**PATIENT BARRIERS TO INITIAL GENETIC RISK ASSESSMENT AND FOLLOW UP**

by

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Dyanna Person, MPH

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**ABSTRACT**

Breast cancer is a major public health concern. Before the recent increase in knowledge regarding breast cancer genetics and the development of BRCA testing, evaluating an individual’s risk of developing breast cancer was tedious. Women who test positive for known pathogenic BRCA mutations have a 40-66% lifetime risk of developing Breast Cancer. Identifying individuals at risk for the disease is beneficial for treating and for preventing the development of breast cancer. Doing so will lessen disease burden, decrease the resources used to treat the disease and increase quality of life for those with the mutations due to the availability of early interventions to those who screen positive. Genetic health care and interventions are becoming more accessible and accepted. Unfortunately, breast cancer risk assessment is still underutilized despite its ability to decrease mortality rates and increase quality of life when used appropriately. African American women are greatly affected by this as mortality rates are higher than Caucasians despite having lower breast cancer incidence rates. Our project was designed to identify patient barriers to breast cancer genetic risk assessment and follow up. We conducted a cross-sectional survey which was implemented in a predominately African American health clinic. We investigated differences in perceptions ad barrier due to religion, medical mistrust, education and stigma by race. Results suggested that African American patients were more likely to see religion as a barrier in unadjusted analysis with a p value of .027. Once we adjusted for age income and education it was no longer significant. After adjustment, we also found that Medical Mistrust was a significant barrier for African American patients. More work is needed to understand reasons for these barriers and solutions for combating them.

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# preface

I would first like to thank my research mentor Dr. Mylynda Massart for taking me on as a researcher and giving me room to develop and learn. She allowed this project to be my own work but always offered the support I needed. I would like to thank my advisor Dr. Kammerer of the Department of Human Genetics and the University of Pittsburgh School of Public Health for her patience and encouragement. I would also like to acknowledge Dr. Tiffany Gary-Webb of the Department of Behavioral and Community Health Sciences as the second reader of this paper. I am grateful for all her insight and direction. I would also like to thank The Beckwith Institute for providing the funding needed to execute this project.

# Introduction

In the U.S , breast cancer affects over 1 million women annually and of those women, almost 200,000 of them die of the disease (Siegel, Miller, & Jemal, 2016). Breast cancer is a major public health concern. Before the recently increased knowledge regarding breast cancer genetics and the development of BRCA testing, evaluating an individual’s risk of developing breast cancer was difficult. Based on studies in the U.S women who test positive for known pathogenic BRCA mutations have a 40-66% lifetime risk of developing Breast Cancer (Sussner 1ã et al., 2009). Researchers have found that identifying individuals at risk for the disease is beneficial for treating and for preventing the development of breast cancer. Preventing breast cancer is more cost effective than treating cancer once it develops. Prevention of the disease also decreases mortality and morbidity caused by the disease progression. When women at risk for breast cancer are identified before the disease begins to manifest, they are able to take advantage of many risk reduction strategies, including ovarian suppression, increased surveillance, or prophylactic surgery, which reduces their risk of breast cancer by 85% to 100% (Kaplan et al., 2014). Thus, one of the first steps in eradicating cancer is identifying genetically at-risk women and preventing the development of the disease.

Unfortunately identifying those at risk is difficult. Although risk assessment tools and strategies exist, they are not commonly used in primary care or practice. Few patients who qualify for risk assessment receive it, which makes identifying at-risk patients nearly impossible. Numerous studies have been done to identify barriers that prevent patients from obtaining genetic services from their healthcare provider. For example “a randomized controlled trial of a multiethnic, multilingual sample of women ages 40 to 74 years from two primary care practices (one academic, one safety net) to test a breast cancer risk assessment and education intervention”. (Kaplan et al., 2014) has shown that barriers range from lack of knowledge of genetic risk assessment to underutilization of the tools available (Trepanier, Supplee, Blakely, McLosky, & Duquette, 2016). Patients have difficulty accessing genetic services given provider-specific barriers; the addition of patient-specific barriers makes access to care almost insurmountable. They are more likely to be unidentified as at-risk compared to Caucasian women (Allford, Qureshi, Barwell, Lewis, & Kai, 2013). George and his colleagues performed a retrospective cohort study with 634 African American and Caucasian women diagnosed with invasive breast cancer in New Jersey between 2005 and 2010. Compared to white women, African-American women experienced a significantly higher risk of 2 months or longer delays in diagnosis and surgical treatment (adjusted relative risks=1.44 (1.12–1.86) and 3.08 (1.88– 5.04), respectively)(George et al., 2015).. A review article by Siegel and colleges and a review of health data by Roseland and collages showed that black women were less likely than white women to survive their breast cancer despite uniform treatment, even after controlling for stage of disease, tumor characteristics, follow-up, and socioeconomic status (Roseland et al., 2015; Siegel et al., 2016).

