infection, there is no statistically significant difference between groups who believe HIV is being used to kill African Americans versus those who do not. However, there is a possible trend that the incentive of free medicine may have some impact on individuals' willingness to participate in research. This trend is noticeable in the group of individuals who are unsure if HIV is being used to kill African Americans. This group has a greater percentage of individuals more likely to participate in research (~89%) as compared to both the group of individuals who believe HIV is being used to kill African Americans (~38%) and the group who does not believe HIV is being used to kill African Americans (~42%).

5.4 AIM 3

Similar to the analysis in Aim 2, cross tabulation tables were utilized to examine any possible effects that knowledge and beliefs of the Tuskegee Study or HIV conspiracy theories may have on participants' opinions concerning medical research. The general responses concerning the participants' perceptions on the value of medical research, how beneficial medical research is and if they would be interested in joining a research recruitment database are listed in Table 10.

Table 10: Perceptions on Medical Research

Participant Response (n=100)	n
Importance of Medical Research	
Very important	94
Somewhat important	5
Not very important	0
Not important at all	0
Don't know	0
Unknown	1
Participated in Medical Research	
Yes	51
No	45
Don't know	3
Unknown	1
Decided Against Participation	
Yes	27
No	68
Don't know	4
Unknown	1
Attitude of Research Involving People	
Very favorable	54
Somewhat favorable	37
Somewhat unfavorable	2
Very unfavorable	3
Neither favorable nor unfavorable	2
Don't know	1
Unknown	1

Table 10: continued

Degree Scientists Benefit from Research	
A great deal	83
A moderate amount	10
Only a little	3
Not at all	0
Depends	4
Degree Your Community Benefits from Research	
A great deal	67
A moderate amount	14
Only a little	10
Not at all	0
Depends	9
Degree Your Family/Friends Benefit from Research	
A great deal	63
A moderate amount	24
Only a little	7
Not at all	1
Depends	5
Degree You Benefit from Research	
A great deal	63
A moderate amount	26
Only a little	6
Not at all	1
Depends	3
Unknown	1
Interested in Entering Database	
Yes	78
No	20
Unknown	2

The vast majority of individuals reported that they felt medical research was very important (94%), with approximately half of all responders indicating that they had participated in medical research in the past. Additionally, 91% of individuals indicated that they felt favorably towards research that involved human subjects. Though nearly all individuals indicated that medical research was of great importance, there was some disparity in who they felt that research benefited the most. Nearly everyone reported that scientists benefit at least moderately from research (93%, with 83% indicating a great deal of benefit). This differs from their perception of benefit to the community (81% and 67%), their family and friends (87% and

63%) and personally (89% and 63%). Of the 100 participants, 78% indicated that they would be interested in joining a recruitment database.

To further analyze the effects that knowledge of the Tuskegee Study may have on medical research perceptions, chi-squared analyses were performed breaking down the responses individuals reported on degree of benefit to scientists, their community, family and friends and to themselves into moderate or greater benefit and little or no benefit categories. The results of these analyses are displayed in Table 11.

Table 11: Effect of Tuskegee Knowledge on Perception of Medical Research Benefits

Degree of Benefit	**Tuskegee Knowledge (Moderate +) (n)**			**p-value (Moderate + vs. Little/None)**
	Unknown	**No**	**Yes**	
Scientist				
Moderate +		34	59	
Little/None		5	2	p = 0.079
Community				
Moderate +		28	53	
Little/None		11	8	p = 0.054
Family/Friends				
Moderate +		30	57	
Little/None		9	4	**p = 0.019**
Individual				
Moderate +		33	56	
Little/None		6	4	p = 0.234
Unknown		0	1	

Results from Table 11 are statistically significant (p=0.019) for how individuals rate the degree of benefit medical research has for family and friends. Individuals who had moderate or better knowledge of the Tuskegee Study were more likely to indicate that there was benefit as compared to those who had little to no knowledge of Tuskegee. Though not statistically significant, there appears to be a similar trend when examining perceived degree of benefit for scientists and the community. Again, individuals who had moderate or better knowledge were more likely to indicate benefit as compared to those with little or no knowledge. Assessment of individual benefit is not significantly different between groups.

Table 12 further examines the perceived degree of benefit by comparing it with the belief of deliberate infection during the Tuskegee Study.

Table 12: Effect of Belief of Deliberate Infection on Perception of Medical Research Benefits

Degree of Benefit	Belief of Deliberate Infection (n)			p-value (Moderate + vs. Little/None)
	Unknown	No	Yes	
Scientist				
Moderate +	7	41	45	
Little/None	1	3	3	p = 0.692
Community				
Moderate +	7	35	39	
Little/None	1	9	9	p = 1.000
Family/Friends				
Moderate +	7	35	45	
Little/None	1	9	3	p = 0.123
Individual				
Moderate +	8	38	43	
Little/None	0	6	4	p = 0.625
Unknown	0	0	1	

Unlike knowledge of the Tuskegee Study, there are no statistically significant differences when comparing individuals who believe there was deliberate infection versus those who do not in relation to the perceived degree of benefit of medical research.

Tables 13 and 14 examine the perceived degree of benefit by comparing it with either the belief that HIV is man-made (Table 13) or with the belief that HIV is being deliberately used to kill African Americans (Table 14).

Table 13: Effect of Belief of HIV as Man-made on Perception of Medical Research Benefits

Degree of Benefit	Belief of HIV as Man-made (n)			p-value (Moderate + vs. Little/None)
	Unknown	No	Yes	
Scientist				
Moderate +	24	40	29	
Little/None	4	2	1	p = 0.286
Community				
Moderate +	23	35	23	
Little/None	5	7	7	p = 0.766
Family/Friends				
Moderate +	25	35	27	
Little/None	3	7	3	p = 0.749
Individual				
Moderate +	25	35	29	
Little/None	3	6	1	p = 0.398
Unknown	0	1	0	

Table 14: Effect of Belief That HIV is Used to Kill African Americans on Perception of Medical Research Benefits

Degree of Benefit	Belief That HIV is Used to Kill African Americans (n)			p-value (Moderate + vs. Little/None)
	Unknown	No	Yes	
Scientist				
Moderate +	15	65	13	
Little/None	2	4	1	p = 0.601
Community				
Moderate +	13	59	9	
Little/None	4	10	5	p = 0.168
Family/Friends				
Moderate +	13	62	12	
Little/None	4	7	2	p = 0.307
Individual				
Moderate +	13	63	13	
Little/None	4	5	1	p = 0.308
Unknown	0	1	0	

There was no difference among groups who do or do not believe HIV is man-made or do or do not believe that HIV is being used to kill African Americans.

Further analysis of the effects of knowledge concerning the Tuskegee Study has on medical research beliefs and participation is displayed in Table 15. Again, chi-squared analyses were performed to examine for possible differences between groups that have moderate or better knowledge of the Tuskegee Study compared to those who have little or no knowledge in relation to research importance, whether individuals had participated or declined participation in research, their attitude towards the involvement of humans in research (favorable, unfavorable or neutral) and if the participant had interest in entering a recruitment database.

