AN ASSESSMENT OF THE FACTORS ASSOCIATED WITH THE WILLINGNESS OF AFRICAN AMERICANS TO PARTICIPATE IN A MINORITY RESEARCH RECRUITMENT DATABASE

by

Andrea Lynne Smith

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This thesis was presented

by

Andrea Smith

It was defended on

March 31, 2010

and approved by

James Butler, DrPH, MEd, Assistant Professor, Department of Behavioral and Community Health Sciences, Graduate School of Public Health, University of Pittsburgh

Craig S. Fryer, DrPH, MPH, Assistant Professor, Department of Behavioral and Community Health Sciences, Assistant Director, Center for Minority Health, Graduate School of Public Health, University of Pittsburgh

Mary A. Garza, PhD, MPH, Assistant Professor, Deputy Director, Center for Minority Health, Department of Behavioral and Community Health Sciences, Graduate School of Public Health, University of Pittsburgh

Elizabeth Gettig, MS, CGC, Associate Professor, Co-Director of the Genetic Counseling Program, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Robin E. Grubs, PhD, CGC, Assistant Professor, Co-Director of the Genetic Counseling Program, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Candace Kammerer, PhD, Associate Professor, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Thesis Director: Stephen B. Thomas, PhD, Phillip Hallen Professor of Community Health and Human Justice, Associate Dean for Diversity, Department of Behavioral and Community Health Sciences, Graduate School of Public Health, University of Pittsburgh

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Andrea L. Smith, MS

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OBJECTIVES: The objective of this study is to determine factors which may affect Health Black Family Project members' participation in the Minority Research Recruitment Database (MRRD), as established through the Center for Minority Health and the Family Health History initiative.

METHODS: MRRD enrollment was offered to 799 African American individuals after participation in a Family Health History session. Of the 799 offered enrollment, 599 (75.0%) agreed to enroll in the database and to be contacted regarded clinical research studies for which they may qualify. Factors assessed to determine their influence on willingness to enroll include demographic data, research attitudes, objective and perceived disease risks, weight, physical activity level, student interviewer, and the degree of control which people believe they possess over their personal health as measured by the Multidimensional Health Locus of Control questionnaire. Chi-square analyses and logistic regression were undertaken to compare these factors with willingness to enroll in the database.

RESULTS: Analyses indicate that the following factors significantly affect willingness to enroll in the MRRD: being over age 65, health insurance status, research attitudes, previously declining research participation, reaction to incentives of money and free medical care, how much they believe family and friends benefit from research, degree to which they believe diet contributes to disease risk, student interviewer, Multidimensional Health Locus of Control

Powerful Others scale, and self-described weight. Logistic regression of selected variables determined that reaction to monetary incentives, student interviewer, and self-described weight are key factors which may influence MRRD enrollment.

CONCLUSIONS: The infrastructure of the MRRD has been shown to be an effective method for recruiting African Americans into a research database. Several factors have emerged as important in the determination of willingness to enroll, which represent both replications of the known literature and new findings unique to this research.

PUBLIC HEALTH SIGNIFICANCE: African Americans are underrepresented in many areas of medical and public health research. More effective strategies are needed to increase recruitment into research studies by understanding factors presented here which may play a role in an individual’s choice to participate in research.

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1.0 INTRODUCTION

This research was conducted within the Center for Minority Health (CMH) in the Graduate School of Public Health at the University of Pittsburgh. Since its establishment in 1994, the CMH has been active in the local community through various projects attempting to improve the overall health of minority populations in the city of Pittsburgh. Projects undertaken by the Center include health promotion and disease prevention activities; community-based research, health education and lay-health-advisory training, as well as information dissemination regarding cultural competency, health communication, and health literacy. Eliminating disparities in morbidity, mortality, and disease burden between ethnic and socioeconomic groups is a main focus of the Center.

The Healthy Black Family Project (HBFP) was established by the Center in 2004 with the particular aim of improving the health of its members through specific healthy living interventions. Currently, the HBFP is a free program open to all members of the public and is a key program in the CMH's goals of reducing disease morbidity and mortality among African Americans living in the Pittsburgh region. The HBFP attempts to bring lessons learned from minority health research to the community. This initiative was designed, implemented, and overseen by the CMH in the University of Pittsburgh's Graduate School of Public Health. The HBFP draws on the Center's guiding principles and beliefs: 1. Social justice governs and sustains equity and equality of opportunity in a free and open society, 2. Excellence is the minimum standard of service delivery for all in systems of medical care and provision of public health practice, 3. Individual autonomy is essential for attainment of personal health and wellbeing, and 4. Partnerships between academic and community stakeholders must be based upon mutual trust and respect (Center for Minority Health 2010)

The Minority Research Recruitment Database (MRRD) was established by the CMH as part of the HBFP in 2004. The goal of the MMRD is to identify individuals who may qualify for, and be interested in, participating in biomedical and public health research. As minorities are often underrepresented in both biomedical and public health research, this is an effort to increase the number of minorities participating in these types of research endeavors. The research presented here is an attempt to characterize factors which may influence a particular individual's decision to join the MMRD. Knowledge of factors which may influence this individual's decision may be useful in the future design and implementation of minority research recruitment strategies. Factors which were compared included demographics, attitudes and beliefs towards research, student interviewer, the degree of control which people believe they possess over their personal health, physical activity, and weight. This research expands upon a study by Kristen Vogel (2004) that examined factors associated with willingness to enroll in the MRRD, and a study by Vera Cheraphako (2008) that examined the effect of health behavior predictor questionnaire Multidimensional Health Locus Control (MHLC) scores on health behavior outcomes in FHH participants.

2.0 BACKGROUND AND SIGNIFICANCE

The following section includes a review of relevant literature regarding racial and ethnic health disparities in the United States and African American participation in medical and public health research.

2.1 RACIAL HEALTH DISPARITIES

2.1.1 Disparities in Health Outcomes

According to the Department of Health and Human Services, racial and ethnic disparities are the disproportionate burden of disease, injury, death, and disability within racial and ethnic minorities is a major public health concern in the United States and are now a well-recognized and studied issue. This section provides a brief review of the relevant literature as it applies to this project.

In the 2000 census, African Americans made up approximately 13% of the population, yet this subset of the population carries a disproportionately high burden of morbidity and mortality due to disease (CDC-OMHD 2009). In 2004, African Americans had the highest age-adjusted death rate of all races and ethnicities and a lower life expectancy than the average American. African Americans' life expectancy is 73.1 years versus 77.8 years for the general population (CDC-OMHD

2009). In particular, African Americans had the highest rates of death due to heart disease, cancer, diabetes, and HIV/AIDS (CDC-OMHD 2009). The death rate is 29% higher for heart disease and 40% higher for stroke in the African American population as compared to the Caucasian population (CDC-OMHD 2009). African Americans also have a higher prevalence of hypertension and diabetes in comparison to Caucasians (Kingston 1997).

Cancer incidence and mortality due to cancer are also higher among African Americans. The mortality rate from cancer is the highest among African Americans compared to any ethnic group in the United States. Among African Americans, death attributed to cancer is 321.8 per 100,000 for males and 189.3 per 100,000 for females. That compares to 234.7 male and 161.4 female deaths due to cancer in the Caucasian population. Incidence rates of many types of cancer are also increased in the African American population, including colon, kidney, liver and bile duct, lung, prostate, and gastric cancers. The incidence of breast cancer is lower among African Americans, though the associated mortality is higher (ACS 2008).

Possible explanations for the disparities in health outcomes include socioeconomic factors, racial bias and discrimination, genetics, distrust of the medical community, and differences in doctor-patient communication. Each of these factors has been shown to contribute to differences in health outcomes, though no single factor alone is explanatory. Therefore, a comprehensive, broad approach to remediate these disparities is necessary.

2.1.2 Disparities in Clinical Research Participation

Of further relevance to this project are the well-documented discrepancies in the rate of participation in clinical research between African Americans and their Caucasian counterparts. There has been an historical underrepresentation of minorities in clinical trials, leading some to question the validity of findings in populations that are not well-represented by study populations (Moreno 2004). Including minorities in clinical research is necessary to generalize efficacy and safety standards across racial groups (King 2002). Racial and genetic differences have been shown in the past to contribute to the variability of subjects' responses to medical treatments (Svennson 1989).

More than 29 drugs have been claimed to have different levels of efficacy among various racial groups. These drugs include ACE inhibitors, antihypertensives, anticoagulants, diuretics, glucocorticoids, hepatitis antiviral treatment, prostaglandin analogs, cytotoxic agents, insulin, morphine, and antipsychotics (Tate 2004). Variation in drug response have led to the suggestion that dosage and/or drug choice could be influenced by the patient's race or ethnicity, though this suggestion has largely not made their way into general practice, nor have been validated in the scientific literature. However, one medication, BiDil, was approved in 2005 for the treatment of congestive heart failure in African Americans (BiDil Prescribing Information 2009). The race-based marketing of this medication has been the subject of much controversy. Some individuals have expressed that the targeting of this medication to African Americans only may set a poor precedent in which a simplistic view of genetic differences among races may overlook socio-cultural factors which could influence disease causation and drug efficacy (Brody 2006)

The exact etiology of these differences in drug responses is still unknown, but it is likely a combination of environmental and genetic differences affecting absorption, metabolism, distribution, and excretion (Tate 2004). Differences in the CYP3A family of P-450 enzymes which metabolize many different drugs from chemically unrelated drug classes has been shown to be an important example of a genetic and physiological differences in drug metabolism among racial groups (Wilkinson 2005). Others have suggested that differences in factors that may be correlated with race, such as age, gender, and body size may account for the majority of the difference in response rate by race (Tate 2004). Whatever the explanation for the differences, the observed variations in drug responses by race suggest that clinical trials involving diverse populations are important for the development of new medications.

However, despite the recognized need to include diverse individuals in research, minorities are generally still underrepresented in clinical trials. In a cross-sectional population-based analysis of all participants in a therapeutic nonsurgical National Cancer Institute Clinical Trial Cooperative Group from 2000 through 2002, researchers found that racial and ethnic minorities were less likely to enroll in cooperative group cancer trials than were Caucasian. Additionally, the proportion of trial participants who were African American was found to have declined in recent years (Murthy 2004). Another assessment of the inclusion of women and racial and ethnic groups in 379 NIMH-funded clinical trials published between 1995 and 2004 in five major mental health journals found that most of the studies reported gender information but less than half of the studies provided complete racial and ethnic information. Most racial and ethnic groups were underrepresented and that pattern did not improved significantly over the last decade. Less than half of the studies had potential for subgroup analyses by gender and race/ethnicity (Mak 2007).

Recommendations by several governing entities and advisory groups have encouraged the increased participation of minorities into clinical research as a way to eliminate health disparities. The most forceful of these recommendations was the Revitalization Act of 1993 (Public Law 104-43) which was put into effect in 1994 (Health 1994). This act mandates the inclusion of women and minorities in clinical research studies and states that cost is not an acceptable reason for exclusion of these groups. Under these guidelines, the National Institute of

Health is to support outreach efforts to recruit and retain women, minorities, and their subpopulations in clinical studies (Health 1994). In 2001, the guidelines were amended to clarify and expand the definition of human research which would fall under the guidelines of this policy.

The Food and Drug Administration (FDA) has also implemented regulations to ensure that new medications are studied in individuals who represent the full spectrum of possible future patients, including different racial groups. The 1998 Guidelines for the Format and Content of the Clinical and Statistical Drug applications require that drug research include analysis of efficacy and safety in “important demographic subgroups” including race (Evelyn 2001). Through efforts to increase enrollment of these minority populations, several barriers to participation in clinical research have been identified, along with several strategies which have been shown some success in increasing minority participation rates.

2.2 FACTORS WHICH AFFECT AFRICAN AMERICANS’ PARTICIPATION IN RESEARCH

In recent years, there has been a wealth of research written about factors which may influence African Americans’ participation in research in an attempt to explain the disparities in research participation between African Americans and other racial groups (Corbie-Smith 2002; Musa 2009; Shavers 2002; Thompson 1996; Killien 2000; Advani 2003; Hatchett 2000). Below are presented three well-described factors that are of relevance to this study: trust in the medical community, socioeconomic factors, and Multidimensional Health Locus of Control. Other factors such as researcher and physician biases have also been proposed as factors or barriers to African Americans’ research participation.

2.2.1 Trust

Distrust of the medical community has often been cited as a reason for lower participations rates among African Americans. Numerous studies have replicated higher levels of distrust in the health care system among African Americans when compared to their non-African American peers (Corbie-Smith 2002; Musa 2009; Shavers 2002). This distrust likely stems in part from the historical mistreatment of African Americans in the medical setting. An important example of this mistreatment which has risen into the public conscious is the Tuskegee Syphilis Study, in which poor African American men were withheld medical treatment for syphilis when it became available (Freimuth 2001). Personal experience with discrimination may also contribute to an increased level of distrust among African American (Musa 2009).

Studies have been conducted looking at how distrust may affect willingness to participate in research. Distrust has since emerged as an important barrier in willingness to participate. Among African Americans, not only are there higher levels of distrust, but distrust has been found to be an important determinant of willingness to participate in research. Additionally, among all individuals who refuse participation, African Americans may be less trusting (Roberson 1994). Corbie-Smith et al (2002) found that race was strongly associated with a higher distrust score, which was calculated using responses to a seven-item index of distrust. African American respondents were less likely than their white counterparts to believe that their physicians would fully explain research participation and more likely to believe that their physician would expose them to unnecessary risks.

In a study by Rajakumar, et al (2009) comparing the attitudes and trust of African American and Caucasian parents towards their children participating in research, African American parents were found to have considerable greater distrust. In this study, 140 African

American parents and 50 Caucasian parents were administered a survey of 8 questions assessing trust in research. Distrust scores for the African American parents were significantly higher than the Caucasian parents, even after controlling for the confounding factor of education level. High distrust scores in African American parents were also associated with less willingness to enroll their children in clinical research. Incentives such as free medicine, financial compensation, medical care, and transportation did not overcome this barrier of distrust. The researchers suggest that this distrust may be a barrier to enrollment of African American children in clinical research.