If researchers can identify patient barriers, interventions can be developed to combat them. Currently Matilda Theiss Health Center is implementing a quality improvement project examining possible patient barriers to genetic services with a patient population in Pittsburgh Pa. Our goal is to collect information that will enable us to provide better care, educate and identify our at-risk patients, and, if successful, encourage other health centers to initiate a similar protocol for their patient population.

Breast cancer is the leading cause of cancer death in women aged 20 to 59 years(Siegel et al., 2016). From 2010-2012 1 in 8 women develop breast cancer (Colditz, Chief, & Craig, 2015). In other words, 1 in 8 women will need to consider treatment options, especially the financial and emotional burden of cancer treatment and intervention. Furthermore, these women of childbearing age, will need to consider how life-saving treatment will affect their reproductive future, as one of the preventative measures for breast cancer include prophylactic oophorectomy (Jagsi et al., 2015). With a cost ranging from of $20,000-$100,000 per person, breast cancer is an expensive disease (Campbell & Ramsey, 2009). Given the high incidence of breast cancer, as well as the financial, reproductive, and quality of life consequences, breast cancer is a major public health concern.

## breast cancer Epidemiology

Cancer is one of the top 10 leading causes of death worldwide. Furthermore, the burden is expected to grow worldwide due to the increase in the numbers of older individuals (Torre et al., n.d.) Globally, in 2012, 1,676,600 women were diagnosed with breast cancer and 521,900 women died from the disease. In developed countries experts reported 793,700 new cases of breast cancer and 197,600 deaths. In developing countries, there were 882,900 new breast cancer cases reported and 324, 300 deaths (Torre et al., n.d.). Researches have estimated that in 2016 there will be 246,660 new cases of breast cancer that will account for 29% of total cancer cases. In Pennsylvania, almost 2000 women are estimated to die from breast cancer in 2016 (Siegel et al., 2016). Many of these women likely underwent expensive radiation, drug and chemotherapy for cancer. Providing women with the opportunity to practice preventative measures for breast cancer would save money, and also save lives. Researchers have also reported that this burden of disease does not affect all populations equally. Based on data collected by the National Cancer Institute, National Cancer Institute’s (NCI’s), Surveillance, Epidemiology, and End Results (SEER), and Centers for Disease Control and Prevention’s National Program of Cancer Registries (NPCR), from 2008-2012, the breast cancer incidence rate non-Hispanic white women were 128.1 individuals per 100,000 per year, whereas the incidence rate in African American women was 124.3 individuals per 100,000 per year. Although the incidence rates were similar, the mortality rates differed: mortality in non-Hispanic white women was 21.9 per 100,000 from 2008 – 2012, whereas mortality in black women was 31.0 per 100,000 from 2008 - 2012. Therefore, fewer African American women were diagnosed with breast cancer, but more died from the disease (Siegel et al., 2016).

## Genetics, Environment, and Epigenetics

### Heritability and Genetics

The importance of genetics when it comes to breast cancer, 10% of women with breast cancer have a family history of the disease. Based on reviews done by Skol and colleagues, women with one premenopausal first-degree relative with breast cancer have a 3.3-fold greater risk, and women with two first-degree relatives with breast cancer are at 3.6-fold greater risk compared to women without a family history of the disease(Skol, Sasaki, & Onel, 2016). The first genes linked to risk of breast cancer were *BRCA1* and *BRCA2*. Mutations in these genes are inherited in an autosomal dominant fashion, but at the mechanism of action at the cellular level is to disrupt

tumor suppressor genes, limiting their functionality. Women with BRCA mutations have a lifetime risk of breast cancer of 50%– 85%(Shiovitz & Korde, 2015). High-penetrance mutations in BRCA1 and BRCA2 account for 5% of all breast cancer cases and up to 25 % of familial breast cancer cases (Skol et al., 2016), however, variants in many genes may increase risk of of developing breast cancer. Five of the highly penetrant genes include *PTEN*, *TP53*, *CDH1I,* and *STK11*. These genes are associated with syndromes that put women at higher risk of breast cancer than women without these mutations. The *PTEN* gene is associated with PTEN Haratoma Tumor Syndrome / Cowden Syndrome and individuals with this mutation have an 85% lifetime risk of developing breast cancer.