Table 15: Effect of Tuskegee Knowledge on Medical Research Perceptions and Participation

Medical Research Beliefs and Participation	Tuskegee Knowledge (Moderate +) (n)			p-value
	Unknown	**No**	**Yes**	
Research Importance				
Very important		37	57	
Somewhat important		2	3	p = 1.000
Unknown		0	1	
Participated				
Yes		15	36	
No		22	23	p = 0.098
Don't know		2	1	
Unknown		0	1	
Declined Participation				
Yes		11	16	
No		25	43	p = 0.447
Don't know		3	1	
Unknown		0	1	
Attitude to Human Research				
Favorable		33	58	p = 0.200
Unfavorable		3	2	
Neutral		3	1	
Database Interest				
Yes		26	52	
No		12	8	p = 0.054
Unknown		1	1	

Though there are no statistically significant differences between groups when examining medical research beliefs and participation, there is a possible trend when examining interest in entering a recruitment database. A greater percentage of individuals who had moderate or better knowledge of Tuskegee were interested in entering a database (~85%) when compared to those who expressed interest in entering the database and had little or no knowledge of Tuskegee (~67%).

Examination of the effects that the belief of deliberate infection during the Tuskegee Study has on medical research beliefs and participation is listed in Table 16.

Table 16: Effect of Belief of Deliberate Infection on Medical Research Perceptions and Participation

Medical Research Beliefs and Participation	Belief of Deliberate Infection (n)			p-value
	Unknown	No	Yes	
Research Importance				
Very important	8	40	46	
Somewhat important	0	3	2	p = 0.705
Unknown	0	1	0	
Participated				
Yes	2	22	27	
No	5	21	19	p = 0.178
Don't know	1	0	2	
Unknown	0	1	0	
Declined Participation				
Yes	5	10	12	
No	3	32	33	p = 0.228
Don't know	0	1	3	
Unknown	0	1	0	
Attitude to Human Research				
Favorable	8	36	47	p = 0.091
Unfavorable	0	4	1	
Neutral	0	4	0	
Database Interest				
Yes	4	37	37	
No	3	7	10	p = 0.089
Unknown	1	0	1	

As with the assessment on effects that knowledge of the Tuskegee Study had on beliefs and participation, there were no statistically significant differences. There were, however, two possible trends when examining the attitudes to human research and with interest in database participation. In regards to attitudes towards human research, individuals who believed there was deliberate infection during the Tuskegee Study were more likely to respond favorably towards human research (~98%) as compared to those who did not believe there was deliberate infection (~82%). The second possible trend occurs among individuals who did not know whether the participants in the Tuskegee Study were infected or not. In this group, only 50% expressed interest in joining a database as compared to greater than 75% of either group who did or did not believe there was deliberate infection.

The effects that belief that HIV is a man-made virus has on medical research beliefs and participation is displayed in Table 17.

Table 17: Effect of Belief of HIV as Man-made on Medical Research Perceptions and Participation

Medical Research Beliefs and Participation	Belief of HIV as Man-made (n)			p-value
	Unknown	No	Yes	
Research Importance				
Very important	25	39	30	
Somewhat important	3	2	0	p = 0.245
Unknown	0	1	0	
Participated				
Yes	10	27	14	
No	16	14	15	p = 0.070
Don’t know	2	0	1	
Unknown	0	1	0	
Declined Participation				
Yes	8	9	10	
No	18	30	20	p = 0.649
Don’t know	2	2	0	
Unknown	0	1	0	
Attitude to Human Research				
Favorable	25	38	28	p = 0.747
Unfavorable	1	2	2	
Neutral	2	2	0	
Database Interest				
Yes	19	36	23	
No	8	5	7	p = 0.277
Unknown	1	1	0	

Similar to previous assessments of medical research beliefs and participation, there are no statistically significant differences; however, there appears to be a possible trend. This trend is observed among individuals who have participated in medical research. In this group, a greater percentage of individuals who did not believe that HIV is man-made have participated in medical research (~64%) when compared to those who did believe HIV is man-made (~47%) and those who did not know (~36%).

The final analysis on medical research beliefs and participation examines the effects of belief that HIV is being used to deliberately kill African Americans. Results from this analysis are listed in Table 18.

Table 18: Effect of Belief That HIV is Used to Kill African Americans on Medical Research Perceptions and Participation

Medical Research Beliefs and Participation	Belief That HIV is Used to Kill African Americans (n)			p-value
	Unknown	No	Yes	
Research Importance				p = 0.541
Very important	15	65	14	
Somewhat important	2	3	0	
Unknown	0	1	0	
Participated				p = 0.535
Yes	8	36	7	
No	7	31	7	
Don't know	2	1	0	
Unknown	0	1	0	
Declined Participation				p = 0.752
Yes	4	17	6	
No	12	48	8	
Don't know	1	3	0	
Unknown	0	1	0	
Attitude to Human Research				p = 0.731
Favorable	16	61	14	
Unfavorable	0	5	0	
Neutral	1	3	0	
Database Interest				p = 0.230
Yes	14	56	8	
No	3	11	6	
Unknown	0	2	0	

Analysis of the effects of the belief that HIV is being used to deliberately kill African Americans revealed no statistically significant differences, nor does there appear to be any trends.

5.5 INFLUENCE OF DEMOGRAPHIC VARIABLES

Multiple demographic factors were examined to determine any possible effects they might have on medical research perceptions and beliefs and knowledge concerning HIV and the Tuskegee Study. Due to the numerous comparisons made, only statistically significant differences are noted in Table 19 below.

Table 19: Effects of Demographic Variables

Medical Research Beliefs and Participation	**Age 50+ (n)**			**p-value**
	Unknown	**No**	**Yes**	
Declined Participation				
Yes	0	12	15	
No	1	18	49	
Don't know	0	4	0	**p = 0.019**
Not Answered	0	0	1	
Family/Friends Benefit				
Moderate +	0	26	61	
Little/None	1	8	4	**p = 0.004**
Individual Benefit				
Moderate +	0	27	62	
Little/None	1	6	3	
Unknown	0	1	0	**p = 0.005**
	Gender (n)			
	Unknown	**Male**	**Female**	
Attitude to Human Research				
Favorable	1	7	83	
Unfavorable	0	3	2	
Neutral	0	1	3	**p = 0.012**

Table 19: continued

	Education (Some college) (n)			
	Unknown	**No**	**Yes**	
Participated				
Yes	1	5	45	
No	2	11	32	
Don't know	0	1	2	**p = 0.024**
Unknown	1	0	0	
Family/Friends Benefit				
Moderate +	3	12	72	
Little/None	1	5	7	**p = 0.040**
Individual Benefit				
Moderate +	2	14	73	
Little/None	1	3	6	**p = 0.011**
Unknown	1	0	0	
	Income ($50,000+) (n)			
	Unknown	**No**	**Yes**	
Participated				
Yes	2	35	14	
No	6	34	5	
Don't know	0	2	1	**p = 0.038**
Unknown	1	0	0	
$500 Incentive				
More likely	4	39	16	
Less likely	0	2	0	p = 0.444
No effect	5	20	2	**p = 0.041**

As can be seen in the table, individuals over the age of 50 had significantly different responses than younger individuals in the areas of declining participation, and how they perceived medical research benefited themselves and family and friends. This study showed that older individuals were less likely to have declined participation and that they were more likely to perceive that they themselves and family and friends would benefit from research.