Because distrust in the medical community has emerged as a major barrier to research participation in the African American community, various trust-building strategies have been employed in an attempt to overcome this barrier and increase clinical research participation. One major strategy which has been used for increasing research participation is the inclusion of trusted community members in the recruitment of participants and the planning of research strategies. This helps to promote community ownership of the project and diminishes distrust that some may harbor for unfamiliar members of the medical or research community.

In a review of various strategies for increasing participation in several cancer prevention and control studies, Paskett et al (1996) found that the use of focus groups, existing organizations, a community spokesperson, and community advisory boards were successful strategies in establishing trust. Studies which employed these strategies were more likely to reach their goal for African American participation. Similarly, McCallum et al (2006) found when studying the recruitment of older African Americans into a psycho-physiological study, community-based strategies were more likely to result in successful recruitment. They proposed a new model for community-based research recruitment which places importance on reciprocity, trust, and the mutual ownership of a research project that is shared between the community, the research team, and the sponsoring institution. This model, they hope, will decrease levels of distrust among potential participants by relying heavily on community involvement

Matching the race of the recruiter to the race of the potential participant has also been advocated as a strategy to decrease distrust and to increase minority participation in research. The underlying assumption supporting this theory is that two individuals who are members of the same racial group are likely to share similar cultural backgrounds and, as a result, will experience a higher degree of understanding and communication than two people from dissimilar backgrounds (Thompson 1996). However, the published literature regarding the efficacy of this strategy is mixed. Some have found significantly higher recruitment rates when the race of the interviewer is matched to the race of the potential participant. For example, Moser et al (2000) found higher cooperation rates among both African American and non-American American women when prospective participants and interviewers were concordant on race in a case-control breast cancer study. Yet others have found that matching the race of the interviewer with the race of the potential participant does not significantly influence recruitment rate. Thompson et al (1996) found that having an African American interviewer did not affect the recruitment rate of African Americans with psychiatric illness into a clinical research study. Other factors, such as a diagnosis of schizophrenia in the patient, were found to be correlated with likelihood of participation refusal. It appears that race-matching in the research recruitment of African Americans may play a factor in recruitment rates; however, to claim that it is necessary or more important than other factors is not supported by research. More research is needed to clarify the complexities of this issue.

2.2.2 Socioeconomic Constraints

Socioeconomic factors are frequently cited as barriers for African Americans' participation in clinical research. 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 2007). As a result, African Americans are more likely to have economic barriers to clinical research participation. Examples of these types of economic barriers are access to transportation, education regarding the importance and goals of clinical reserarch, health insurance coverage, childcare, and time constraints (Killien 2000).

The limited data regarding the effect of health insurance status on participation among all racial groups in clinical research has yielded conflicting results. For example, a 1996 survey of patients recruited for a trial of cardiac arrhythmia suppression medications found that those who chose to enroll were seven times more likely to lack health insurance than those who chose not to enroll. Additionally, among patients who joined the trial, those without health insurance were more likely to cite free medical care as an incentive (Gorkin 1996). However, higher enrollment rates among the uninsured are not the norm across all research studies (Gifford 2002). Suggestions to account for the lower rates of participation among the uninsured have included the requirements of many participants or their insurance companies to pay for associated medical care, restrictive entry criteria for trials, and the details of research logistics, such as inaccessible locations (Sateren 2002; Olsen-Garewal 2001). However, the effect of insurance status is unknown in the African American population.

Advani et al (2003) found that education, income, and belief that God would determine the outcome of disease were associated with decreased clinical research participation across all races and ethnicities. However, because African Americans are more likely to have lower incomes and educations levels, they suggested that initiatives targeting these issues may have the potential to increase participation among African Americans. General attitudes towards and understanding of medical research has also been shown to be a predictor of research participation among African Americans. Many misconceptions regarding the purpose, motivations, risks, and outcomes of medical research exist and may be more frequently found in the African American population due to historical inequities in access to education, healthcare, and medical research (Advani 2003).

Hatchett et al (2000) also found that interest in, and understanding of, research may be a motivating factor for research participation among African Americans. In their study, approximately 35% of African Americans who agreed to participate in a behavioral research study cited “interest in research” as their motivating factor for agreeing to participate. Motivating factors also included an opportunity to contribute information (21% of participants) and to be involved in an informational and educational study (14% of participants). These were the greatest non-monetary reasons for research involvement.

Strategies for increasing knowledge and improving attitudes towards clinical research have been suggested as mechanisms to increase minority participation in research. Some have suggested community-awareness programs developed through a community advisory panel to inform and educate community members about a particular study and the purpose of clinical research studies in general. This may be accomplished through a community-based speaker's bureau, participation in church and community health fairs, dissemination of information to community physicians via newsletters, educational messages via the mass media, and word-of-mouth (Harris 1996). Brown et al (2000) propose a three-prong model to increase minority females’ participation in research studies or trials. Acceptance, awareness, and access are the three prongs of this model. The researchers suggest that minority women's participation is dependent on their awareness, as defined as "an understanding of the importance of the research process and the value of the individual woman's participation."

2.2.3 Multidimensional Health Locus of Control

The Multidimensional Health Locus of Control (MHLC) is a scale used as a predictor of health behavior. It has not been studied directly in relation to willingness to participate in clinical research because of difficulties comparing enrollment and non-enrollment groups. However, it is possible and logical that the MHLC scale is an accurate predictor of this behavior as well. The scale is designed to assess the degree to which an individual feels that their actions or other external factors out of their control are responsible for their health status. It consists of three subscales, each which assess a specific factor known to determine health behavior: Internality, Powerful Others, and Chance. The Internality subscale assesses the degree to which an individual feels they are in control of their own health or how their personal decisions and actions determine their health status. The Chance subscale assesses the degree to which an individual feels that chance occurrences determine their health status. Lastly, the degree to which an individual feels that health professionals, family members, religious figures, and friends influence their health status is assessed by the Powerful Others subscale. The MHLC has been used as a predictor of health behavior and as a mechanism to tailor interventions to target populations (Wallston, Wallston & DeVellis 1978).

Since its creation in the 1970s, the MHLC scales' utility in predicting health behavior has been assessed in many different studies. Some patterns have emerged related to health behavior and scores on each of the subscales. A large scale analysis of MHLC, health value, and likelihood to participate in health behaviors in 11,632 individuals from the UK found that individuals scoring high on the Internality subscale were more likely to participate in a higher number of health behaviors (Normal 1998). Bronson et al. (1981) also found that individuals who scored high on the Internality subscale were higher on measures of health behavior, knowledge about health problems, and health plans than low scorers. Dishman et al. (1980) showed that internal individuals were more likely to stay in a physical activity program than persons who were external.

According to Norman, et al (1998), those who scored high on the Chance subscale were less likely to engage in preventative health behaviors. A strong belief in powerful others was found to be related to performance of fewer health behaviors, which the authors hypothesize may reflect the belief in the ability of the medical professional to cure illness and protect health. Grady (1981) found that women who agreed to participate in her breast self examination study had higher Powerful Others and Internality scores than those who refused to participate, possibly supporting the idea that those who believe that health can be controlled by powerful others are more likely to participate in health education programs.

The relationship between MHLC scale score and information seeking behavior has also been explored. Wallston, Allston, and Maides (1976) and Toner and Manuck (1979) found that among college students asked to pretend they had been diagnosed with hypertension, internals were more willing to read a greater volume of hypertension brochures than externals. Similarly, Sproles (1977) found that renal dialysis patients who scored high on the Internality score were better informed about their condition, were interested in learning more information, and were more willing to attend patient education classes than externals. DeVellis et al. (1980) conducted a nationwide survey of individuals with epilepsy and found that the best single predictor of information seeking behavior was a high Powerful Others score.

In a study exploring the relationships between HBFP members' MHLC scores, risk perception, and health behavior participation, Cherepahko (2008) found several significant associations. Individuals at high risk for diabetes were more likely to underestimate their risk if they scored low on Powerful Others, individuals at moderate risk for cardiovascular disease were more likely to overestimate their risk if they scored high on Powerful Others, and women at low risk for ovarian cancer were more likely to overestimate their risk if they scored high on the External subscale. There was no significant association found between MHLC subscale scores and MRRD participation.

3.0 SPECIFIC AIMS

3.1 AIM 1

To examine demographic factors, objective disease risks based on FHH, and risk perception associated with the decision to enroll in the MRRD.

Hypothesis: Based on past research on factors which may influence MRRD participation, females and individuals without healthcare coverage are expected to enroll in the MRRD at significantly higher rates than males. All other demographic factors, objective disease risks, and risk perception are not expected to significantly contribute to willingness to join the MRRD (Vogel 2004).

3.2 AIM 2

To explore attitudes towards research, student characteristics, and MHLC associated with the decision to enroll in the MRRD.

Hypothesis: Based on past research, individuals who believe that medical research is very important, individuals who respond more favorably to a financial incentive, and individuals who have not refused an offer to participate in research in the past are expected to be more likely to enroll in the MRRD (Vogel 2004). MHLC results are not expected to significantly impact willingness to participate in the MRRD (Cherepakho 2008). Student interviewer choice is not expected to impact participation.

3.3 AIM 3

To assess self-reported weight category, self-reported physical activity level, and measured Body Mass Index (BMI) associated with the decision to enroll in the MRRD.

Hypothesis: Individuals with a heavier perceived weight, lower physical activity level, and higher BMI are expected to be more likely to enroll in the MRRD. This hypothesis is based upon the belief that individuals at higher risks for health conditions are more likely to participate in research where they may be able to reduce their risks or be treated for conditions for which they have already developed. Individuals with reduced activity levels and heavier weights are known to be at higher risk for various health conditions.

3.4 AIM 4

To develop a model examining determinants associated with the decision to enroll in the MRRD. Factors to be considered include those which were found to differ significantly between the enrollment and non-enrollment group, based upon chi-squared analyses.

4.0 METHODS

4.1 HEALTHY BLACK FAMILY PROJECT

The HBFP is geographically centered around the neighborhoods of Pittsburgh termed the Health Empowerment Zone (HEZ). The HEZ includes East End neighborhoods of Pittsburgh which were chosen for their large proportion of African Americans and large number of residents living below the poverty line. As of 2004, the HEZ contained approximately 79.1% African American residents with an average of 25.7% of residents living below the poverty line. See Figure 1 below which outlines the zip codes included in this zone and their corresponding neighborhoods (Hunte 2002).

Zip Code	Neighborhoods
15147	Penn Hills
15206	Lincold, Lemington, Belmar, East Liberty, Larimer, Garfield
15207	Glen Hazel
15208	Point Breeze North, Homewood South, Homewood North, Homewood West
15213	Terrace Village, Upper Hill
15219	Crawford Roberts, Terrace Village, Middle Hill, Bedford Dwellings, Upper Hill
15221	Homewood North, East Hills, Wilkinsburg
15224	Garfield

Figure 1. Health Empowerment Zone

The HBFP is based out of two local community centers – the Hosanna House located in Wilkinsburg, PA and the Kingsley Center located in East Liberty, PA. Fitness classes ranging from African dance to cycling are available and taught by trained fitness instructors at both of these locations. Participation in HBFP classes is predicated on attending a HBFP orientation, medical clearance by the participants' physician, and a health assessment by one of the HBFP fitness instructors. Body mass index (BMI), a measure of body fat using height and weight measurements, is calculated during the initial health assessment and at subsequent follow-up assessments. Smoking cessation classes, stress management, nutrition information and assistance, and diabetes support are also available.

4.2 THE FAMILY HEALTH HISTORY SESSION

The family health history (FHH) initiative has been a part of the HBFP since its inception in 2004. It was designed to make members aware of how their particular family health history may impact their risk for certain diseases and to provide strategies that may be used to reduce that risk. Chronic diseases such as hypertension, diabetes, and cardiovascular disease are a large focus of the FHH sessions because of their prevalence in the African American community, the considerable morbidity and costs that the community bears as a result, the degree to which family history has been shown to impact risk for these diseases, and the availability of certain strategies to reduce risks for these diseases. Such strategies include behavior modification of diet and exercise habits which can be addressed through classes available through the HBFP. Cancer is another focus of these family health history sessions because of the known links between family history and cancer risks and the availability of screening and risk reduction strategies.

Colon, prostate, breast, and ovarian cancer risks are focused on because of their prevalence in the population and links to known genetic causes or predispositions.

To date, 935 family health histories have been performed at local churches, retirement centers, health/community fairs, local community centers, and barbershops/salons in the HEZ. After joining the HBFP, new members receive a phone call from a genetic counseling graduate student to let them know about the family health history initiative and offer participation. The student then meets with the participant at an agreed upon time and location for their FHH session. Typical sessions last between 45 minutes and 1 hour and 15 minutes.

During the one-on-one meeting, the participant is asked to recall health information for their family members including any specific diagnoses, age at diagnoses, cause of death, and age at death. The student records all of the family health history in a pedigree, evaluates the participant's risk for the diseases mentioned above, communicates these risks to the participant, and shares prevention and screening suggestions with the participant based on their personal and family health history of disease. Participants are given a hand-written copy of their family health history and are encouraged to share the information with other family members and their physician. After meeting with the participant, the genetic counseling student uses the hand-drawn family health history to create a computer-generated version of the pedigree using Progeny® software. The computer version is then mailed to the participant, along with health education materials which are relevant to the particular participant's personal health history, family health history, and expressed concerns. They also receive a certificate of appreciation for participating.

4.3 RISK ANALYSIS

Evaluation of participants' risk for several diseases is based upon criteria established by Scheuner et al (1997) who presented guidelines to stratify individuals' risks for common diseases. The guidelines stratify risk into average (population risk), moderate, and high risk, based upon the number of affected relatives, degree of relatedness, and the age of onset of disease in affected family members (Figure 2). The guidelines are applicable to heart disease, stroke, diabetes, colon cancer, prostate cancer, ovarian cancer, and endometrial cancer.

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

*Premature coronary artery disease: 55 or younger in males; 65 or younger in females
*Premature stroke, diabetes, colon cancer, and prostate cancer: 50 or younger
*Premature breast and ovarian cancer: 50 or younger or premenopausal

Figure 2. Scheuner Criteria

Participants' risk for cardiovascular disease, hypertension, Type 2 diabetes, and cancers of the prostate (men only), colon, breast, and ovaries (women only) is evaluated using these criteria. As Scheuner did not assess hypertension risk and therefore did not set guidelines for qualification of early onset, we defined premature hypertension for ourselves as onset <=50 years.