Individuals diagnosed with Li-Fraumeni Syndrom have a 25% increased chanced of developing breast cancer before age 75 compared to women without this mutation. Li-Fraumeni Syndrome is a genetic disease which increases one's risk of developing certain cancers. The *CHDI* gene is associated with Hereditary Diffuse Gastric Cancer and these women are 39% more likely to develop lobular breast cancer than women without this mutation.(Shiovitz & Korde, 2015). Skol and colleagues conducted a reviews and found that GWAS has helped us identify over 80 genes that contribute to breast cancer risk. Many of these variants were similar across different populations, supporting the hypothesis that variants contributing to sporadic breast cancer were likely to be similar across populations of different ancestries. Over 10% of the global population are thought to have one of these variants (Skol et al., 2016).

Because variants in the BRCA1 and 2 genes account for 12%-31%(Scalia-Wilbur, Colins, Penson, & Dizon, 2016) of the total risk of developing breast cancer, researchers have identified other genes that play a role in breast cancer development and outcomes. For example, individuals who have mutations in the TP53 gene (Tumor Protein 53), inherit a familial predisposition to several different cancers including breast cancer. Risk alleles at this locus show an autosomal dominant inheritance pattern and women with this mutation are estimated to have a 49% chance of developing breast cancer. This mutation in the TP53 gene has also been seen in women who develop breast cancer before age 30, which is 20 years before recommended breast cancer screening for the average population (Lee, Malak, Klimberg, Henry-Tillman, & Kadlubar, 2016; Scalia-Wilbur et al., 2016).

Several Mutations in the serine-threonine kinase STK11 result in Peutz-Jeghers syndrome which is associated with the development of hamartomas (a benign growth that resembles a cancerous tumor) around the body and multiple malignancies, including those of the uterus, breast, and ovary. These patients also have a 15-fold increased risk of developing breast cancer compared to the general of people without this disease (Caminsky et al., 2016; El-Amraoui & Petit, 2005; Scalia-Wilbur et al., 2016). Another breast cancer risk locus is the PTEN tumor suppressor gene. Many mutations in this locus result in Cowden Syndrome and are inherited in an autosomal dominant fashion. Individuals with this mutation have a lifetime risk of breast cancer of over 85% (Scalia-Wilbur et al., 2016). Variants in several other genes such as CHEK2, PALB2, and ATM have been shown to moderate familial penetrance, when it comes to breast cancer(Scalia-Wilbur et al., 2016).

Variants in CHEK2, have recently been associated with a 3- to 5-fold increase of breast cancer. Researchers conducted a large meta- analysis of 26,000 cases compared to 26,000 controls and found that the aggregated odds ratio of breast cancer in general, early-onset breast cancer, and familial breast cancer was 2.7, 2.6, and 4.8, respectively. The corresponding cumulative risk of breast cancer by 70 years among those heterozygous for the CHEK2 mutation 1100delC was 37%. In another study, 718 families with a family history of breast cancer were negative for the BRCA mutations were evaluated and 5% of them were found to have the CHEK2 mutation. 13.5% of these families also had cases of male breast cancers(Scalia-Wilbur et al., 2016).

Germline PALB2 mutations appear to increase the risk of early-onset breast cancer, although further research is necessary to confirm this. The risk of breast cancer was evaluated by Antoniou et al, who studied 362 members of 154 families who were less than 40, 40-60, and more than 60 years with a PALB2 mutation. In their study, women with a PALB2 mutation who were less than 40 years, 40-60 years, and more than 60 years old had an increased risk of breast cancer ranging from 8-9, 6-8, and 5-fold higher, respectively (Scalia-Wilbur et al., 2016). Studies have shown that those heterozygous for the ATM gene mutation have an elevated risk of breast cancer. In a study by Renwick et al, 443 individuals from hereditary breast cancer families were screened for an ATM mutation along with 521 normal patients who served as controls. A total of 12 variants were identified among the cases, only two of these variants appeared in controls. These data indicated that the risk of breast cancer associated with an ATM mutation was approximately 2.37 (95% CI: 1.51-3.78) (Scalia-Wilbur et al., 2016).