Although there were only a small number of men who participated in this study (11%), there was still a significant difference in how they perceived the involvement of human subjects in research study when compared to women. Although both the majority of men and women were in favor of human research, a larger proportion of men responded negatively (30% versus 3%).

Education also played a significant role in participant response regarding medical research perceptions. Individuals with at least some college education were more likely to participate in medical research and more likely to perceive that themselves and family and friends benefited from research when compared to individuals who only had a high school education or less.

Interestingly, income also played a significant role in two instances. Individuals who made $50,000 or more were more likely to participate in research and also were more likely to be positively influenced by financial compensation as an incentive to participate. In comparison, individuals who made less than $50,000 stated at a greater frequency that financial compensation of $500 would have no effect on their decision to participate in research.

6.0 DISCUSSION

6.1 DEMOGRAPHIC DATA

Demographic data revealed a large percentage of women participating in the study as opposed to men, 88% vs. 11%. This was expected as the vast majority of individuals in the Healthy Black Family Project are women. Additionally, previous research has shown that men typically do not seek health information as readily as women, which is a possible reason for why we see a greater level of female participation (Copeland 2000). Unfortunately, this impairs the ability of the study to be generalized to both men and women and therefore, the perceptions and beliefs observed in this study may be an overrepresentation of one gender. Additionally, it hampers comparison of this study with others that were able to analyze differences in gender more completely, such as the Klonoff study in 1999 that observed a significant difference between men and women's beliefs concerning the origin of HIV.

There were adequate ranges in the areas of age and income, indicating that our population is not over representing a single age or income bracket; however, there is a high percentage, 82%, of individuals at or over the age of 40 in our population. Due to this result, it was more difficult to accurately interpret younger individuals' perceptions of medical research, especially considering our small overall sample size of 100 participants.

Our population group is also well-educated, with nearly 80% reporting some level of college education. Again, this made it difficult to make accurate comparison between those with and without some level of college education. With 95% of individuals in this study being of African American ethnicity and 95% having some form of health insurance, it was not possible to make comparisons with other studies that were able to examine differences in these factors. Despite these limitations, this study was able to determine the effect of several demographic factors on individuals' perceptions concerning medical research, which is explicated in section 6.5.

6.2 AIM 1

One of the more interesting results observed was the high level of inaccurate information concerning the Tuskegee Study. Nearly half of our sample group believed that the men in the study were deliberately infected with syphilis. Such a high number indicates that even though our population is both well-educated (80% with some college education) and state that they have moderate or greater familiarity with the study (61%), there is still a great deal of misinformation that persists. One possible reason for this may be that information concerning the Tuskegee Study is often passed through word of mouth, which lends itself to high level of inaccuracies (Reverby 2001). This may explain why there was a propensity for individuals who stated they had moderate or greater knowledge of Tuskegee to also indicate that the men in the study had been deliberately infected. Because this level of inaccurate information has been observed in this and in other studies (Green 2000; Shavers 2000; Katz 2008), an important future step might be to analyze from what sources individuals are getting their information.

Similarly, there was also a large degree of misinformation concerning the origin of HIV and its perceived use against the African American community. Nearly one third of our sample group believed that HIV was of man-made origin; another 28% were unsure of the virus' true origin. Overall, this indicated that 58% our sample population was not able to accurately state that HIV was not man-made. Of additional concern is the fact that 14% of our population believed that HIV is being used to kill African Americans. These numbers are similar to previous studies results, which have also shown a significant proportion of individuals believing HIV is man-made and that a conspiracy exists involving the use of HIV to kill African Americans (Kolnoff 1999; Ross 2006).

It is possible that these numbers reflect the distrust towards the medical community seen in African Americans, especially those that are aware of the Tuskegee Study. It also may be a reflection of the prevalence and greater disparity in HIV/AIDS cases observed in the African American community as opposed to others (CDC 2008) or the fact that HIV/AIDS has been such a destructive and devastating influence on the African continent, with not nearly the same impact on European and predominantly Caucasian populations. Not surprisingly, individuals who believed HIV was man-made were more likely to believe that it is being used to kill African Americans. It is possible that when a source of information indicates one conspiracy belief concerning AIDS (its man-made origin), it might also be likely to indicate another misconception (its use to control the African American population). Therefore, any individual who utilizes that source of information would have a greater chance of believing both conspiracy theories.

Overall, these data show that there has been a failure of the medical and educational communities to deliver accurate information in a way that is deemed trustworthy by the African American community. It also indicates that African Americans still feel a degree of racial prejudice concerning medical matters, and that prejudice has transformed itself into an inherent distrust of the medical establishment. This makes it vitally important for the medical community to be aware of the perceptions and concerns that African Americans have regarding research and research participation. Although a significant effort should be made to help accurately educate all individuals concerning these matters, it is perhaps more important to simply be understanding of those concerns and beliefs. By being more understanding, there is a greater chance of establishing trust, which is critical for medical research to move forward with African American and other minority participation.

6.3 AIM 2

In each instance of offering an incentive, the majority of participants stated that they would be more likely to participate in research. The incentive with the greatest overall impact was the financial compensation of $500. One could speculate that this is likely due to its universal appeal; free medical care or free medicine may not be as likely to increase the willingness of young and/or healthy individuals to increase their willingness to participate in research. However, the amount of $500 is a large value and could be distorting the effect of financial compensation. It is possible that a lesser amount would not have as large an effect. The incentive that was least likely to encourage participation was free medicine. This may be caused by the commonly cited perspective of feeling like a “guinea pig” when participating in research studies (Corbie-Smith 1999). Another possibility for this finding may be the way in which the question concerning free medicine as an incentive is worded in the survey.

On several occasions, individuals completing the survey would ask whether the free medicine was medicine that they were already taking or was it a new medicine being studied. It is possible that confusion over what type of medicine being offered could have impacted the participants' response, as it seems likely that people would be more concerned, and thus less likely to participate in research in circumstances where the medicine being offered was experimental.