4.4 PRE- AND POST-SURVEYS

All individuals who participate in the FHH initiative are given the opportunity to complete a survey immediately before and after (pre-survey and post-survey, respectively) the family health history is obtained and assessed by the genetic counseling student. After explaining the general agenda for the meeting and showing the participant a sample pedigree, the genetic counseling student offers the participant the opportunity to participate in the surveys. Individuals are not required to complete the surveys as part of the FHH initiative. However, all participants who complete both surveys are given a five dollar Giant Eagle grocery store gift certificate in return for their participation. The student explains that they will receive the gift card after completion of the surveys in appreciation of their time and effort. In compliance with IRB requirements, informed consent is obtained before completing the surveys. IRB Approval letters can be found in Appendix F.

After signing the required consent form, the participant is given the pre-survey to complete. This survey consists of questions regarding demographic variables, body image perception, physical activity habits, health risk perception, and a Multidimensional Health Locus of Control survey (Appendix B). After the genetic counseling student completes the individual's family health history and discusses the individual’s specific risks, how they arrived at that risk analysis, risk reduction strategies, and screening options, they are asked to complete the post-survey. The questions on the post-survey include the topics of health risk perception, opinions towards research, their experience with having their family health history performed, and information seeking behavior (Appendix C). If the participant agrees to participate, they are contacted approximately one month following their family health history session for a follow-up survey (Appendix D). This survey is designed to collect information about changes in relationships with healthcare professionals and family members, physical activity levels, behavior changes, and information seeking behavior as a result of participation in the family health history initiative.

All surveys were designed by the CMH staff, genetic counseling program directors, and genetic counseling student CMH employees to assess various aspects of the participants’ backgrounds, lives, beliefs, and attitudes. The majority of the demographic questions and all of the questions about research opinions came directly from a study completed by S.B. Thomas, et.al (2001). This study examined the influence of demographic variables on willingness to participate in a medical research study. Other questions have been added over the past years to answer specific research questions of interest. Survey information collected is then 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.

4.4.1 Pre-Survey

4.4.1.1 Section 1: General Information

Section one contains questions regarding standard demographic variables, the individual’s knowledge of genetics, self-rated health, health insurance coverage, whether or not the individual has a primary care physician and self-described weight. Body image questions are also included which ask the individual to examine images of female and male bodies of increasing Body Mass Indices (BMIs) and to answer questions regarding which bodies look healthy, underweight, overweight, similar to theirs, similar to family members, and similar to community members.

4.4.1.2 Section 2: Physical Activity Habits

This section contains two questions. The first question is whether or not the individual feels that he or she is physically active based on the national recommendations for physical activity taken from the Center for Disease Control (CDC, 2005). Individuals who indicated that they were not physically active were asked about any plans to become physically active and if their plans included starting in the next 30 days or in the next 6 months. Those who said they were not physically active were asked if they participated in some physical activity, but not enough to fit the definition.

4.4.1.3 Section 3: Risk Perception

Section three includes questions that determine participants’ perception regarding various aspects of health risk perception. They are first queried regarding how much they believe smoking, diet, exercise, and family history contribute to an individual’s risk for disease. They are also questioned as to what they feel their risk is to develop several conditions and how they feel that risk does or does not differ from other individuals of the same age. Participants are asked to rate their level of concerns for developing these conditions and are asked to list any relatives who have had any of these conditions. The next series of questions assesses the individual's perception of risk for common chronic diseases for a person who is the same age as the participant.

4.4.1.4 Section 4: Multidimensional Health Locus of Control (MHLC)

In the fourth and last section of the pre-survey, participants are to complete the MHLC questionnaire which is designed to assess the degree to which an individual feels that they are in control of their own health. In this questionnaire, individuals are asked to rate how strongly they agree or disagree with the series of 18 statements provided. The three dimensions of Multidimensional Health Locus of Control – Internality, Chance, and Powerful Others – are assessed with three different subscales built into the questionnaire. After completion of the MHLC, the individual's score can be calculated and Multidimensional Health Locus of Control can be assessed in each of these three dimensions.

4.4.2 Post-Survey

4.4.2.1 Section 1: Physical Activity Habits

Section 1 asks if the participant believes that he or she will increase her physical activity habits as a result of the family health history session.

4.4.2.2 Section 2: Risk Perception

Section 2 of the post-survey asks similar questions to those asked in Section 2 of the pre-survey. The questions are repeated to determine if creation of the pedigree and the subsequent counseling by the student has changed the risk perception of the participant. Participants are again asked how much they believe smoking, diet, exercise, and family history contribute to an individual's risk for disease; what they believe their risk is to develop specific conditions over their lifetime based on their family health history; and how they feel that risk differs from others of a similar age.

4.4.2.3 Section 3: Opinions on Research

Section 3 includes many questions designed to elicit the participant's opinions regarding various aspects of research. Participants are asked if they generally feel favorable or unfavorable to medical research involving humans; if the offer of free medical care, a $500 incentive, or free medicine would make them more or less likely to participate in research; and how much they believe scientists, community, family and friends, and they themselves benefit from medical research. Participants are asked if they would be interested in having their name in a research recruitment database and what their expectations were of such a database. If the participant indicates that they are not interested, they are asked for their primary reasons for not wanting to be part of the database. Participants were also asked if they have ever participated in medical research in the past or been given the opportunity to do so. Several questions are also included which elicit the participant's knowledge and beliefs towards the Tuskegee Syphilis Study and HIV/AIDS conspiracy theories. Lastly, participants are asked to describe their experience with having their family health history session.

4.4.2.4 Section 4: Information Seeking Behavior

In section 4, each participant is asked where they search for health information and to choose a statement that most closely resembled their level of information seeking behavior. The four options included: 1. I am aware of health conditions that run in my family and I do not 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 concern me 4. I actively keep up with current research on health conditions that concern me. Participants are also asked to indicate the frequency of their information seeking behavior.

4.5 THE MINORITY RESEARCH RECRUITMENT DATABASE

The MRRD was established at the onset of the FHH initiative as a strategy to increase the recruitment of minorities into medical and public health research. Individuals who choose to enroll in the MRRD agree to be contacted by an employee of the CMH should a University of Pittsburgh research study become available for which they would be eligible, based on their personal or family health history. The individual is sent information by mail regarding the research study and how to become involve if they so wish. Contact information is kept entirely within the database and is not released to any study investigator at any time. Participants are able to withdraw their enrollment in the database at any time by contacting the CMH. They are not offered any direct compensation from their decision to enroll in the MRRD.

Family health history participants are offered enrollment in the MRRD at the end of their family health history session. They are introduced to the idea of such a database in Question 16 of the post-survey (Appendix C), in which they are asked if they would theoretically be interested in participating in such a database. After completion of the post-survey, the genetic counseling student explains the MRRD and offers enrollment. After verbal agreement, participants are asked to read and sign another consent form to officially enroll in the database.

4.6 DATA ANALYSIS

Data entered into Perseus Survey Solutions and Progeny® were exported into an Excel spreadsheet. Missing data points were checked against the original questionnaires to correct for any human errors in entering the data. Information regarding enrollment in the MRRD was exported from the Progeny software and added to the Excel spreadsheet. The data were then analyzed using the statistical software SPSS version 16.0.

Participants' ages were grouped into categories based on standard demographic survey categories (18-35, 36-50, 51-65, and over 65) and the categories were used in the analysis. Using the responses of participants in the MHLC questionnaire, a score was calculated for each participant for the internality, chance, and powerful others subscale (Appendix D: Scoring Directions). Individuals who did not respond or responded "I don't know" were excluded from the analysis of that question.

Univariate analysis performed using descriptive statistics. Bivariate analysis was performed using chi-squared analysis and t-tests. Chi-squared analysis compared the "MRRD-enrolled" group to the "MRRD-declined" for all categorical factors. To detect any differences in the female cohort, chi-square analysis was repeated in the all-female cohort for factors which were found to be significant. T-tests for independent groups were used for continuous quantitative data. Multivariate analysis was performed using stepwise logistic regression to analyze the influence of a combination of different factors in predicting MRRD enrollment. P values of 0.05 were considered significant for all statistical tests.

5.0 RESULTS

Since the initiation of the family health history initiative in 2004, 935 family health histories were completed with the assistance of 21 Masters level students in the Genetic Counseling Program. Of the 935 individuals who had their family health history completed, 821 agreed (88%) agreed to complete pre- and post-survey questionnaires. Each of the 935 family health histories includes at least a three generation pedigree. Health information is included about every member of the family that is included. Exceptions exist for individuals who knew limited or no health information for particular members of the family. The family health history information collected, along with the pre- and post-survey data, has provided the CMH with a robust data set regarding many aspects of participants' lives.

All individuals who completed the survey portion of the family health history were invited to join the MRRD. Of the 821 eligible participants, 615 (74.9%) elected to enroll in the database and 206 (25.1%) declined enrollment. The number of individuals who self-identified as African American or Black was 799 (97.3%). The MRRD enrollment rate among African Americans only was 75.0% with 599 enrolling and 200 declining enrollment. Table 1 contains MRRD enrollment by race.

Table 1. MRRD Enrollment by Race and Ethnicity

Race	Enrolled in Database	Declined Enrollment	Total (%)
African American/Black	599	200	799 (97.3)
Caucasian/White	20	6	26 (3.2)
Asian	1	1	2 (0.2)
Native Hawaiian or Other Pacific Islander	2	0	2 (0.2)
American Indian or Alaskan Native	30	14	44 (5.4)
Other	11	4	15 (1.8)
Ethnicity (%)			
Latino/Hispanic	4	4	8 (1.0)
Not sure/Don't know	5	2	7 (0.9)
TOTAL			**821***

*Column does not add to 821 because individuals were able to choose >1 race

Further data analysis examined the African American cohort only (n=799) and compared selected variables between individuals who enrolled in the database to those who declined enrollment. Variables included in this analysis included demographics, research attitudes, objective and perceived disease risks, student interviewer, and the degree of control which people believe they possess over their personal health as measured by the MHLC. MHLC data were available for 283 (35.4%) African American participants.

5.1 AIM 1

A review of the study population revealed that it was largely female, with female comprising 84.2% of the population. The majority of participants were between ages 51-65 (43.4%), followed by 36-50 (29.7%), over 65 (24.8%), and 18-35 (12.1%). The study participants were generally well-educated, with the majority reporting having completed some college (44.9%). A fifth (19.8%) of the sample reported completing high school, 18.1% were college graduates, 14.4% had post-college education, and only 2.8% had completed less than a high school degree. Forty-four percent of participants had a self-reported income between $20,000 and $50,000, though there was a significant spread ranging from greater than $10,000 to less than $75,000. See Table 2 for a breakdown of all demographic variables. The percentage within each subcategory is placed in parentheses.

Table 2. Demographic Variables

Demographic Variable	Number of Participants (%)
Age	
18-35	97 (12.1)
36-50	237 (29.7)
51-65	347 (43.4)
66+	118 (24.8)
Gender	
Male	126 (15.8)
Female	673 (84.2)
Education	
Grade 8 or less (Elementary)	3 (0.4)
Grades 9-11 (Some high school)	19 (2.3)
Grade 12 or GED (High school graduate)	157 (19.8)
College 1 year to 3 years (Some college or technical school)	356 (44.9)
College 4 years or more (College graduate or post-graduate)	143 (18.1)
Graduate level (Masters or PhD)	114 (14.4)
Household Income	
Less than $10,000	79 (9.6)
Between $10,000 and $20,000	141 (17.2)
Between $20,001 and $35,000	186 (22.7)
Between $35,001 and $50,000	145 (17.7)
Between $50,001 and $75,000	111 (13.5)
Greater than $75,000	83 (10.1)

Table 2 continued

Knowledge of Genetics	
Poor	78 (9.9)
Fair	303 (38.5)
Good	315 (40.0)
Very Good	77 (9.8)
Excellent	14 (1.8)
TOTAL	**799**

The demographic information was collected during the pre- and post-surveys and then analyzed to examine any significant differences between African American participants who enrolled in the MRRD when compared to participants who declined enrollment. There were no significance differences in participants' likelihood of joining the MMRD in regards to age group, gender, ethnicity, education level, or income level. Additionally, self-rated knowledge of genetics did not impact the likelihood of joining the MRRD. See Appendix A.1 for a breakdown of enrollment versus declined enrollment by demographic variable.

However, a pattern did emerge when the age groups were collapsed into those who were age 65 or under and those over age 65. Individuals over age 65 were less likely to join the MRRD than individuals age 65 or less (p=0.021). See Table 3.

Table 3. Enrollment by Age

	Enrolled into Database (% enrolled in category)	**Declined Enrollment (% declined in category)**	**p**
Age			0.021*
18-65	521 (76.5)	160(23.5)	
66+	78 (66.1)	40 (33.9)	

This trend did not hold for the African American female cohort (n=673) – women over age 65 were not significantly less likely to join the MRRD than women under age 65 (p=0.100). See Table 4.

Table 4. Female Enrollment by Age

	Enrolled into Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Age			0.100
18-65	440 (76.7)	134 (23.3)	
66+	68 (68.7)	31 (31.3)	

Self-rated health was examined for its potential impact on MRRD participation. The majority of participants rated their general health as good (53.7%), 23% rated their health as fair, 17.3% rated their health as very good, 3.0% rated their health as poor, and 2.9% rated their health as excellent. Self-rated health did not impact participants' likelihood of joining the MRRD. See Appendix A.1.

The majority of participants (73.7%) have health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare. Participants who did not have health care coverage were more likely to elect to enroll in the MRRD as compared to participants who did have health care coverage (p=0.039). See Table 5.

Table 5. Enrollment by Health Care Coverage

	Enrolled in Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Health Care Coverage			0.039*
Yes	525 (73.7)	187 (26.3)	
No	65 (84.4)	12 (15.6)	

This trend held for the African American female cohort as well (p=0.053). See Table 6.