A recent review of the literature has identified additional loci, including BRIP1, NBN, RAD51, BARD1, MRE11A, MUTYH, NF1, and RAD50, that have may be associated with breast cancer. Researchers have identified these genes as moderately penetrant but do not know the role they play in breast cancer risk or development. More research still needs to be done to determine the roles that these genes play (Scalia-Wilbur et al., 2016).-

### Environmental Factors

Several environmental factors are also known to increase the risk of developing breast cancer. Some of these environmental factors include exposure to certain chemicals, dietary choices and radiation exposure (Cauchi, Camilleri, & Scerri, 2016; George et al., 2015; White, Bradshaw, et al., 2016). PAH (polycyclic aromatic hydrocarbons which are found in tobacco smoke, certain grilled food, and pollution) sources were associated with hypo- and hypermethylation at multiple promoter regions in breast tumors. Researchers used a population-based case-control study and measured promoter methylation of 13 breast cancer-related genes in breast tumor tissue. Study participants included 1508 breast cancer cases and 1,556 controls who were English-speaking women residing in Nassau and Suffolk counties on Long Island, New York. Five PAH exposure sources were assessed (White, Chen, et al., 2016) Current active smoking, residential ETS, grilled/smoked meat intake, and synthetic log burning were assessed by a trained interviewer using a structured questionnaire, and vehicular traffic exposure was assessed by a validated historical geographic model. In this study, White and colleagues identified biologically plausible associations with aberrant DNA methylation in the tumor tissue. DNA methylation represents a potential biologic mechanism for environmental chemicals, such as PAH, to influence breast cancer risk.(White, Chen, et al., 2016). DNA methylation plays an important role in breast carcinogenesis and is a major mechanism of epigenetics. Epigenetics is the change in DNA expression without actual changes in the actual genetic code. These changes involve methylation and modification of histones (Weinhold, 2006). Increased methylation at the promoter regions of specific genes may silence tumor suppressor genes, that is, making them inactive, thus increasing the chance of tumor development.

### Epigenetic Factors

As described above, in addition to environmental and single gene effects on breast cancer susceptibility, other genetic factors have recently been reported to influence breast cancer etiology. Researchers have reported links between breast cancer and epigenetics (Cauchi et al., 2016). In general, epigenetic modifications are controlled by several different molecular events including histone modifications, polycomb/trithorax protein complexes, and methylation influence epigenetic regulation. These modifications change the expression of the genes present in the DNA. Epigenetics is critical during development and normal growth because it regulates genes needed for development. Epigenetic modifications also respond to changes in the environment and consequently change phenotype(Jovanovic, Rønneberg, Tost, & Kristensen, 2010; Weinhold, 2006). Epigenetic processes are required for differentiation of specific organs during development (Kiefer, Ph, Buckley, & Ph, 2007). These epigenetic mechanisms also have the ability to turn genes on and off, including genes that are protective against the development of cancer (Jovanovic et al., 2010). The initiation of epigenetic changes can be caused by environmental factors such as diet, exposure to chemicals and biological changes in the body(Jovanovic et al., 2010; Weinhold, 2006).

## family history and testing

### Family History and Testing

BRCA testing has become commonplace for all individuals with a family history of breast cancer (Biswas et al., 2016; Harbeck & Gnant, 2016; Myers et al., 2015). Before BRCA testing is offered, patients are screened based on their family history. During patient appointments, the current standard of care states that clinicians ask questions about family history, cancer, and other diseases. However, many physicians do not feel comfortable asking in-depth questions concerning a patient’s family history and genetic risk. Also, some clinicians are so busy that they do not have time to spend asking these questions (Trepanier et al., 2016). Patients who have first or second-degree relatives who have been diagnosed with breast cancer are at increased risk of developing the disease themselves. First degree relatives are individuals separated by one generation from the proband, such as parents, siblings and children, and second-degree relative are those separated by two generations from the proband, such as grandparents, aunts and uncles. After the patient denotes that they have cancer in their family, providers are supposed to enquire about family members diagnosed with cancer, as well as, their cancer type and their age at diagnosis. Clinicians who are comfortable with these concepts will often draw a pedigree to check for an autosomal dominant inheritance pattern that indicates patients may harbor a risk-alleles for BRCA1 or BRCA2 (Moyer, Services, & Force, 2014; Scalia-Wilbur et al., 2016). If clinicians prefer not to draw the patient’s pedigree themselves, they also have the option of offering Genetic Cancer Risk Screening tools to their patients (Moyer et al., 2014).The United States Task Force has determined that all tools are equally beneficial, so it is up to the discretion of the clinician which test they will use (Moyer et al., 2014).

# Health DIsparities

### Disparities

Over the past 30 years, many measures of health disparities (such as breast cancer incidence) between African American women and U.S. Caucasian women have decreased, however, breast cancer mortality/survivorship disparity has increased. According to the National Cancer Institute , African-American women have a 40% higher breast cancer mortality rate when compared to Caucasian women, despite their lower incidence rate of breast cancer (McCarthy, Yang, & Armstrong, 2015). Although these disparities may result from differences in the type of breast cancer or course of disease for each population, other factors such as access to care and interventions may have a greater effect (McCarthy et al., 2015). One factor that contributes to this disparity is a delay in care for patients.