The analysis that examined the influence of knowledge and beliefs regarding the Tuskegee Study on the willingness to participate in research based on incentives showed intriguing results. In reference to free medical care, there were statistically significant differences between the groups. Though there appears to be an impact showing that individuals with greater knowledge regarding the Tuskegee Study are more likely to not be affected by the incentive of free medical care ($p = 0.001$) or more likely to be negatively influenced ($p = 0.046$), this difference is absent when examining those who believed there was deliberate infection of syphilis. This could indicate that familiarity itself of the Tuskegee Study may play a greater role in influencing individual's choice to participate in research when free medical care is offered as an incentive as opposed to what specific beliefs and knowledge one has regarding the study.

The results showing that knowledge of the Tuskegee Study could be impacting individuals' willingness to participate in research are contradictory to some studies (Katz 2008a; Katz 2008b; Green 2000) but are consistent with others (Freimuth 2001; Sengupta 2000; Green 1997). Reasons for the conflicting data are not clear as studies on both sides share common methodology (focus group studies, survey questionnaires and random and non-random sampling in the population). It is important to note that this study specifically broke down willingness to participate based on types of incentives, while other studies did not take this into account.

Outside of free medical care, differences in knowledge and beliefs concerning the Tuskegee Study did not appear to affect willingness to participate based on the other examined research incentives. Additionally, the presence or absence of the inaccurate belief that individuals were deliberately infected with syphilis did not appear to impact participation willingness based on any research incentives. This suggests that for the majority of research studies utilizing incentives to encourage participation, the impact of knowledge and beliefs regarding the Tuskegee Study are expected to be minimal with regards to influencing willingness to participate.

This minimal to no effect was also observed when analyzing the responses concerning HIV. The only marked difference observed resulted from the analysis comparing individuals who were unsure if HIV was man-made to those who either believed it was or was not. Individuals who were unsure were more likely to state that the incentive of financial compensation would have no effect on their decision to participate in research as compared to the other two groups. It is possible that these unsure individuals believe that money may be used as means to lure individuals into studies and are, therefore, less likely to be influenced by its offer. However, this is only speculation and further data would be needed to arrive to a more accurate conclusion.

Overall, it does not appear that knowledge and beliefs concerning the Tuskegee Study and HIV have a large impact on willingness to participate in research studies. However, it is important to note that there was a significant effect when examining how knowledge regarding Tuskegee affected individuals' willingness to participate in research studies where free medical care was offered. Based of this, it may be more practical to utilize other incentives as a means to encourage participation. The offer of financial compensation resulted in the greatest number of individuals willing to participate, making this the most practical incentive to offer when designing a research study that is attempting to encourage African American participation.

6.4 AIM 3

The focus of this aim was to examine how knowledge and beliefs of the Tuskegee Study and HIV affect individuals' perceptions on the importance of medical research and who benefits from research, as well as how such knowledge and beliefs influence one's willingness to be part of a research recruitment database.

The majority of all responses were positive with regards to the importance of research. Greater than 90% of people felt it was very important and were favorable towards research that involved human subjects. Approximately half of the sample population reported previous participation in studies. It was interesting to note that although the majority of individuals indicated that scientists, the community, their family and friends and themselves all benefited greatly from research, the greater perceptions of benefit correlated with the more distantly removed groups from one's self. Specifically, 63% of responders indicated that they and family and friends greatly benefited from research; however 67% indicated that the less closely related community greatly benefited and 83% indicated scientists greatly benefited. This could indicate that although African Americans believe research is important, they perceive that the importance is less likely to affect them then it is to others. This is intuitive, as it is easy to recognize how scientists benefit from research; however, since most people are not diagnosed with every condition that is studied, many studies will not have a personal impact. The nature of scientific research is based on population studies; therefore, it has greater benefit first to the population, then to a lesser degree to a specific community, then even less so to a family and an individual.

No statistically significant results emerged from the analysis examining the impact of Tuskegee and HIV knowledge and beliefs on participants' perceptions with regards to the perceived degree of benefit for scientific and local communities, family and friends and personal selves. This suggests that these factors had no significant impact on perceived degree of benefit. Interestingly, one significant difference was related to individuals who stated they had moderate or greater knowledge of the Tuskegee Study. These individuals were more likely to perceive medical research as beneficial to family and friends when compared to individuals who had little or no familiarity with Tuskegee. One possibility for this observation could be that since these individuals are more aware of the Tuskegee Study, they might also be more aware of medical research as a whole. Although the Tuskegee Study was highly unethical, they might also be aware of the positive reforms that came about, in part, due to the study and be more aware of the benefits that current research has had in society in general.

The second part of this aim looked at how knowledge and beliefs regarding Tuskegee and HIV influence perceptions on the importance of medical research, how favorable one was to human subject involvement in research, how it affected one's personal decisions if they had or declined to participate in research and finally, if they would be interested in joining a minority research recruitment database. In no instances, for any of the factors, were there any statistically significant differences between groups. In fact, the overwhelming majority indicated that they felt research was very important, were favorable to human subject involvement in research and were interested in joining regardless of their knowledge or beliefs concerning Tuskegee and HIV. These findings are consistent with previous studies that have shown that knowledge concerning the Tuskegee Study does not appear to influence people's willingness to participate in medical research (Katz 2008a, Katz 2008b, Green 2000). A possibility for these findings could be related to the sample population we analyzed. The individuals who are members of the Healthy Black Family Project are people that are concerned about health and health information and that itself might make them more receptive to medical research. Additionally, the Healthy Black Family Project is well-respected and trusted in the community. This trust may likely positively influence how members respond to medical research and increase their willingness to be part of a recruitment database.

Overall, it does not appear that knowledge and beliefs concerning Tuskegee and HIV have significant influence on the perceived importance of medical research, desire to be part of research studies or alter one's beliefs on the use of humans in research studies. Any differences that are observable and do show separation in how these factors are perceived is likely to come from other variables.

6.5 INFLUENCE OF DEMOGRAPHIC VARIABLES

It was interesting to note that older participants (age 50 and above), were less likely to have declined participation in research as opposed to the younger generation. One would expect that individuals who lived during the time of the Tuskegee Study would be more likely to view research in a negative light and would therefore be less likely to participate in research. However, it is possible that because individuals are more prone to health problems as they age, that older participants might be more receptive to research and also, in conjunction, view the benefits of research more greatly than the younger population. Additionally, it is possible that these older participants are more likely to be recruited for research studies concerning chronic health conditions.

The observation that men were less likely to view human subjects in research studies favorably was not unexpected. Women typically seek out health information more readily than men, and in relation, could view medical research more favorably. Additionally, the Tuskegee Study's primary impact was on the men who had participated. This past injustice might then have a greater impact on African American males' views on research when compared to women.

The finding that an increased level of education resulted in more positive views on medical research and a greater likelihood of participation was anticipated. These individuals are more likely to be familiar with medical research and/or research practices, which, one would expect, might make an individual more comfortable with participating in research, less likely to feel coerced and more likely to understand the benefits of research.