Table 6. Female Enrollment by Health Care Coverage

	Enrolled in Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Health Care Coverage			0.053
Yes	442 (74.2)	154 (25.8)	
No	58 (85.3)	10 (14.7)	

Participants were asked if they had one person who they think of as their personal doctor or health care provider. Greater than 94% of participants responded that they had one or more person(s) they think of as their personal doctor or health care provider. Individuals without a personal doctor were not significantly more or less likely to join the MRRD than those with one or more personal doctors (Appendix A.1).

The personal health history of participants was analyzed to determine if having a particular condition influences an individual's likelihood of joining the MRRD. Cardiovascular disease, hypertension, diabetes, breast cancer, colon cancer, ovarian cancer, and prostate cancer disease status was analyzed for all of the participants based on personal health information that they provided on their family pedigree available through Progeny. Approximately half (47.3%) of participants reported not having or not having had any of these conditions, 31.7% reported having or having had one condition, 16.4% reported two conditions, 4.1% reported three conditions, and 0.5% reported four conditions. There was no difference in likelihood of joining the database by number of conditions (Appendix A.1).

A total of 358 individuals (45.2%) reported having hypertension, 154 having diabetes (19.4%), 76 having cardiovascular disease (9.6%), 21 having breast cancer (2.7% of all participants and 3.1% of women), 2 having ovarian cancer (0.3% of women), 10 having prostate cancer (7.9% of men), and 9 having colon cancer (1.1%). Analyses of cardiovascular disease, hypertension, diabetes, breast cancer, and colon cancer revealed no statistical differences in enrollment rates between those that had the condition and those that did not: cardiovascular disease, hypertension, diabetes, breast cancer, and colon cancer. Only two women and 10 men reported having ovarian and prostate cancer, respectively. These low numbers did not allow for meaningful statistical analyses (Appendix A.1).

Each individual's objective risk disease risks based on family history was compared to their likelihood of joining the MRRD. Objective risk was stratified into average, moderate, or high risk for hypertension; cardiovascular disease; diabetes; and cancers of the colon, breast, ovary, and prostate based on the Scheuner criteria. Men were excluded from the analysis of ovarian cancer and women were excluded from the analysis of prostate cancer. Individuals who already had the condition were considered to have "high risk." The majority of participants were assigned a high risk for hypertension (63.1%) and diabetes (43.1%). Objective risk was split for cardiovascular disease with 40.6% having low risk, 21.8% having moderate risk, and 37.6% having high risk. The majority of participants had a low risk for all of the cancer types examined. Objective risk for any of the above conditions was not found to impact likelihood of joining the MRRD (Appendix A.1).

Participants were asked if they felt that the risk for a healthy man and healthy woman their own age to develop several conditions was low (<10% lifetime risk), moderate (10-50%), or high (>50%). The conditions include cardiovascular disease; hypertension; diabetes; Alzheimer's disease; and cancers of the lung, colon, breast, ovary (women only), and prostate (men only). The majority felt that a healthy woman has a moderate risk for breast cancer (55.9%), ovarian cancer (54.8%), colon cancer (50.9%), lung cancer (45.9%), and Alzheimer's disease (43.4%). Conversely, the majority felt that a healthy woman has a high risk for cardiovascular disease (45.7%), diabetes (46.4%), and hypertension (55.3%). Participants also felt that a healthy man would have a high risk for these conditions. Fifty-two percent felt that a healthy man has a high risk for cardiovascular disease, 45.5% for diabetes, and 57.6% for hypertension. In addition, the majority (59.0%) felt that a healthy man has a high risk for prostate cancer. Additionally, the majority felt that a healthy man has a moderate risk for colon cancer (46.7%), lung cancer (48.2%), and Alzheimer's disease (43.4%). A large majority (72.6%) felt that a healthy man would have a low risk for breast cancer. MRRD enrollment was not significantly affected by response to any of these questions. See Appendix A.1 for complete data.

During the pre- and post-surveys, participants were asked to rate their risk for the above conditions as low (<10% lifetime risk), moderate (10-50%), or high (>50%). During the post-survey, the majority of participants rated their risk for breast cancer, colon cancer, ovarian cancer, lung cancer, and Alzheimer's disease as low. Perceived risk for hypertension was split with 39.8% rating their risk as high, 34.7% rating their risk as moderate and 25.5% rating their risk as low. Diabetes and cardiovascular disease risk was similarly split with 30.6% and 29.7% estimating their risk to be high, 34.6% and 41.2% estimating moderate risk, and 34.8% and 29.1% estimating low risk, respectively. Forty-five percent of men perceived their prostate cancer risk to be moderate, 38% perceived it to be low, and 16.9% perceived it to be high.

Perceived risk data from the post-survey was analyzed for its correspondence with MRRD participation. Post-survey data was presumed to more accurately reflect participants' risk attitudes at the time they were offered enrollment in the MRRD. Individuals who already had the condition were excluded from analysis. Perceived risk by condition was not found to significantly influence enrollment. However, perceived risk for Alzheimer's disease approached significant (p=.058), with individuals who rated themselves to be at moderate risk being the most likely to join the database. See Appendix A.1 for additional information.

Participants were also asked to rate how they felt their risk for the above listed conditions compared to a healthy man or woman their own age in both the pre- and post-surveys. Post-survey data was examined here for reasons stated above. Comparisons were made between those who thought their risk was "much lower" or "somewhat lower" vs. "same" vs. "somewhat higher" or "much higher." The largest numbers of participants felt their risk was "much lower" or "somewhat" lower with the exception of hypertension. The majority (43.3%) of individuals felt that their risk was "somewhat higher" or "much higher" for hypertension, 34.2% felt that it was "much lower" or "somewhat lower," and 22.4% felt that their risk was the same. No significant differences were found in MRRD enrollment as related to perceived relative risk for any of the conditions (Appendix A.1).

In both the pre- and post-surveys, participants were asked how often they believed each of the following factors increases (or contribute to) an individual's chance or risk for developing a disease: smoking, exercise, diet, and family health history. In both the pre- and post-survey, the majority of participants indicated that they believe that smoking, diet, and exercise always contribute to disease risk. The percentage who indicated that they believe each of the above factors always contribute to disease risk in the pre-survey was 75.8%, 69.3%, and 62.5%, respectively. In the post-survey, those numbers went up slightly to 78.0%, 70.8%, and 67.7%, respectively. For example, in the pre-survey, 46.9% of participants indicated that they believe family history sometimes contributes to disease risk and 40.1% believed that family history always contribute to disease risk. Additionally, in the post-survey, 47.3% of participants believed that family health history always contributes to disease risk and 51.5% of participants believe that it contributes sometimes.

There is no significant difference in MRRD enrollment between those who felt that smoking, exercise, or family health history always contributes to disease risk in the pre- or post-survey when compared to those who felt that those factors sometimes or never contribute to disease risk (Appendix A.1). However, individuals who felt that diet always contributes to disease risk in the post-survey were more likely to enroll in the MRRD compared to individuals who felt that diet sometimes or never contributes to disease risk (p=.022) (Table 7). This trend did not hold for the pre-survey question regarding the contribution of diet to disease risks, as seen in Appendix A.1.

Table 7. Enrollment by Belief in Contribution of Diet to Disease Risk

	Enrolled in Database (% enrolled in category)	**Declined Enrollment (% declined in category)**	**p**
Diet Contributes to Disease: Post-survey			0.035*
Never/Sometimes	121 (67.6)	58 (32.4)	
Always	329 (76.0)	104 (24.0)	

This post-survey trend was maintained in the all female cohort (p=0.036). See Table 8.

Table 8. Female Enrollment by Belief in Contribution of Diet to Disease Risk

	Enrolled in Database (% enrolled in category)	**Declined Enrollment (% declined in category)**	**p**
Diet Contributes to Disease: Post-survey			0.036*
Never/Sometimes	99 (67.3)	48 (32.7)	
Always	292 (76.4)	90 (23.6)	

5.2 AIM 2

In the past, 41.2% of participants had participated in medical research. Past research participation did not significantly affect choice to participate in the MRRD. See Appendix A.2. Individuals who had been offered the chance to participate in medical research in the past and had declined (30.7% of all participants) were less likely to join the database (p=0.040) when compared to those who had not declined participation in research in the past. See Table 10 below. This pattern was not maintained in the African American female cohort as seen in Table 12 below (p=0.100).

Participants were asked several questions regarding their attitudes towards medical research, including the importance of medical research. None of the participants felt that medical research was “not important at all” and 91.2% of participants believe that medical research was “very important.” An additional 7.2% believed that medical research was “somewhat important.” As see in Table 11 below, individuals that felt that medical research was “very important” were more likely to enroll in the MMRD than those that felt that medical research was “somewhat important” or “not very important” (p=0.004). This was maintained in the female cohort (p=0.034) as seen in Table 12.

Participants were asked to describe their general attitude towards medical research involving humans. Half of participants described their attitude as “very favorable;” 41.8% described their attitude as “somewhat favorable;” and the remaining 8.2% described their attitude as “neither favorable not unfavorable” (3.3%), “somewhat unfavorable” (4.1%), or “very unfavorable” (0.8%). Due to the small number who responded “very unfavorable,” responses were grouped into “very favorable” versus “somewhat favorable” versus “neither favorable nor unfavorable” versus “very/somewhat unfavorable.” This factor was found to be significantly associated with MRRD enrollment. Generally, increasing enrollment rates were found with associated with MRRD enrollment. Generally, increasing enrollment rates were found with increasing favorability towards research involving humans (p=0.012), as shown in Table 10 below. As shown in Table 11, this was replicated in the female cohort with p=0.013.

When asked if the offer of free medical care, $500, or free medicine would make them more or less likely to participate in research, the largest percentage of participants for each of these incentives indicated that the incentive would make them more likely to participate in research (49.8%, 56.2%, and 42.2%, respectively). Given the incentive of free medical care, 32.9% indicated that it would not affect willingness to participate and 6.0% indicated that it would make them less likely to participate. Approximately twenty-five percent of participants indicated that the offer of $500 would have no effect on their willingness to participate and 5.4% indicated that it would make them less likely to participate. Given the incentive of free medicine, 32.4% indicated that it would have no effect on willingness to participate and 12.1% felt that it would make them less likely to participate.

Analysis showed that individuals who were more motivated by free medical care and monetary compensation were more likely to join the MRRD (p=0.001 and p=0.008, respectively) as seen in Table 8. Individuals who were motivated by free medicine also appeared to be more likely to join the MRRD, but this did not reach statistical significance (p=0.073), as seen in Appendix A.2. The African American female cohort was also significantly more likely to join the MRRD if they were motivated by free medical care (p=0.001) and $500 (p=0.030). See Table 11. Participants who responded with “no effect” were removed from all of the above analyses.

All participants were asked how much they believe scientists, their community, family and friends, and they themselves benefit from medical research. The majority of participants felt scientists (80.3%), their community (59.3%), family and friends (58.1%), and themselves

(60.9%) benefit a “great deal” from medical research. A small minority felt that scientists (4.6%), their community (8.3%), family and friends (8.2%), and they (6.7%) do not benefit at all from medical research. As shown in Table 10 below, MRRD enrollment differed significantly by response regarding how much family and friends benefit from research. Individuals who stated that their family and friends benefited more from research were significantly more likely to join the MRRD (p=0.036) when participants who responded “depends” were removed from analysis. This pattern was maintained in the female cohort with p=0.036 (Table 11). The other factors did not significantly influence enrollment in the database. However, there did appear to be a trend that was maintained. Those who felt that scientists, their community, and themselves benefited more from research were more likely to enroll in the database but this did not reach statistical significance (p=0.205, 0.124, and 0.100, respectively). See Appendix A.1.

MRRD enrollment was analyzed by a student interviewer to detect any differences in enrollment by student. Over the past five years, a total of 11 genetic counseling graduate students from the Department of Human Genetics in the University of Pittsburgh’s Graduate School of Public Health have been employed by the CMH to perform family health histories in the community. Of these 11 students, eight self-identified as Caucasian or white, one self-identified as both Caucasian and Asian, one self-identified as Asian, and one self-identified as African American. Ten of the 11 students were female and all were between the ages of 22 and 31. English was the native language of all of these students. An additional ten genetic counseling students performed 3 or less family health histories each at community events. A total of 24 family health histories were performed by these 10 students, with the remaining 797 family health histories being performed by the 11 CMH genetic counseling students. Of these 797 family health histories, 778 were with African American participants. See Table 9 for interviewer characteristics.

Table 9. Student Interviewer Characteristics

Student	Race	Gender	Age
1	Caucasian	Female	23-24
2	Caucasian	Female	22-24
3	Caucasian	Male	27-28
4	Caucasian	Female	23-24
5	Caucasian/Asian	Female	22-23
6	Caucasian	Female	22-23
7	Caucasian	Female	27-28
8	Caucasian	Female	23-24
9	African American	Female	22-23
10	Caucasian	Female	22-23
11	Asian	Female	30-31

The MRRD enrollment or recruitment rate varied between the 11 students who performed more than three family health histories from 55.0% to 96.4%. As seen in Table 10, choice of student interviewer was a factor which significantly affected enrollment ($p<0.001$). Analyses were also performed by comparing the recruitment rate of each student to the recruitment rate of all other students. Individuals who were interviewed by student number nine were significantly more likely to join the MRRD ($p=0.006$) and individuals interviewed by student number 4 and 7 were significantly less likely to join the MRRD ($p=<0.001$ and $p=0.009$, respectively). Those interviewed by student number eight and number 11 appeared to be more likely to join the database with p values approaching significance (p=0.063 and p=0.072, respectively). As shown in Table 11, differences by student interviewer were similar among the female cohort.

Lastly, there were no significant differences in enrollment between those that rated their family health history experience as enjoyable (56.2%), informative (72.6%), uncomfortable (0.7%), or neutral (3.1%).

Table 10 shows a summary of all of the factors which were found to significantly affect MRRD enrollment. A summary of other factors which were examined can be found in Appendix A.2

Table 10. Enrollment by Research Attitudes

	Enrolled in Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Importance of Medical Research			0.004*
Very Important	555 (76.3)	172 (23.7)	
Somewhat important/not very important	34 (58.6)	24 (41.4)	
Declined Research			0.040*
Yes	171 (70.1)	73 (29.9)	
No	411 (77.1)	122 (22.9)	
General Attitude Towards Research			0.012*
Very Favorable	306 (80.1)	76 (19.9)	
Somewhat Favorable	226 (70.8)	93 (29.2)	
Neither Favorable Nor Unfavorable	16 (64.0)	9 (36.0)	
Very Unfavorable/ Somewhat Unfavorable	25 (67.6)	12 (32.4)	

Table 10 continued

Free Medical Care			0.001*
More Likely	321 (80.8)	76 (19.2)	
Less Likely	185 (70.6)	77 (29.4)	
$500			0.008*
More Likely	353 (80.8)	84 (19.2)	
Less Likely	26 (61.9)	16 (38.1)	
Family and Friends			0.036*
Great Deal	360 (78.6)	98 (21.4)	
Moderate Amount	143 (73.7)	51 (26.3)	
A little/Not at all	83 (66.4)	42 (33.6)	
Student Interviewer			<0.001*
1	37 (82.2)	8 (17.8)	0.290
2	81 (76.4)	25 (23.6)	0.719
3	52 (74.3)	18 (25.7)	1.000
4	44 (55.0)	36 (45.0)	<0.001*
5	42 (76.4)	13 (23.6)	0.873
6	42 (75.4)	14 (24.6)	1.000
7	57 (63.3)	33 (36.7)	0.009*
8	70 (83.3)	14 (18.7)	0.063
9	27 (96.4)	1 (0.6)	0.006*
10	73 (74.5)	25 (25.5)	1.000
11	55 (84.6)	10 (15.4)	0.072

As mentioned above, analyses of the factors which were found to be significant were repeated in the African American female cohort and presented below in Table 11.

Table 11. Female enrollment by Research Attitudes and Student Interviewer

	Enrolled in Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Importance of Medical Research			0.034*
Very Important	471 (76.3	146 (23.7)	
Somewhat important/not very important	29 (61.7)	18 (38.3)	
Declined Research			0.100
Yes	148 (70.8)	61 (29.2)	
No	346 (77.1)	103 (22.9)	

Table 11 continued

General Attitude Towards Research			0.013*
Very Favorable	257 (80.6)	62 (19.4)	
Somewhat Favorable	195 (71.7)	77 (28.3)	
Neither Favorable Nor Unfavorable	13 (59.1)	9 (40.9)	
Very Unfavorable/ Somewhat Unfavorable	21 (67.7)	10 (32.2)	
Free Medical Care			0.026*
More Likely	219 (79.6)	56 (20.4)	
Less Likely	56 (67.5)	27 (32.5)	
$500			0.030*
More Likely	296 (81.1)	69 (18.9)	
Less Likely	24 (64.9)	13 (35.1)	
Family and Friends			0.063
Great Deal	306 (78.3)	85 (21.7)	
Moderate Amount	119 (75.8)	38 (24.2)	
A little/Not at all	72 (67.3)	35 (32.7)	
Student Interviewer			<0.001*
1	32 (82.1)	7 (17.9)	0.443
2	68 (76.4)	21 (23.6)	0.895
3	46 (73.0)	17 (27.0)	0.647
4	37 (56.1)	29 (43.9)	<0.001*
5	38 (79.2)	10 (20.8)	0.604
6	38 (79.2)	10 (20.8)	0.604
7	49 (62.8)	29 (37.2)	0.011*
8	59 (84.3)	11 (15.7)	0.078
9	24 (96.0)	1 (4.0)	0.015*
10	64 (74.4)	22 (25.6)	0.893
11	41 (87.2)	6 (12.8)	0.053

A total of 283 participants completed the portion of the pre-survey which included the Multidimensional Health Locus of Control (MHLC) questionnaire. Of these 283 participants, 226 (79.7%) elected to enroll in the database and 57 (20.3%) chose not to enroll in the database. The mean score on the Internal subscale for individuals who enrolled in the database was 26.6

compared to 25.7 for the group which declined enrollment. Internality score does not appear to be a good predictor of database enrollment because this difference was not statistically significant (p=0.238). The mean score on the Chance scale was 13.8 for the enrolled group versus 14.3 in the declined group. Chance score was not a statistically significant predictor of enrollment (p=0.502). The enrolled group had a mean score on the Powerful Others scale of 20.1 and the declined group had a mean score of 18.4. This difference was statistically significant (p=0.032), signifying that the Powerful Others score may be a predictor of willingness to enroll in the MRRD. Table 12 is a summary of the mean subscale scores for the enrolled and declined groups.

Table 12. Enrollment by MHLC Subscale Mean Scores

	MRRD Enrolled Mean Score	MRRD Decline Mean Score	p
Internal	26.6	25.7	0.238
Chance	13.8	14.3	0.502
Powerful Others	20.1	18.4	0.032*

This trend did not hold in the female cohort. All MHLC subscales, including Powerful Others, were not significant predictors of MRRD enrollment, as shown in Table 13. The mean Powerful Others score for women who enrolled in the MRRD was 19.9, compared to 18.9 for the women who declined enrollment.

Table 13. Female Enrollment by MHLC Subscale Mean Scores

	MRRD Enrolled Mean Score	MRRD Decline Mean Score	p
Internal	26.5	26.1	0.526
Chance	13.7	14.5	0.352
Powerful Others	19.9	18.9	0.282

5.3 AIM 3

Physical activity level in participants was assessed by a question in the pre-survey which asked participants if they were physically active. Physically active was defined using the national recommendation which includes moderate physical activity for 30 minutes a day five or more days a week or vigorous physical activity for 20-30 minutes a day three or more days a week (CDC 2005). Based on this definition, a little over half (56.2%) of participants responded that they were physically active. Of this 56.2%, 38.1% of participants felt that they had been physically active for longer than six months and 17.3% felt that they had been physically active for less than six months. Of the 43.8% of participants who are not physically active, 34.2% stated that they planned to become physically active in the next 30 days, 8.3% planned to become active in the next six months, and 1.3% had no plans to become physically active. The likelihood of enrolling in the MRRD was not significantly different between those who were and were not physically active.

Participants were asked to describe their weight as underweight, healthy, overweight, or obese. The majority of respondents stated that they were overweight (59.2%). Twenty-three percent felt that they were of average weight, 16.3% felt that they were obese, and 1.6% felt that they were underweight. As shown in Table 14, individuals who described themselves as overweight or obese were more likely to enroll in the MRRD when compared to individuals who described themselves as underweight or of healthy weight (p=0.047).

Table 14. Enrollment by Physical Activity and Weight

	Enrolled into Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Self-Described Weight			.047*
Overweight/Obese	354 (75.0)	118 (25.0)	
Healthy/Underweight	102 (66.7)	51 (33.3)	

As shown in Table 15, this factor was analyzed in the female cohort and was also found to also be significant (p=0.044).

Table 15. Female Enrollment by Physical Activity and Weight

	Enrolled into Database (% enrolled in category)	Declined Enrollment (% declined in category)	p
Self-Described Weight			.044*
Overweight/Obese	316 (75.4)	103 (24.6)	
Healthy/Underweight	77 (65.8)	40 (34.2)	

The average BMI for all participants who were offered enrollment in the database and had available BMI information was 33.47 with a minimum of 17.91 and a maximum of 61.81. The average BMI for participants who elected to enroll in the database was 33.76 with a minimum of 17.91 and a maximum of 59.25. The average BMI for participants who elected to not enroll in the database was 32.67 with a minimum of 18.29 and a maximum of 61.81. The difference in BMIs between those who elected to enroll in the MRRD when compared to individuals who declined enrollment in the MRRD was not significant (p = 0.185). See Appendix A.3 for results.

5.4 AIM 4

A stepwise logistic regression was performed to assess the influence of the following variables on willingness to participate in the MRRD: age, health care coverage status, general attitude towards research, student interviewer, post-survey belief in the contribution of diet to disease risks, reaction to monetary incentives in willingness to participate in research, and self-described weight. After exclusion of individuals who did not have complete information for each factor, data on 468 individuals were available for analysis. Although 11 genetic counseling students performed four or more family health histories for the Healthy Black Family Project, two students were not represented in the logistic regression analysis incorporating all covariates because two of the survey questions (contribution of diet and self-described weight) were added after their tenure in the Healthy Black Family Project.

Willingness to enroll in the MRDD was significantly associated with monetary incentives (more likely versus less likely versus no effect; $p = 0.001$), student interviewer ($p = 0.008$), and self-described weight (underweight/healthy versus overweight versus obese; $p = 0.044$) (Table 16). These three factors together account for between 8.8% (Cox & Snell R Square) and 13.3% (Nagelkerke R Square) of the variation in enrollment ($p < 0.001$). Together they correctly predicted 96.8% (335/346) of those who chose enrollment and 19.7% (24/122) of those who declined enrollment, for an overall percentage of 76.6% predicted correctly.

Table 16. Logistic Regression - Complete Analysis

	Beta	Wald Chi-Square	p	Odds Ratio
Response to $500 Incentive		15.074	0.001*	
More Likely	0.649	7.853	0.005*	1.914
Less Likely	-0.682	2.471	0.116	0.506
No Effect				Reference
Student Interviewer		20.589	0.008*	
1	0.093	0.029	0.866	1.097
2	.000	0.000	0.999	0.999
3	0.181	0.179	0.672	1.198
4	-0.848	4.870	0.027*	0.428
5	0.221	0.234	0.629	1.247
7	-0.435	1.405	0.236	0.647
8	0.730	2.598	0.107	2.076
9	2.000	3.504	0.061	7.387
10				Reference
Self-described Weight				
Underweight/ Healthy Weight	-0.506	0.406	0.044*	0.603
Overweight/ Obese				Reference

The analysis was also performed excluding the question regarding contribution of diet to disease risks and self-described weight so that all student interviewers could be represented and to increase the sample size to a total of 738 participants. As shown in Table 17, the only factor which emerged as a significant predictor of enrollment in the MRRD was the student interviewer (p<.001). This factor correctly identified 100% of (550/550) those who chose enrollment and 0.0% (0/187) of those who declined enrollment for an overall percentage of 74.6% predicted correctly. It accounted for between 5.0% (Cox & Snell R Square) and 7.3% (Nagelkerke R Square) of the variation in enrollment (p<0.001).

Table 17. Logistic Regression - Excluding Co-Variates

	Beta	Wald Chi-Square	p	Odds Ratio
Student Interviewer		32.910	<.001*	
1	-0.173	0.109	0.741	0.841
2	-0.457	1.205	0.272	0.633
3	-0.531	1.427	0.232	0.588
4	-1.472	12.133	<0.001*	0.230
5	-0.420	0.777	0.378	0.657
6	-0.574	1.533	0.216	0.563
7	-1.156	7.954	0.005*	0.315
8	0.071	0.023	0.879	1.074
9	1.529	2.015	0.156	4.615
10	-0.648	2.414	0.120	0.523
11				Reference

6.0 DISCUSSION

6.1 AIM 1

Demographic characteristics were compared between the individuals who enrolled in the database and those who declined enrollment. With the exception of individuals over age 65 being less likely to join the database, demographics did not differ significantly between the groups. Vogel found in 2004 that women were more likely to join the database than men, but this finding was not replicated. The difference in findings may be because 1. The participants offered enrollment in the MRRD in the first sample that was analyzed differ significantly from the participants offered enrollment later in this study and/or 2. Vogel's findings found a false association between gender and enrollment due to its smaller sample size.

The sample size for Vogel's study was significantly smaller at 126 participants, including only 27 men. The larger sample size which is now available may reflect more accurately the lack of association between gender and enrollment. However, if there is truly no association between gender and MRRD enrollment, we still do not have data to conclude the male and female MRRD enrollees would ultimately participate in research opportunities at the same rate.

Alternatively, there may be significant differences in the men and women who participated in the FHH initiative and were offered enrollment in the MRRD at the beginning of its existence when compared to later participants. The majority of the later FHH sessions took place at the Kingsley Center, while earlier FHH session took place in more diverse settings including churches and community outreach events.

Participants age 65 or older were less likely to join the MRRD. This may be due to higher distrust levels or differences in the perceptions of patient-doctor trust among the elderly, which has been noted in the literature (Mascarenhas 2006). Additionally, individuals over age 65 are likely to have Medicare or another form of health coverage, a factor which was shown in this study to decrease likelihood of enrolling in the MRRD. This trend did not hold for African American females. Several explanations for this may be proposed including higher family involvement in older African American females, possibly increasing their awareness of conditions that may be running in the family or their concern for other family members. Additionally, women are generally more experienced and knowledgeable health care consumers in comparison to men (Copeland 2000).

Various factors regarding healthcare access and objective disease risk were examined in aim one to determine if any of these factors may significantly influence enrollment in the MRRD. Individuals without healthcare coverage were significantly more likely to join the database, though having a personal doctor was not influential in MRRD enrollment. Self-rated health, perceived risk for a number of conditions, and objective disease risk based on the participant’s FHH and Scheuner criteria were not influential variables for enrolling in the MRRD. However, several variables which measured participants’ attitudes towards and their response to research incentives were found to significantly affect enrollment rates.

The higher rate of participation in individuals without health insurance may be due to a number of contributing factors. It is likely that this represents a true contributing factor because other demographic factors (e.g. income and education level) which may be expected to be correlated with health insurance status did not help define willingness to enroll in the MRRD.

Individuals without health insurance may be enrolling in the database with hopes that it may be a way to gain access to healthcare which they are otherwise unable to access. Enrolling uninsured individuals into clinical research studies raises ethical concerns which all researchers should be aware of when recruiting individuals from the MRRD. As Pace et al (2003) point out, enrolling uninsured individuals may make them “susceptible to undue inducement to join trials and the possibility that their inability to access research products after trials leads to their exploitation.”

The current health and current health risks of participants was not found to be influential in their decision to enroll in the MRRD. Neither the number of health conditions that a participant reported having or having a particular condition were found to be influential in likelihood of enrolling in the MRRD. Objective risk for a number of common conditions based on family health history does not appear to influence willingness to participate in the MRRD. Though objective disease risk is communicated to each participant after drawing out the family health history and before being offered enrollment in the MRRD, this is not necessarily surprising given that objective risk may be a less influential factor than perceived risk. From this analysis, it appears that an individual’s personal health status and risks are not influential in their willingness to participate in research.