There were some interesting results regarding the relationship with income and medical research perceptions. It was not unexpected that individuals with a higher income were more likely to have participated in research and perceived more benefit from research. Income and education can be correlative and, from the previously mentioned statements regarding education, one could expect these findings. However, it was intriguing that individuals with a higher income were more likely to be positively influenced by the incentive of financial compensation as opposed to those of a lower income. One would expect that individuals with less financial security would be more likely to be positively influenced by the prospect of compensation. It is possible, however, that individuals with a lower income may feel that the researchers are using the incentive of financial compensation in a coercive manner. They might reason that the researchers are conducting a dangerous study and feel that if they simply offer a lot of money, people would participate regardless of the consequences. This would correlate with what happened to the participants in the Tuskegee Study. Those members were poor and the offer of a fully paid burial service, access to medical care, transportation and food acted as powerful, and possibly coercive, motivators.

In conclusion, it is important for researchers to be aware of how these demographic variables can act as an influencing force, especially in cases where a researcher is attempting to recruit from a specific socioeconomic bracket, gender, ethnicity and age group.

6.6 LIMITATIONS OF THE STUDY

There were several limitations that influenced the effectiveness of this study. The initial limitation was the relatively small sample size of 100 participants. There were several trends in the data (p-values between 0.5 - 1.0) that might have been more clearly defined had there been a larger sample size. Additionally, this small sample size prevented a more detailed exploration into the influence of demographic variables on willingness to participate and perceptions on research. Another limitation to the study was the relative uniformity of the sample population. The vast majority of individuals were women and individuals over the age of 40. Any differences that may be observed in a male and/or a younger population would likely have been missed in our sample group.

There were also some limitations to the number of questions that could be asked regarding the Tuskegee Study and HIV. As can be observed in the appendices, the Pre- and Post-Survey Questionnaires currently stand at 10 and 7 pages respectively and are taking participants roughly 30 minutes to complete, but have taken some people upwards of one hour.

Because the focus of the family health history is on the family tree and discussing health conditions and preventative measures, and not on the optional surveys, there was concern that any added length to the surveys would begin to detract from the primary purpose of the session. Due to this, a greater exploration into the breadth of knowledge individuals have on Tuskegee and HIV or identification of the sources of information that people are using to base their perceptions on could not be identified.

Another possible limitation to the study may involve participants' inaccurate interpretation of some questions. As stated earlier, during the course of taking the surveys, several individuals remarked that they were unsure if the question regarding the incentive of free medicine meant that the medicine offered would be medications that they are already taking or new experimental medications. Lastly, a possible concern relates to the way in which the surveys were administered; the genetic counseling students sit next to the participants while they answer the surveys, which may make them feel uncomfortable. On several occasions, members wanted to be sure, particularly on the questions concerning HIV beliefs, that there answers would be kept anonymous. If this indicates that there is concern within our sample group that the anonymity of their responses may be breached, then it is possible that some of those answers may not reflect their actual beliefs.

6.7 FUTURE PLANS

There are multiple avenues that can be taken in the future with this data. As the sample size continues to grow, there will be a greater ability to tease out information where there appeared to be possible trends. Additionally, with changes to the survey questionnaires, it may be possible to add in questions regarding more specific details regarding the Tuskegee Study and HIV.

An important area that can be explored would be to try and identify the sources of information that people are using to learn about the Tuskegee Study and HIV. Understanding where people are getting their information may be helpful to more accurately determine how that knowledge is or is not affecting their decision making. It might also give a definitive reason as to why one can see correlations of inaccuracies, such as the greater likelihood of believing HIV is used to kill African Americans when that individual also believes HIV is man-made.

Another important area to examine would be to attempt get a more diverse sample population, such as increasing the number of males and number of younger individuals. This would be important to get a more accurate consensus of how Tuskegee and HIV knowledge affect the African American community.

Examining the likelihood of participating in medical studies where blood is drawn would be another valuable area to explore. This would be important considering studies that require isolating and storing DNA samples from their participants. The line between participating in a study where one answers questions, exerts physical effort or undergoes non-invasive screening procedures may be very different than a study that requires blood drawn or tissue samples. Individuals' beliefs concerning the Tuskegee Study or HIV may play a larger role in influencing the decision to participate in these types of studies.

Another area that can be studied is to determine if studies being run by government agencies, as opposed to academic institutions, alter peoples' willingness to participate in medical research. Given that the Tuskegee Study was jointly run by a government agency and that HIV conspiracy beliefs often involve the government, it is possible that a study being run by a government institution may be more scrutinized by the public as opposed to a study being run by a university.

Lastly, it would be interesting to determine how knowledge of these topics affects the Caucasian population. The majority of studies involving both the Tuskegee Study and HIV conspiracy theories have focused on the African American community and it would be interesting to determine if there are segments or different social groups in the Caucasian population that are also affected.

7.0 CONCLUSIONS

The initial aim of this study revealed that a large degree of misinformation persists in the African American community in regards to both the Tuskegee Study and HIV. This aspect alone is concerning in that it shows that there has been a failure by the medical and science community in the ability to accurately educate the public concerning these matters. Additionally, it is important for individuals conducting research studies to be aware of these perceptions when attempting to recruit African Americans into their research. One of the most common disconnects noted between the African American and medical community has been in the issue of trust. By understanding the concerns and beliefs of the African American community, there will be a greater chance to improve the level of trust within that community.

Aim 2 revealed that the level of knowledge and the beliefs concerning the Tuskegee Study and HIV had minimal effect on the willingness for African Americans to participate in research when incentives are offered. This is positive in that it indicates there is one less obstacle that may be preventing African Americans from participating in research. However, it should be noted that there was a significant difference when taking into account the amount of knowledge an individual had on the Tuskegee Study and their response to participating in research based on free medical care. In this instance, individuals that had little to no knowledge of Tuskegee were more positively influenced to participate in research as compared to those that stated that had moderate or better knowledge of the study. Taking this into account, it may be beneficial for future research to utilize alternative incentives as a means to encourage participation. In particular, the offer of financial compensation was the most positively received incentive across the board in this study.