Intuitively, it may be expected that those with higher perceived personal disease risks would be more willing to join a research database with the option of participating in medical research. However, this research showed no difference in willingness to enroll in the MRRD compared to perceived disease risks for several conditions. Additionally, perceived risks for a healthy man and healthy woman were not influential on MRRD enrollment. This lack of association between both perceived and objective disease risk may have implications for the recruitment of African Americans into clinical trials. For example, recruitment of African

Americans from high risk clinics may not lead to higher recruitment rates than recruitment of low-risk individuals.

Another factor that was considered for its influence on database enrollment was how often participants believe smoking, exercise, diet, and family health history contribute to disease risk. Interestingly, the only factor which appeared to have a significant effect on enrollment was how often the participant believes diet contributes to disease risk when asked during the post-survey. It is unclear why individuals who feel that diet always contribute to disease risk joined the database at a higher rate than those who felt that it sometimes or never contributes to disease risk, though some thoughts may be proposed. Why this pattern did not also hold true for exercise or smoking is unknown. Intuitively, belief in the contribution of exercise especially seems to be a factor that would correlate strongly with belief in the contribution of diet.

Individuals who believe that personal decisions, such as choice of diet, affect health outcome may feel that they have more control over their personal health. It seems natural, therefore, to expect that individuals who feel that they have more personal control over their health are more likely to be willing to participate in medical research. This may be because of a possible belief that research leading to possible prevention strategies, interventions, or treatments may be capable of improving their health or the health of others. This issue of personal control over health is also examined in the MHLC questionnaire.

As contrasted to the post-survey data, how often the participant believes diet contributes to disease risk when asked during the pre-survey was not significantly associated with MRRD participation. This difference between the pre- and post-survey responses may be attributed to the taking of the family health history, the objective risks that the student conveyed to the participant, or the students’ advice on the importance of diet and exercise in reducing risks for many common conditions. The conveying of risk reduction strategies is an important part of the FHH initiative and it is likely that most students spend the majority of their time talking about risk reductions strategies for the most common conditions (hypertension, cardiovascular, disease), which generally consist of diet and exercise modifications. It is possible to conjecture that participants who consider the students' advice most on the importance of diet in disease risk reduction are also ones that might recognize the importance of research.

6.2 AIM 2

Past research experiences, attitudes towards medical research, and response to various incentives were examined for their correlation with likelihood of enrolling in the MRRD. Interestingly, past participation in medical research did not influence a participants' likelihood of enrolling in the MRRD. Refusal to participate in research in the past, however, was associated with significantly less willingness to enroll in the database. This is likely due to some underlying beliefs, attitudes, life situations, or past life experiences which may make participants more likely to refuse both research opportunities and MRRD enrollment. The female cohort's past experiences in declining research participation, however, was not significantly correlated to MRRD enrollment. This may be because women are less likely to decline research participation based on principles, but instead are more open to participation on a case-by-case basis. This lack of association in women may also be due to a more limited sample size.

Not surprisingly, individuals who felt that medical research is very important were more likely to enroll in the database when compared to individuals who felt that research is somewhat important or not important at all. Additionally, individuals who described their general attitude towards medical research involving humans as increasingly favorable were increasingly more likely to join the database. Both of these trends were maintained in the all female cohort, suggested that women's enrollment is also influenced by their beliefs in the importance of research and their attitudes towards medical research involving humans.

The influences of three different incentives (free medical care, monetary compensation, and free medicine) were examined for their influence on likelihood of enrolling in the MRRD. The high percentage of participants who felt that monetary compensation would increase their likelihood of participating in research is not a surprising finding given the literature which has been written supporting the idea that financial compensation is often a leading factor in the decision to participate in research (Sears 2001; Bentley 2004). Additionally, the relatively large sum of money ($500) which was offered as a potential incentive may be inflating a more realistic influence of monetary compensation.

A smaller portion of participants felt that the offer of free medicine would influence their decision to participate in research. This may be due to distrust regarding medications involved in research procedures. Alternatively, it may serve as less of an incentive for individuals who are not currently taking any medication. There may also be uncertainty regarding the purpose of the medication and if it would be a free version of medications which they are already prescribed or a new medication which they would be asked to take.

Individuals who reacted most positively to the theoretical compensation of free medical care or monetary compensation in the form of $500 were more likely to join the MRRD. Those who were more likely to participate in research given the incentive of free medicine were not significantly more likely to join the database. The offer of free medicine was not as strongly tied to willingness to participate in the database or as likely to increase research participation. The former may indicate that participants felt that enrollment in the MRRD was most likely to result in research incentives including monetary compensation and free medical care and less likely to include the compensation of free medicine. This association was maintained in the female cohort, who were similarly likely to enroll if they felt the $500 and free medical care would make them more likely to participate in research.

When asked how often they believe scientists, community, family and friends, and they benefit from research, it was interesting to find that a majority of participants felt that the above named groups benefit “a great deal” from research. However, the percentage who felt that scientists benefit (80.3%) was markedly higher than those who felt that the community (59.3%), family and friends (58.1%), and they (60.9%) benefit. The higher portion of individuals who felt that the community (8.3%), family and friends (8.2%), and they (6.7%) do not benefit at all from medical research when compared to scientists (4.7%) may be due to historical inequities in the distribution of medical research advances. Regardless of the reality, what is most important for tailoring research recruitment strategies is that this perception exists and appears to be correlated with willingness to participate in research (or a research recruitment database in our case). However, the percentage of participants who felt that each group did not benefit at all from medical research is low and perhaps lower than expected given the historical inequities in the dissemination of medical discoveries to the African American community. Overall, these numbers seem to show that our population feels that many benefits can be derived from medical research and that many different people can, and do, benefit.

Additionally, it was interesting to find that only belief that family and friends benefit greatly from research was influential in a participant’s decision to join the MRRD. This may be due to an altruistic motive to help family and friends by participating in research. The trend may not have held when asked about the community at large because a direct and personal connection is more motivational than an indirect and non-tangible connection to the community. The lack of influence in how much an individual feels they benefit from research and MRRD enrollment may suggest that MRRD enrollment is an altruistic decision for many individuals.

In the female cohort, the belief in the benefits derived from research to family and friends approached, but did not reach, significance (p=0.063). This suggests that the belief in the benefits derived from research to family and friends may be slightly less motivational for enrollment in the MRRD among females. Of note, females were not less likely to believe that family and friends benefit from research, that belief was simply not as firmly associated with MRRD enrollment.

The role in which the student interviewer may have in influencing an individual’s decision to join the MRRD was also explored in this section. This question was included in this section regarding trust because trust in the student interviewer may play a significant role in whether or not a participant feels comfortable enough to join the MRRD. Trust between interviewer and participant may be attributed to many factors which include personal demeanor; mutual respect; and possibly age, race, or gender matching. However, it must be kept in mind that other factors such as the way in which the student interviewer presents the information to the participants, the location in which they were interviewed, or they way in which they were recruited to the HBFP or the FHH session may influence the student’s recruitment rates as well. Therefore, any differences in recruitment rates may not be solely attributed to trust levels between participants and interviewer. Additionally, it is impossible without further studies to pinpoint what factors make one student more or less capable of creating trust with a participant when compared to other students.

The recruitment rate varied between students from 55.0% to 96.4% with an overall recruitment rate of 74.9%. Participants interviewed by student number nine were significantly more likely to join the database when compared to those interviewed by the other students. Student number nine was also the only African American student interviewer. Race-matching has been shown in the past to increase uptake into medical research due to an increased level of trust (Moser 2000). Therefore, the race-matching which occurred in the sessions between participants and student number nine may have been influential in their higher likelihood of joining the MRRD. However, the numbers are not large enough (n=28) to say for sure whether or not this is a pattern that would continue and not all research has supported the claim that race-matching is influential in the recruitment of African Americans into research (Thompson 1996). Other factors, such as mutual respect or the way in which the MRRD was presented, may have been equally influential in her high rates of recruitment. In fact, the variability in recruitment rates among the Caucasian students suggests that the variability in recruitment rates cannot be attributed to race alone.

The recruitment rates for two students (numbers four and seven) were significantly lower when compared to the recruitment rates of the other students. It is unclear why the recruitment rates for these students were significantly lower, though age (23-24 and 27-28, respectively), race (Caucasian), and gender (female) cannot fully account for these differences. Other personal characteristics or the way in which each presented the database could have been contributing factors. Additionally, these two students conducted FHH sessions during the same two years of the initiative. It is possible that the participants during these years differed significantly. Possible factors which could account for these differences could include differences in recruitment strategies, location of FHH sessions etc. Further research is needed to explore this finding.

Though the rates varied by student, the overall high rate of enrollment suggests that the MRRD infrastructure is an effective method of recruitment into a research database. Ten of 11 genetic counseling students which performed four or more FHH sessions were not African American, suggesting that race-matching is not a prerequisite for creating an effective method of research recruitment. Given the demographics of the students when compared to the demographics of our participants, gender- and age-matching do not also appear to be necessary for effective recruitment. There were no significant differences in willingness to participate by the student's gender or age, though 91% of interviews were performed by female students and all students were between age 22 and 30.

Participants' Multidimensional Health Locus of Control (MHLC) scores on each of the subscales (Internality, Chance, Powerful Others) were compared to their likelihood of joining the MRRD. Given the results from Cherepakho (2008), no significant differences were expected in scores between those who enrolled in the database and those who declined enrollment. However, a significant difference in the Powerful Others subscale was found – the mean score on this subscale for individuals who joined the database was significantly higher than the mean score for those individuals who declined participation.

The Powerful Others subscale assesses the degree to which an individual feels that "powerful others," such as health professionals, family members, religious figures, and friends, influence their health status. From the questionnaire results, it seems that those who believe that these individuals play a more influential role in their personal health status are more likely to enroll in the database. Conversely, those who believe that the influence of these people is smaller are less likely to join the database. These findings are consistent with Grady (1981) who found that women who agreed to participate in a breast self-examination study had higher Powerful

Others and Internality scores and DeVellis et al. (1980) who found that the best single predictor of information seeking behavior was a high Powerful Others score. Though this study compared database enrollment, rather than research enrollment or information seeking, there appear to be parallels. However, the results found here are contradictory to at least one study which has shown high Power Others scores to be associated with fewer health behaviors (Norman 1998).

The individuals who score high on the Powerful Others subscale believe that their health status is affected by important people in their lives. Perhaps individuals who score high on the Powerful Others subscale agree to enroll in the MRRD at higher rates because they believe it is likely to put them in contact with “powerful” individuals such as physicians or researchers. These individuals who scored high on the Powerful Others subscale will likely believe that these individuals have the capability of having a greater impact on their health than they could create on their own. Individuals who score lower on this subscale may feel that participation in a clinical research study will have less of an impact on their health outcome than behavioral modifications that they can make on their own.

Cherepakho (2008) found no significant differences in enrollment by subscale, though only 54 individuals had participated in the MHLC portion of the pre-survey at that time. This small population size limited her statistical analysis to binary comparisons between those who scored below the mean subscale score and those who scored above the mean subscale score and their likelihood of MRRD participation. Her analysis did, however, show the Powerful Others subscale to be closest to reaching statistical significance with a p value of 0.073, compared to 0.369 for the Chance scale and 0.770 for the Internality scale.

6.3 AIM 3

One measure of physical activity (self-described) and two measures of weight (self-described and Body Mass Index) were compared to MRRD enrollment. Self-described physical activity level and Body Mass Index (BMI) were not predictive of database enrollment. However, a significant difference in self-described weight was found when the categories “underweight,” “healthy weight,” “overweight,” and “obese” were collapsed into underweight/healthy weight and overweight/obese (p=0.047).

Individuals who described themselves as overweight or obese were more likely to join the MRRD when compared to individuals who described themselves to be of healthy weight or underweight. A possible explanation for this pattern is that individuals who recognize themselves as overweight or obese also appreciate that they are at risk for many conditions due to their weight. Therefore, they are looking to the MRRD as a means to possibly reduce those risks or treat pre-existing conditions. However, this hypothesis is questionable given the findings of Amburgey (2009) that disease risks were not consistently associated with body image perceptions in a group of HBFP participants and the lack of association found between MRRD participation and personal health history.

One hypothesis as to why self-described weight was found to be significant while BMI was not, has to do with participant perception. BMI is a standardized, objective measure, while self-described weight is left to the interpretation of the participant. Individuals who describe themselves as overweight may be obese and vice versa. In fact, Amburgey (2009) found that a group of HBFP participants significantly underestimated their measured BMI when asked to estimate their body size in pictures. Finding a correlation in the subjective measure but not the objective measure is suggestive that perceived weight is more important in predicting database enrollment. This could be tentatively generalized to the statement that perceived weight plays a larger role in research participation in African Americans than objective BMI. There is no known literature studying how perceived weight may influence research in biomedical or public health research.

6.4 AIM 4

Two stepwise logistic regressions were conducted in this study. The first contained data from 468 participants and used the covariates of age, health care coverage status, general attitude towards research, student interviewer, post-survey belief in the contribution of diet to disease risks, reaction to monetary incentives in willingness to participate in research, and self-described weight. The analysis revealed the following factors to be significant predictors of MRRD enrollment: reaction to monetary incentives, student interviewer, and self-described weight. All of the covariates used for this analysis had previously been found to significantly correlated with willingness to join the MRRD using Chi-square analysis; however, of the covariates analyzed, these three variables appear to most strongly predict enrollment. Self-described weight and student interviewer appear to be more important in affecting MRRD enrollment than expected. Possible explanations for their effect on willingness to enroll in the MRRD are explained in 6.3 and 6.2, respectively.

A second stepwise logistic regression was conducted using data from 738 participants and including the co-variates of age, health care coverage status, general attitude towards research, student interviewer, and reaction to monetary incentives in willingness to participate in research. Of these co-variates, only student interviewer emerged as a significant predictor of

MRRD enrollment. Though this analysis used data from 738 (92.4%) participants rather than 468 (58.6%) participants, it accounted for less of the variation in enrollment (5.0-7.3% versus 8.8-13.3%) and corrected predicted enrollment for a smaller percentage of participants (74.6% versus 76.7%). Additionally, the second model correctly predicted 0% of those who declined enrollment, compared to 19.7% of those who declined enrollment in the first model. For these reasons, the first model appears to more accurately capture the factors which may be influential in MRRD enrollment.

7.0 CONCLUSIONS

Use of the family health history session to recruit individuals into a research recruitment database has shown to be an effective method of recruitment in the African American community. At this point, it is impossible to completely predict factors that lead to the high enrollment rate (74.9%) among African American individuals who participated in the FHH session, though some significant factors were identified in this study. The FHH initiative is one aspect of the Healthy Black Family Project (HBFP), a community-based program that has gained the respect and trust of the African American community in Pittsburgh. Participation in the database is only offered after the participant has spent time with the student interviewer talking about his or her family and the health implications. Presumably during this time, a level of trust is built between participant and student interviewer. Distrust has been implicated in the past as a possible reason for the lower rate of medical research participation in African Americans (Corbie-Smith, 2002). This barrier to research participation is mitigated in large part by the infrastructure of the MRRD recruitment.

An additional factor that was not part of this research study which may play some role in the high rate of recruitment is a selection bias in the population. Individuals who choose both to participate in the HBFP and in the FHH initiative are likely more motivated regarding their health than the African American population in Pittsburgh as a whole. The success of this recruitment strategy and the factors which may influence participants decision to enroll in the

MRRD (as presented above) have implications for future interventions to increase minority recruitment into medical research.

The main aim of this study, however, was to assess the factors which may influence the willingness of African Americans in participating in the MRRD. The following factors have been found to increase the likelihood of participation: lack of health care coverage, being under age 65, the belief that diet is always influential in disease risks, the belief that medical research is very important, being more likely to participate in research if given the incentive of $500 or free medical care, the belief that friends and family benefit greatly from medical research, being offered participation by particular student interviewers, scoring higher on the Powerful Others MHLC subscale, and describing oneself as overweight or obese. Some of these findings are not surprising given the past research by Vogel (2004) and other research regarding factors which affect African Americans' willingness to participate in medical research. However, the influences of the following variables appear to be unique to this study: belief that diet is always influential in disease risks and describing oneself as overweight or obese.

The results of this study have implications for public health. African Americans are underrepresented in many areas of biomedical and public health research. Understanding the factors which may play a role in African Americans' choice to participate in research may lead to more effective recruitment into clinical research studies. Increasing minority research participation is part of a long-term strategy to eliminate racial health disparities. This research also highlights the importance of family health history session in building rapport between interviewer and interviewee.

7.1 LIMITATIONS

Several limitations of this research exist related to the ability to generalize results to other populations or research settings. One major limitation for the ability to generalize is the study population that was examined. Participants were a self-selected group of individuals who are likely highly motivated regarding their health. Additional socioeconomic factors suggest that this study population is of a higher socioeconomic status than most African American populations which have been studied in the past. For example, the majority were both insured (73.7%) and had completed some college of more (77.4%). Lastly, the study population was largely female (84.2%) and over age 50 (68.2%). Therefore, any results found in this study cannot be applied to other populations without hesitation. Secondly, the infrastructure of recruitment for the MRRD is unique in that it has the possibility of alleviating much of the barrier of distrust that may otherwise exist in the recruitment of African Americans into research. Therefore, generalizing these results to other research recruitment setting may not be possible.

Several other limitations of this study exist. One important limitation is that it is yet unknown how often recruitment into the MRRD will successfully result in participation in a clinical research study. Though the MRRD has been successful as a means to find individuals who may be interested in research participation, no attempts have been made to contact enrollees to offer participation in a clinical research study. Without information regarding uptake into clinical research, the efficacy of the MRRD as a means to increase minority research participation is still undetermined. An additional limitation to this study is that only individuals who consented to participate in a FHH session were offered the opportunity to participate in the MRRD.

7.2 FUTURE STUDIES

Future studies are needed to clarify and build upon results found in this study. Several questions from the pre- and post-surveys could be added to the analysis to further describe participants who decided to enroll in the database and those who declined enrollment. In particular, questions which may help clarify the distrust levels of each of these groups may be of interest. In particular, questions regarding the Tuskegee Syphilis Study and HIV/AIDS conspiracy theory could be added to the analysis. Questions from the follow-up survey taken one month after completion of the family health history were not analyzed in this study, but could be of interest for future research.

As mentioned above, the MRRD has not been evaluated for its ability to effectively recruit individuals into specific research studies. One obvious opportunity for future studies is to contact MRRD enrollees regarding research opportunities and to analyze which participants ultimately decide to enroll in the study. This would both help to determine the impact and effectiveness of family health histories in increasing minority recruitment in clinical research trials and to further investigate any factors which may influence research participation among African Americans.

Further multivariate statistical analysis to assess relationships between factors and any potential interactions may be helpful to clarify the significance of certain findings and the ways in which multiple interactions may work together to influence MRRD enrollment. Though the sample size used in this population was sufficiently large for many analyses, a larger sample size would be helpful in clarifying some trends which emerged, but which did not reach statistical significance. Increasing the number of males in particular would be beneficial. Additionally, recruitment of non-African Americans in the FHH initiative would allow for analysis of factors which may influence database enrollment in non-African Americans and allow for comparison between racial groups.

APPENDIX A

DATA TABLES

A.1 AIM 1

	Enrolled into Database (% enrolled in category)	Declined Enrollment (% declined in category)	p value
Gender			0.448
Male	91 (72.2)	35 (27.8)	
Female	508 (75.5)	165 (24.5)	
Education			0.730
Grade 8 or less (Elementary) / Grades 9-11 (Some high school)	16 (72.7)	6 (27.3)	
Grade 12 or GED (High school graduate)	120 (76.4)	37 (23.6)	
College 1 year to 3 years (Some college or technical school)	259 (72.8)	97 (27.2)	
College 4 years or more (College graduate or post-graduate)	112 (78.3)	31 (21.7)	
Graduate level (Masters or PhD)	86 (75.4)	28 (24.6)	
Household Income			0.807
Less than $10,000	60 (75.9)	19 (24.1)	
Between $10,000 and $20,000	103 (73.0)	38 (27.0)	
Between $20,001 and $35,000	144 (77.4)	42 (22.6)	
Between $35,001 and $50,000	111 (76.6)	34 (23.4)	
Between $50,001 and $75,000	87 (78.4)	24 (21.6)	
Greater than $75,000	59 (75.7)	24 (28.9)	
Knowledge of Genetics			0.342
Poor	63 (69.2)	28 (30.8)	
Fair	234 (74.3)	81 (25.7)	
Good	231 (76.2)	72 (23.8)	
Very Good/Excellent	63 (80.8)	15 (19.2)	
Self-rated Health			0.349
Poor	16	8	

Fair	146	36	
Good	313	112	
Very Good	99	38	
Excellent	17	6	
Health Care Coverage			0.039
Yes	525 (73.7)	187 (26.3)	
No	65 (84.4)	12 (15.6)	
Personal Doctor			0.592
Yes, one or more	555 (74.5)	190 (25.5)	
No	35 (79.5)	9 (20.5)	
Have Condition			
Hypertension	269 (75.2)	89 (24.8)	1.000
Diabetes	110 (71.4)	44 (28.6)	0.252
Cardiovascular Disease	55 (72.4)	21 (27.6)	0.577
Colon Cancer	7 (77.8)	2 (22.2)	*
Breast Cancer	17 (81.0)	4 (19.0)	0.798
Ovarian Cancer	0 (0.0)	2 (100.0)	*
Prostate Cancer	8 (80.0)	2 (20.0)	*
Number of Conditions			0.089
0	289 (76.5)	89 (23.5)	
1	189 (74.7)	64 (25.3)	
2	89 (67.9)	42 (32.1)	
3 or more	32 (86.5)	5 (13.5)	
Objective Risk – Hypertension			0.985
Average	134 (75.3)	44 (24.7)	

Moderate	85 (75.2)	28 (24.8)	
High	372 (74.7)	126 (25.3)	
Objective Risk – Cardiovascular Disease			0.570
Average	246 (76.9)	74 (23.1)	
Moderate	127 (73.8)	45 (26.2)	
High	218 (73.4)	79 (26.6)	
Objective Risk - Diabetes			0.570
Average	229 (73.2)	84 (26.8)	
Moderate	105 (77.8)	30 (22.2)	
High	256 (75.3)	84 (24.7)	
Objective Risk – Breast Cancer			0.208
Average	493 (74.0)	173 (26.0)	
Moderate	43 (75.4)	14 (24.6)	
High	53 (84.1)	10 (15.9)	
Objective Risk – Ovarian Cancer			0.546
Average	477 (76.0)	151 (24.0)	
Moderate	16 (66.7)	8 (33.3)	
High	10 (71.4)	4 (28.6)	
Objective Risk – Colon Cancer			0.666
Average	527 (75.0)	176 (25.0)	
Moderate	43 (71.7)	17 (28.3)	
High	21 (80.8)	5 (19.2)	
Objective Risk – Prostate Cancer			0.238
Average	83 (74.1)	29 (25.9)	

Moderate	12 (63.1)	7 (36.8)	
High	5 (100.0)	0 (0.0)	
*Not sufficient numbers for analysis			
Men's Risk - Hypertension			0.841
Low	61 (78.2)	17 (21.8)	
Moderate	165 (75.0)	55 (25.0)	
High	305 (75.3)	100 (24.7)	
Men's Risk – Cardiovascular disease			0.869
Low	60 (73.2)	22 (26.8)	
Moderate	195 (75.3)	64 (24.7)	
High	281 (75.9)	89 (24.1)	
Men's Risk - Diabetes			0.450
Low	68 (70.8)	28 (29.2)	
Moderate	222 (76.8)	67 (23.2)	
High	247 (76.7)	75 (23.3)	
Men's Risk – Breast Cancer			0.676
Low	357 (76.3)	111 (23.7)	
Moderate	108 (73.5)	39 (26.5)	
High	24 (80.0)	6 (20.0)	
Men's Risk – Colon Cancer			0.864
Low	68 (78.2)	19 (21.8)	
Moderate	248 (75.4)	81 (24.6)	
High	219 (76.0)	69 (24.0)	
Men's Risk – Prostate Cancer			0.578
Low	38 (70.4)	16 (29.6)	

Moderate	182 (76.8)	55 (23.2)	
High	321 (76.6)	98 (23.4)	
Men’s Risk – Lung Cancer			0.342
Low	114 (76.0)	36 (24.0)	
Moderate	255 (77.5)	74 (22.5)	
High	146 (71.9)	57 (28.1)	
Men’ Risk – Alzheimer’s Disease			0.123
Low	161 (77.4)	47 (22.6)	
Moderate	205 (76.8)	62 (23.2)	
High	96 (68.6)	44 (31.4)	
Women’s Risk - Hypertension			0.228
Low	64 (81.0)	15 (19.0)	
Moderate	175 (72.6)	66 (27.4)	
High	306 (77.3)	90 (22.7)	
Women’s Risk – Cardiovascular disease			0.226
Low	75 (78.1)	21 (21.9)	
Moderate	205 (72.2)	79 (27.8)	
High	249 (77.8)	71 (22.2)	
Women’s Risk - Diabetes			0.600
Low	84 (77.1)	25 (22.9)	
Moderate	206 (74.9)	69 (25.1)	
High	261 (78.4)	72 (21.6)	
Women’s Risk – Breast Cancer			0.826
Low	75 (76.5)	23 (23.5)	
Moderate	291 (75.8)	93 (24.2)	

High	160 (78.0)	45 (22.0)	
Women's Risk – Colon Cancer			0.811
Low	127 (76.0)	40 (24.0)	
Moderate	255 (77.0)	76 (23.0)	
High	113 (74.3)	39 (25.7)	
Women's Risk – Ovarian Cancer			0.793
Low	108 (76.6)	33 (23.4)	
Moderate	274 (76.5)	84 (23.5)	
High	116 (73.9)	41 (26.1)	
Women's Risk – Lung Cancer			0.412
Low	161 (75.9)	51 (24.1)	
Moderate	239 (77.3)	70 (22.7)	
High	109 (71.7)	43 (28.3)	
Women' Risk – Alzheimer's Disease			0.635
Low	166 (75.1)	55 (24.9)	
Moderate	201 (76.4)	62 (23.6)	
High	87 (71.9)	34 (28.1)	
Post-Survey Perceived Risk - Hypertension			0.958
Low	102 (76.1)	32 (23.9)	
Moderate	138 (75.8)	44 (24.2)	
High	161 (77.0)	48 (23.0)	
Post-Survey Perceived Risk – Cardiovascular disease			0.315
Low	145 (74.7)	49 (25.3)	
Moderate	214 (77.8)	61 (22.2)	

High	142 (71.7)	56 (28.3)	
Post-Survey Perceived Risk - Diabetes			0.556
Low	156 (73.9)	55 (26.1)	
Moderate	158 (75.2)	52 (24.8)	
High	146 (78.5)	40 (21.5)	
Post-Survey Perceived Risk – Breast Cancer			0.722
Low	328 (74.7)	111 (25.3)	
Moderate	135 (74.6)	46 (25.4)	
High	43 (79.6)	11 (20.4)	
Post-Survey Perceived Risk – Ovarian Cancer			0.832
Low	279 (74.6)	95 (25.4)	
Moderate	103 (74.6)	35 (25.4)	
High	20 (80.0)	5 (20.0)	
Post-Survey Perceived Risk – Colon Cancer			0.536
Low	316 (73.8)	112 (26.2)	
Moderate	148 (75.9)	47 (24.1)	
High	38 (74.9)	9 (19.1)	
Post-Survey Perceived Risk – Prostate Cancer			0.618
Low	20 (74.1)	7 (25.9)	
Moderate	22 (68.8)	10 (31.2)	
High	10 (83.3)	1 (16.7)	
Post-Survey Perceived Risk – Lung Cancer			0.931
Low	347 (75.4)	113 (24.6)	
Moderate	120 (74.1)	42 (25.9)	
High	46 (74.2)	16 (25.8)	