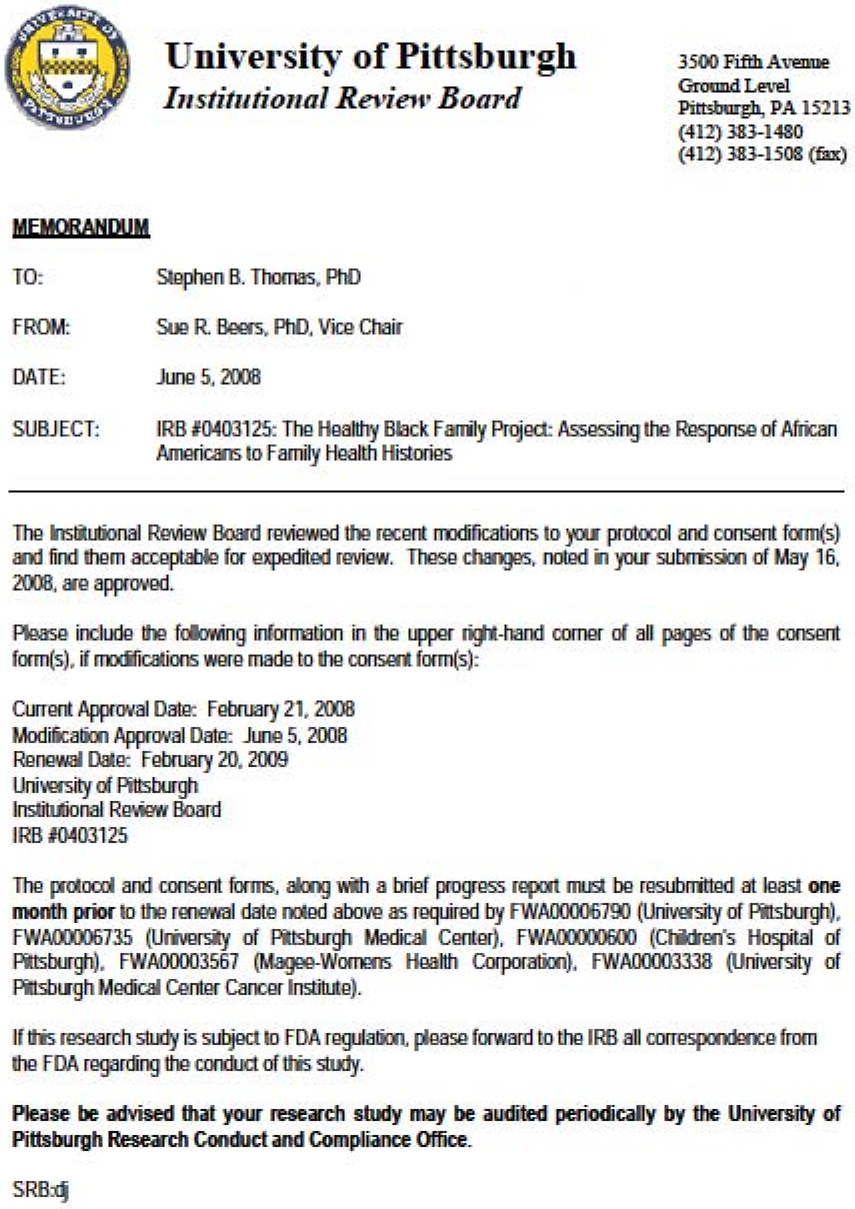
The final aim of this study showed that the level of knowledge and beliefs concerning the Tuskegee Study and HIV had minimal to no effect on the perceptions of the importance of medical research, who benefits from research, if individuals had or had not already participated or declined to participate in research and if they would be willing to enter a recruitment database. Again, this is positive in that it shows that these topics are not acting as hurdles that need to be overcome in order to improve the perceptions of medical research in the community. However, it is important to note that individuals responded that scientists greatly benefit from research more than any other group. This notion should be taken into account for any study attempting to recruit African Americans. By discussing how that research is important for the African American community and for the individual as well, it might increase the willingness of people to participate.

In relation to genetic counseling, this study is important as it reinforces how critical it is for individuals in the medical profession to be able to effectively listen to their patients or research participants. This study revealed that misconceptions remain regarding the scientific community; if a genetic counselor was not receptive to possible misconceptions that their clients believe, it would impair the effectiveness of that counselor in helping that individual.

Overall, this study showed that the effects of the level of knowledge and beliefs regarding the Tuskegee Study and HIV appear to be minimal when influencing individuals' willingness to participate in research and how they perceive the importance of research as a whole. However, it should be noted that our population group, members of the HBFP, are very health savvy. This aspect could be influencing their perceptions, making them more receptive to medical research and less likely to be influenced by misconceptions of the scientific community. Additionally, it was shown that demographic factors, particularly age and education can play a significant role in influencing individuals' willingness to participate in research. Specifically, individuals over the age of 50 and individuals with at least some college education were less likely to have declined participating in research or more likely to have participated in research, respectively. Also, it was shown that men were more likely to have negative feelings towards research involving human participants. This study also revealed that there was a large degree of misinformation within the African American community concerning these topics and that there was a disparity between who they felt benefited the most from research. These factors need to be taken into account for any researcher attempting to recruit African Americans in to their study. By doing so, it can improve the likelihood of building trust between the researcher and the future participants, which can positively influence one's willingness to participate in medical research.

APPENDIX A

IRB APPROVAL LETTER



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)

MEMORANDUM

TO:	Stephen B. Thomas, PhD
FROM:	Sue R. Beers, PhD, Vice Chair
DATE:	June 5, 2008
SUBJECT:	IRB #0403125: The Healthy Black Family Project: Assessing the Response of African Americans to Family Health Histories

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The Institutional Review Board reviewed the recent modifications to your protocol and consent form(s) and find them acceptable for expedited review. These changes, noted in your submission of May 16, 2008, are approved.

Please include the following information in the upper right-hand corner of all pages of the consent form(s), if modifications were made to the consent form(s):

Current Approval Date: February 21, 2008
Modification Approval Date: June 5, 2008
Renewal Date: February 20, 2009
University of Pittsburgh
Institutional Review Board
IRB #0403125

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month prior** to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

If this research study is subject to FDA regulation, please forward to the IRB all correspondence from the FDA regarding the conduct of this study.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

SRB:dj

APPENDIX B

PRE-SURVEY QUESTIONNAIRE

An important aim of genetic counseling is to provide risk information so that individuals and families can make better informed decisions about their health and that of their families. The purpose of this survey is to explore your perceptions of risk for developing certain health conditions. We want to understand whether family health histories (i.e., sharing information about diseases in your family) can help provide you with a more accurate assessment of your risk for developing particular health conditions.

If there is a question that you do not feel comfortable answering, you can skip it and continue on.

Please answer the following questions to the best of your ability.

DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.

The survey should take approximately 10 minutes.

We would like to thank you in advance for your willingness to participate in this survey.

Section 1: General Information

1) What is your age?

__ __ age in years

2) What is your gender?

1 - Male
2 - Female

3) Are you Hispanic or Latino?

1 - Yes
2 - No
3 - Don’t know

3a) Which one or more of the following would you say is your race? **(Check all that apply)**

1 - White
2 - Black or African American
3 - Asian
4 - Native Hawaiian or Other Pacific Islander
5 - American Indian, Alaska Native
6 - Other [specify] ___________________________

4) What was the total household income from all sources last year?

1 - Less than $10,000
2 - Between $10,000 and $20,000
3 - Between $20,001 and $35,000
4 - Between $35,001 and $50,000
5 - Between $50,001 and $75,000
6 - Greater than $75,000

5) What is the highest grade or year of school you completed?