Post-Survey Perceived Risk – Alzheimer's Disease			0.058
Low	352 (75.2)	116 (24.8)	
Moderate	108 (79.4)	28 (20.6)	
High			
Relative Risk - Hypertension			0.137
Much Lower/ Somewhat Lower	142 (78.9)	38 (21.1)	
Same	87 (73.7)	31 (26.3)	
Somewhat Higher/ Much Higher	160 (70.2)	68 (29.8)	
Relative Risk – Cardiovascular disease			0.791
Much Lower/ Somewhat Lower	191 (75.5)	62 (24.5)	
Same	131 (74.9)	44 (25.1)	
Somewhat Higher/ Much Higher	144 (72.7)	54 (27.3)	
Relative Risk – Diabetes			0.261
Much Lower/ Somewhat Lower	183 (74.4)	63 (25.6)	
Same	114 (78.1)	32 (21.9)	
Somewhat Higher/ Much Higher	132 (70.2)	56 (29.8)	
Relative Risk – Breast Cancer			0.239
Much Lower/ Somewhat Lower	329 (73.1)	121 (26.9)	
Same	114 (77.0)	34 (23.0)	
Somewhat Higher/ Much Higher	58 (81.7)	13 (18.3)	
Relative Risk – Ovarian Cancer			0.069
Much Lower/ Somewhat Lower	276 (73.4)	100 (26.6)	
Same	86 (75.4)	28 (24.6)	
Somewhat Higher/ Much Higher	36 (90.0)	4 (10.0)	

Relative Risk – Colon Cancer			0.454
Much Lower/ Somewhat Lower	308 (72.8)	115 (27.2)	
Same	134 (76.6)	41 (23.4)	
Somewhat Higher/ Much Higher	48 (78.7)	13 (21.3)	
Relative Risk – Prostate Cancer			0.301
Much Lower/ Somewhat Lower	31 (67.4)	15 (32.6)	
Same	16 (84.2)	3 (15.8)	
Somewhat Higher/ Much Higher	9 (81.8)	2 (18.2)	
Relative Risk – Lung Cancer			0.703
Much Lower/ Somewhat Lower	333 (74.8)	112 (25.2)	
Same	120 (76.4)	37 (23.6)	
Somewhat Higher/ Much Higher	44 (71.0)	18 (29.0)	
Relative Risk – Alzheimer's Disease			0.592
Much Lower/ Somewhat Lower	318 (74.8)	107 (25.2)	
Same	128 (78.5)	35 (21.5)	
Somewhat Higher/ Much Higher	56 (73.7)	20 (26.3)	

A.2 AIM 2

	Enrolled in Database (% enrolled in category)	Declined Enrollment (% declined in category)	p value
Past Research Participation			1.000
Yes	240 (74.8)	81 (25.2)	
No	342 (74.5)	117 (25.5)	
Scientists Benefit			0.205
Great Deal	482 (76.3)	150 (23.7)	

Moderate Amount	73 (68.9)	33 (31.1)	
A little/Not at all	37 (77.1)	11 (22.9)	
Community Benefits			0.124
Great Deal	362 (77.5)	105 (22.5)	
Moderate Amount	134 (73.2)	49 (26.8)	
A little/Not at all	89 (70.6)	63 (29.4)	
Participant			0.100
Great Deal	376 (78.0)	106 (22.0)	
Moderate Amount	149 (73.4)	54 (26.6)	
A little/Not at all	64 (66.7)	32 (33.3)	
FHH Rating			
Enjoyable	312 (75.9)	99 (24.1)	0.306
Informative	387 (74.4)	133 (25.6)	1.000
Uncomfortable	2 (40.0)	3 (40.0)	
Neutral	15 (68.2)	7 (31.8)	0.466

A.3 AIM 3

	Enrolled into Database (% enrolled in category)	**Declined Enrollment (% declined in category)**	**p value**
Physically Active			0.767
Yes, > 6 months	175 (72.0)	68 (28.0)	
Yes, < 6 months	77 (71.3)	31 (28.7)	
No, plan to in 30 days	162 (75.7)	52 (24.3)	
No, plan to in 6 months / No, don’t plan to	45 (75.0)	15 (25.0)	
BMI	Mean = 33.8	Mean = 32.7	0.185

APPENDIX B

PRE-SURVEY

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

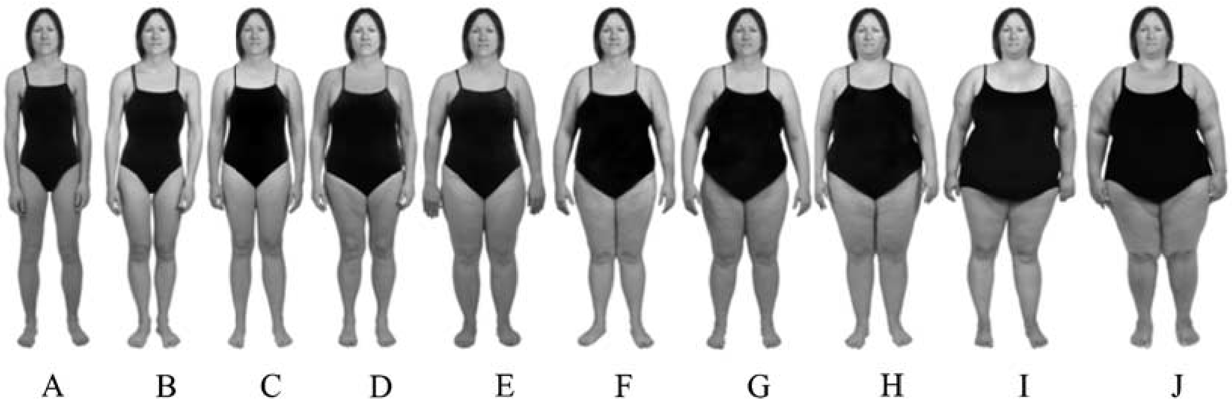
8) Do you smoke?

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

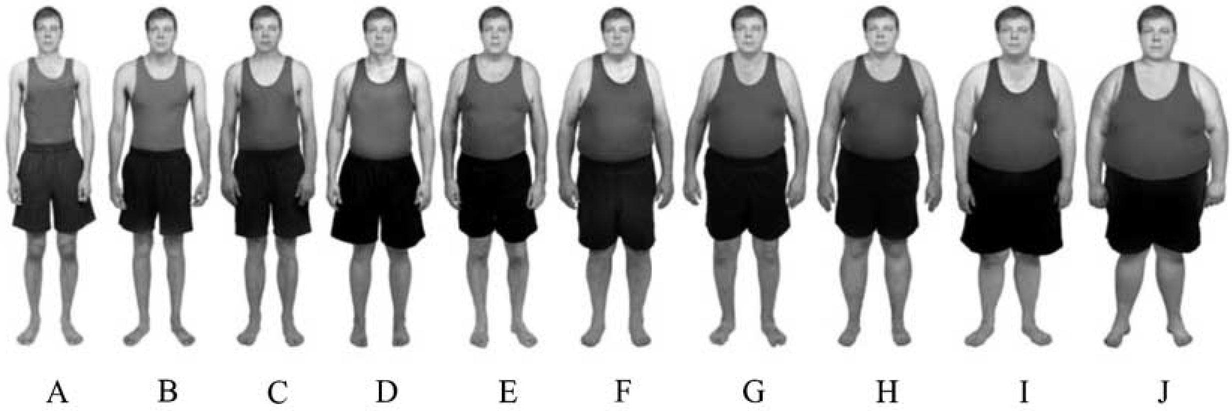
(e) Which bodies look obese? A B C D E F G H I J none

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 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

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.

APPENDIX D

FOLLOW-UP SURVEY

Date: ___________________

Person Making Phone Call: ________________________________

INTERVIEWER: ASK TO SPEAK WITH THE INDIVIDUAL WHO GAVE US HIS OR HER NAME AND TELEPHONE NUMBER. IF YOU ARE TOLD THAT THE PERSON IS NOT HOME, SCHEDULE A CALL-BACK. WHEN YOU ARE SPEAKING WITH THE INDIVIDUAL, READ…

Hi, my name is ___________ and I am calling from the Center for Minority Health at the University of Pittsburgh. About a month ago, you completed a survey and had your family health history (family tree) completed at ______________. As you may recall, you agreed to let us contact you for a follow-up questionnaire. I just have a couple of brief questions to ask you. It should take about five minutes. Is it okay to proceed with the questions?

☐ **Yes** ☐ **No** – end interview

If Yes → Proceed to Question 1

If No → Thank you for your time. Have a great day.

1) After having your family health history drawn out, which statement best describes how you felt? **(Circle all that apply)**

1 - More Informed
2 - More Concerned
3 - Same as before
4 - Confused
5 - Worried

2) Did you tell any one that you had your family health history drawn out?

1 - Yes	If Yes → Proceed to Question 2a and 2b
2 - No	If No → Proceed to Question 3

2a) Who did you tell about your family health history?

2b) What did you tell them?

3) Has anything about your family health history changed since we met?

1 - Yes If Yes → Proceed to Question 3a

2 - No If No → Proceed to Question 4

3a) What has changed about your family health history?

4) Have you contacted any other relatives or researched old records to learn more about your family history?

1 - Yes

2 - No

5) Did you look over the materials/information we sent you with your family health history?

1 - Yes If Yes → Proceed to Question 6a

2 - No If No → Proceed to Question 7

6a) Did you find the materials/information sent to you helpful?

1 - Yes → Proceed to Question 6b

2 - No → Proceed to Question 7

6b) Would you like any additional information?

1 - Yes

2 - No

7) Have you seen a health care professional since you had your family health history done?

1 - Yes	If Yes → Proceed to Question 7a
2 - No	If No → Proceed to Question 8

7a) Did you show your family health history to the health care professional?

1 - Yes

2 - No

8) In regards to the following statement: “Having my family health history drawn out has made me more comfortable in talking my doctor about health concerns,” would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

9) In regards to the following statement: “Having my family health history drawn out has made me more comfortable in talking to my family about health concerns,” would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

10) Do you have any plans to show your family health history to your family in the next six months?

1 - Yes

2 - No

11) Do you plan to show your family health history to a health care professional (i.e., doctor, nurse, pharmacist, physician assistant, or genetic counselor) in the next six months?

1 - Yes

2 - No

12) During our meeting, you answered a question about your physical activity; I am going to read that question to you again to see if your answer has changed.

I am going to read you the 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.

Based on this definition, which of these statements best describes your level of being physically active? **(Select only one response)**

1 - Yes, I have been physically active for more than 6 months

2 - Yes, I have been physically active for less than 6 months

3 - No, I have not been physically active, but I am planning on starting in the next 30 days

4 - No, I have not been physically active, but I am thinking about starting in the next 6 months

5 - No, I have not been physically active and I don’t plan to start in the next 6 months

If Answered 3, 4, or 5 → Proceed to Question 12a

If Answered 1 or 2 → Proceed to Question 12b

12a) Have you increased your physical activity, but not enough to fit the definition?

1 - Yes

2 - No

12b) Did having the family health history drawn out play a role in increasing your physical activity?

1 - Yes

2 - No

13) What kind of physical activity, if any, do you engage in? **(Circle all that apply)**

1 - Walking
2 - Jogging
3 - Aerobics
4 - Bicycling
5 - Housework/yardwork
6 - Swimming
7 - None
8 - Other___________________________

14) Have you made any other lifestyle changes since we did your family health history?
(Circle all that apply)

1 - Improved Diet

2 - Smoking cessation

3 - Talking to doctor about health concerns

4 - Increased health screening (mammogram, colonoscopy, PSA)

5 - Joined a support group

6 - Other_____________

7 - None

If Answered 7 (No changes) → Proceed to Question 14a

If Answered 1 thru 6 → Proceed to Question 15

14a) Do you want to or are you planning on making any changes?

1 - Yes	→ Proceed to Question 14b
2 - No	→ Proceed to Question 15

14b) Are there any barriers that prevent you from making changes?

1 - Yes → Proceed to Question 14c

2 - No → Proceed to Question 15

14c) What are the barriers that prevent you from making changes?
(After response proceed to Question 14d)

14d) Is there anything that would help you make the changes you want?
(ie: classes, support groups)

15) In regards to the following statement: "Having my family health history drawn out motivated me to increase my knowledge about health conditions that run in my family," would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

If Answered 1, 2, or 3 → Proceed to Question 15a

If Answered 4, 5, or 6 → Proceed to Question 16

15a) How have you increased your knowledge/understanding? (talked to doctor, family, friends, internet, library, etc.) (After response proceed to Question 15b)

15b) Which of the following statements most closely resembles your information seeking behavior: **(Select only one response)**

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.

16) In regards to the following statement: "How frequently do you research or look for information about health conditions that concern you," would you say that you look very frequently, frequently, occasionally, rarely, very rarely, or never? **(Select only one response)**

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.

APPENDIX E

MHLC SCORING DIRECTIONS

SCORING INSTRUCTIONS FOR THE MHLC SCALES

Subscale	**Form**	**Possible Range**	**Items**
Internal	A, B, C	6-36	1,6,8,12,13,17
Chance	A, B, C	6-36	2,4,9,11,15,16
Powerful Others	A, C	6-36	3,5,7,10,14,18

APPENDIX F

IRB APPROVAL LETTERS

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Dr. Stephen Thomas
From: Sue Beers PhD, Vice Chair
Date: 2/10/2009
IRB#: IRB0403125
Subject: THE HEALTHY BLACK FAMILY PROJECT: Assessing the Response of African Americans to Family Health Histories

---

Your research study has received expedited review and approval from the University of Pittsburgh Institutional Review Board under:
45 CFR 46.110.(7)

Please note the following information:

Approval Date: 2/9/2009
Expiration Date: 2/19/2010

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

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).

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

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Dr. Stephen Thomas
From: Sue Beers PhD, Vice Chair
Date: 2/13/2009
IRB#: IRB #0411088:
Subject: HEALTHY BLACK FAMILY PROJECT: Minority Research Recruitment Database

---

Your research study has received expedited review and approval from the University of Pittsburgh Institutional Review Board under:
45 CFR 46.110 (7).

Please note the following information:

Approval Date: 2/12/2009
Expiration Date: 2/25/2010

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

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).

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

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