1 - Grades 8 or less (Elementary)
2 - Grades 9 through 11 (Some high school)
3 - Grade 12 or GED (High school graduate)
4 - College 1 year to 3 years (Some college or technical school)
5 - College 4 years or more (College graduate or post-graduate)
6 - Graduate level (Masters or PhD)

6) How would you rate your knowledge on genetics?

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

7) How would you describe your general health?

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

8) Do you smoke?

1 - Yes
2 – No

9a) How would you describe your weight?

1 - Underweight
2 - Healthy weight
3 - Overweight
4 - Obese

9b)

1. For each of the questions below, please write the letter for only **ONE** body. Select the body that is the best choice.

(a) Which body looks most like the adult women in your family? _______

(b) Which body looks most like your women friends? _______

(c) Which body looks most like the adult women in your community? _______

2. For each of the questions below, please circle the letters for **ALL** bodies that fit the description.

(a) Which bodies look healthy? A B C D E F G H I J none

(b) Which bodies look underweight? A B C D E F G H I J none

(c) Which bodies look normal weight? A B C D E F G H I J none

(d) Which bodies look overweight? A B C D E F G H I J none

(e) Which bodies look obese? A B C D E F G H I J none

3. **For women only** – men should not complete this section:

(a) Which body looks most like yours? _______

(b) Which body would you most like to have? _______

9c)

1. For each of the questions below, please write the letter for only **ONE** body. Select the body that is the best choice.

    (a) Which body looks most like the adult men in your family? _______

    (b) Which body looks most like your male friends? _______

    (c) Which body looks most like the adult men in your community? _______

2. For each of the questions below, please circle the letters for **ALL** bodies that fit the description.

    (a) Which bodies look healthy? A B C D E F G H I J none

    (b) Which bodies look underweight? A B C D E F G H I J none

    (c) Which bodies look normal weight? A B C D E F G H I J none

    (d) Which bodies look overweight? A B C D E F G H I J none

    (e) Which bodies look obese? A B C D E F G H I J none

3. **For men only** – women should not complete this section:

    (a) Which body looks most like yours? _______

    (b) Which body would you most like to have? _______

10) Do you have one person you think of as your personal doctor or health care provider?

1 - Yes, only one
2 - Yes, more than one
3 - No
4 - Don’t know / Not sure

11) Was there a time in the past 12 months when you needed to see a doctor but could not because of the cost?

1 - Yes
2 - No
3 - Don’t know / Not sure

12) Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

1 - Yes
2 - No
3 - Don’t know / Not sure

Section 2: Physical Activity Habits

Definition of Physical Activity: The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

11) Based on this definition, are you physically active?

1 - Yes, I have been for more than 6 months
2 - Yes, I have been for less than 6 months
3 - No, but I am planning on starting in the next 30 days
4 - No, but I am thinking about starting in the next 6 months
5 - No, and I don’t plan to start in the next 6 months

12) If you answered **NO** to question 11, do you get some physical activity but not enough to fit the definition?

1 - Yes
2 - No

Section 3: Risk Perception

13) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease?

(**Please respond for each item listed**)

1=Never
2= Sometimes
3=Always
4=Don't know / Not sure

Smoking ________
Having a poor diet ________
Lack of exercise ________
Family history (other family members with a disease) ________

14) What do you think the chances are of a **healthy woman the same age as you** to develop the following health conditions sometime in her life?

(**Please respond for each condition listed**)

1=Low (<10%)
2=Moderate (10-50%)
3=High (>50%)
4=Don't know / Not sure

Breast cancer ________
Ovarian cancer ________
Colon cancer ________
Heart disease ________
Lung cancer ________
Diabetes ________
Alzheimer's disease ________
High Blood Pressure ________

15) What do you think the chances are of a **healthy man the same age as you** to develop the following health conditions sometime in his life? (**Please respond for each condition listed**)

(**Please respond for each condition listed**)

1=Low (<10%)
2=Moderate (10-50%)
3=High (>50%)
4=Don't know / Not sure

Breast cancer _______
Colon cancer _______
Prostate cancer _______
Heart disease _______
Lung cancer _______
Diabetes _______
Alzheimer's disease _______
High Blood Pressure _______

16) Have you ever been concerned about your chances for developing any of these health conditions?

1 - Yes
2 - No

16a) If yes, which condition(s)? ___________________________________

17) On a scale from 1 (not concerned) – 5 (extremely concerned), how would you rate your concern about developing any of the above health condition(s)? _______

18) Do you have a blood relative (mother, father, sister, brother, uncle, aunt, grandmother, grandfather) who had or has a health condition that you are concerned about developing sometime in your life?

1 - Yes
2 - No
3 - Don't know / Not sure

18a) If **YES**, who had the condition and what was it?

***DO NOT INCLUDE NAMES OF FAMILY MEMBERS, ONLY THE RELATIONSHIP TO YOU**

____
____
____

19) Have you ever talked to a health provider about your concern for developing that particular health condition?

1 - Yes
2 - No
3 - Don’t know / Not sure

19a) If yes, which condition (s)? ____

20) At this time, what do you think your chances are of developing any of the following health conditions sometime in your life? (**Please respond for each condition listed**)

1=Low (<10%)
2=Moderate (10-50%)
3=High (>50%)
4=Don’t know / Not sure
5=I already have the condition

Breast cancer ______
Ovarian cancer (Females Only) ______
Colon cancer ______
Prostate cancer (Males Only) ______
Heart disease ______
Lung cancer ______
Diabetes ______
Alzheimer’s disease ______
High Blood Pressure ______

21) At this time, what do you think your chances are of developing any of the following health conditions someday, compared with most individuals your age?

(**Please respond for each condition listed**)

ML=Much lower
SL=Somewhat lower
S=Same
SH=Somewhat higher
MH=Much higher
DK=Don't know / Not sure
AH=I already have the condition

Breast cancer _______
Ovarian cancer (Females Only) _______
Colon cancer _______
Prostate cancer (Males Only) _______
Heart disease _______
Lung cancer _______
Diabetes _______
Alzheimer's disease _______
High Blood Pressure _______

Section 4: Multidimensional Health Locus of Control

Questions 22- 39:
Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree(1) to strongly agree(6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1= STRONGLY DISAGREE **(SD)**	4= SLIGHTLY AGREE **(A)**
2= MODERATELY DISAGREE **(MD)**	5= MODERATELY AGREE **(MD)**
3= SLIGHTLY DISAGREE **(D)**	6= STRONGLY AGREE **(SA)**

		SD	MD	D	A	MA	SA
22	If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
23	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
24	Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
25	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
26	Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
27	I am in control of my health.	1	2	3	4	5	6
28	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
29	When I get sick, I am to blame.	1	2	3	4	5	6
30	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
31	Health professionals control my health.	1	2	3	4	5	6
32	My good health is largely a matter of good fortune.	1	2	3	4	5	6
33	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
34	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
35	Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
36	No matter what I do, I 'm likely to get sick.	1	2	3	4	5	6
37	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
38	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
39	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Thank you for taking the time to answer these few questions.
Your participation is greatly appreciated.

APPENDIX C

POST-SURVEY QUESTIONNAIRE

We hope that you enjoyed having your family health history done.

We would like to ask you a few more questions about risk to see if the family health history session changed your ideas about what conditions you might be at risk for. In addition, this post-session survey is looking at your opinions regarding participating in research.

If there is a question that you do not feel comfortable answering, you can skip it and continue on.

Please answer the following questions to the best of your ability.

DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.

The survey should take approximately 10 minutes.

We would like to thank you in advance for your willingness to participate in this survey.

Section 1: Physical Activity Habits

1) Based on our discussion, do you think that you will increase your physical activity?

1 - Yes
2 - No

Section 2: Risk Perception

2) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease?

(**Please respond for each item listed**)

1=Never
2= Sometimes
3=Always
4=Don't know / Not sure

Smoking ________
Having a poor diet ________
Lack of exercise ________
Family history (other family members with a disease) ________

3) Based on your family health history, what do you think your chances are of developing any of the following health conditions sometime in your life?

(**Please respond for each condition listed**)

1=Low (<10%)
2=Moderate (10-50%)
3=High (>50%)
4=Don't know / Not sure
5=I already have the condition

Breast cancer ______
Ovarian cancer (Females Only) ______
Colon cancer ______
Prostate cancer (Males Only) ______
Heart disease ______
Lung cancer ______
Diabetes ______
Alzheimer's disease ______
High Blood Pressure ______

4) Based on your family health history, what do you think **your chances** are of developing any of the following health conditions **someday**, compared with most individuals your age?

(**Please respond for each condition listed**)

ML=Much lower
SL=Somewhat lower
S=Same
SH=Somewhat higher
MH=Much higher
DK=Don't know / Not sure
AH=I already have the condition

Breast cancer _______
Ovarian cancer (Females Only) _______
Colon cancer _______
Prostate cancer (Males Only) _______
Heart disease _______
Lung cancer _______
Diabetes _______
Alzheimer's disease _______
High Blood Pressure _______

Section 3: Opinions on Research

5) How important do you feel that medical research is?

1 - Very important
2 - Somewhat important
3 - Not very important
4 - Not important at all
5 - Don’t know

6) Have you ever participated as a subject in any medical research studies?

1 - Yes
2 - No
3 - Don’t know

7) Have you ever been offered the chance to participate in a medical research study, but decided not to participate?

1 - Yes
2 - No
3 - Don’t know

8) If you were to describe your general attitude towards medical research involving people, would you say that you feel …?

1 - Very favorable
2 - Somewhat favorable
3 - Somewhat unfavorable
4 - Very unfavorable
5 - Neither favorable nor unfavorable
6 - Don’t know

9) Would the offer of <u>free medical care</u> make you more likely or less likely to agree to participate in research?

1 - More likely
2 - Less likely
3 - No effect
4 - Don’t know

10) Would the offer of <u>$500</u> make you more likely or less likely to agree to participate in research?

1 - More likely
2 - Less likely
3 - Have no effect
4 - Don't know

11) Would the offer of <u>free medicine</u> make you more likely or less likely to agree to participate in research?

1 - More likely
2 - Less likely
3 - Have no effect
4 - Don't know

12) How much do you think scientists benefit from medical research?

1 - A great deal
2 - A moderate amount
3 - Only a little
4 - Not at all
5 - Depends

13) How much do you think your community benefits from medical research?

1 - A great deal
2 - A moderate amount
3 - Only a little
4 - Not at all
5 - Depends

14) How much do you think your family and friends benefit from medical research?

1 - A great deal
2 - A moderate amount
3 - Only a little
4 - Not at all
5 - Depends

15) How much do you think you benefit from medical research?

1 - A great deal
2 - A moderate amount
3 - Only a little
4 - Not at all
5 - Depends

16) Do you have an interest in having your name in a database that would allow you to receive information about clinical research studies related to your family health history?
NOTE: Answering YES to this question DOES NOT enter you into any database nor does it sign you up to receive any information.

1 - Yes
2 - No

16a) If you answered **YES**, what are your expectations? (**Please circle all that apply**)

1 - I expect to receive information about *all* of the latest research studies.
2 - I expect to receive information about studies that I am eligible for.
3 - I expect to be rewarded for participating in research (paid, free health care, etc.)
4 - I expect to get the best health care available.
5 - Other:____

16b) If you answered **NO**, what are your primary reasons? (**Please circle all that apply**)

1 - I am not interested in participating in research.
2 - I am not interested in anything tied to my family/my genetics.
3 - I do not want to be part of a database.
4 - I do not want to disclose my contact information.
5 - Other:____

17) How would you describe your experience with having your family health history taken? (**Please circle all that apply**)

1 - Enjoyable
2 - Informative
3 - Uncomfortable/Unpleasant
4 - Neutral/No opinion

18a) From 1932-1972, a medical experiment involving African Americans was conducted. This experiment was known as the Tuskegee Syphilis Study. How much have you heard or read about this study?

1 – A great deal
2 – A moderate amount
3 – A little amount
4 – None at all

18b) Of these statements regarding the Tuskegee Syphilis Study, which one do you believe is most accurate?

1 – In the study, the government deliberately infected the men with syphilis
2 – The men in the study already had syphilis, but were not given treatment
3 – The men in the study already had syphilis, but the government accidentally gave them the wrong treatment
4 – The men in the study believed they were getting effective treatment
5 – I do not have any strong beliefs regarding the study

19) Some people believe that AIDS is a man-made virus. Do you believe that this is true?

1 – Yes
2 – No
3 – Don't Know

20) Some people believe that HIV and AIDS are being used to deliberately kill African Americans. Do you believe this is true?

1 – Yes
2 – No
3 – Don't Know

Section 4: Information Seeking Behavior

21a) Where do you seek information regarding health conditions you are concerned about? **(Check all that apply)**

__ Doctor
__ Library
__ Internet
__ Family and friends
__ Community health fair
__ Magazines/ Newspapers
Other______________

21b) From the options you checked above, please rate them in order of which you use most frequently to least frequently.

22) Circle the statement that most closely resembles your information seeking behavior.

1 - I am aware of the health conditions that run in my family, but I do not feel the need to do any more research on these conditions.
2 - I am aware of the health conditions that run in my family and I read about these conditions when the information is provided for me.
3 - I have done some of my own research on health conditions that I am concerned about.
4 - I actively keep up with current research on health conditions that I am concerned about.

23) How frequently do you research health conditions that you are concerned about?

1 - Very Frequently
2 - Frequently
3 - Occasionally
4 - Rarely
5 - Very Rarely
6 - Never

Thank you for taking the time to answer these few questions.
Your participation is greatly appreciated.

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