To investigate why African American women, delay breast cancer care, Nonzee and colleagues performed a study with 138 participants in health care centers in Chicago. They explored reasons why predominantly low-income and minority women adhered to or delayed breast or cervical cancer screening, follow-up, and treatment despite access to cancer care-related services. They used semi-constructed qualitative interviews based on the Social-Ecological Model (Kumar et al., 2012), and The Theory of Reasoned Action(Trafimow, 2009). Results of their study revealed that despite access to breast and cervical cancer screening and diagnostic services, low-income women faced barriers driven by gaps in resource knowledge, perceptions of cancer, embarrassment, and prioritization of competing obligations (Nonzee et al., 2015).

Stigma and attitudes about health are a concern for the African American community when regarding breast cancer. Variation in culture and beliefs are a potential barrier in this community. Sussner and colleagues found that African American patients may experience stigma from a cancer diagnosis or from the idea that they and their family could be at risk for cancer (Sussner et al., 2011). African Americans also have fatalistic views about a cancer diagnosis and believe a cancer diagnosis is a death sentence (Allford et al., 2013). Multiple studies including women of African descent have reported that patients are concerned with how they will be perceived or treated after testing results are found (Sussner et al., 2011; Thompson et al., 2012). African American women are also concerned about how the information will be used and fear that it will negatively affect them and their family (Sussner et al., 2011).

As described previously, African Americans have lower breast cancer survival rates than Caucasian women (Coughlin, Yoo, Whitehead, & Smith, 2015; Roseland et al., 2015), but data on why African Americans and other minorities are less likely to undergo initial breast cancer screening is limited. Although provider-specific barriers to care have been identified, knowledge is lacking as to why patients would refuse, ignore, or feel no need for these services. In addition to patient-specific barriers, cultural reasons may also explain the reduced use of these services by African Americans. Studies to investigate some of these gaps in knowledge and develop strategies to help clinicians better care for this population are needed.

### Risk Assessment

In the era of personalized medicine, health care providers have improved methods by which to estimate a woman’s risk of breast cancer and provide appropriate and effective screening and prevention options (Lewis, 2014). This risk assessment is important for the identification and management of those patients at higher risk for the development of breast cancer, as well as to risk stratify patients who have average population risks, thus alleviating potential anxiety and unnecessary costly interventions.

Patient-centered decision tools are evidence-based to help patients and providers work together to understand the patient’s personal risk, and then develop patient-specific management plans. The tools used to accomplish this goal include: first, facilitating risk stratification; second, providing the appropriate background information and available options for management; and third, use this information to allow a patient to make informed, values-based medical decisions with their provider (Collins et al., 2014).

Currently, patients who are identified as being at-risk have several evidence-based interventions available to them including risk-reducing bilateral mastectomy, premenopausal bilateral salpingo-oophorectomy, and multiple medications including tamoxifen, raloxifene or anastrozole (Collins et al., 2014). Additional lifestyle modifications are highly recommended including weight loss and reduced alcohol consumption. Enhanced screening with earlier mammograms and breast MRI would also increase the likelihood of early detection and more effective treatment. Surgery can reduce the risk of breast cancer by 85-100% with mastectomy and 37-100% with oophorectomy (Moyer et al., 2014), resulting in significant reduction in morbidity and mortality as well as health costs associated with the care of these malignancies. Finally, the integration of risk assessment through the enhancement of electronic health care records will enable increased access to personal health information for the patient and the opportunity for a point of care intervention for the provider.

Patients who inherit known cancer-causing mutations are at significantly higher risk than the average population for the development of cancer, the development of cancer at an earlier age of onset, and increased cancer mortality (Myers et al., 2015). An individual with a mutation in BRCA1 or BRCA2 has a 45-65% risk of breast cancer and a 10-39% risk of ovarian cancer by age 70 compared to 12.3% for breast cancer and 1.4% for ovarian cancer amongst the general population (Moyer, 2013). Current estimates are that 1 in 300-500 women carry one of these mutations amongst the general population (Moyer, 2013). The combined prevalence of the BRCA mutations is 2.1% amongst Ashkenazi Jewish women (Nelson et al., 2013). These hereditary cancers are estimated to account for 5-10% of cancers. Per the National Comprehensive Cancer Network (NCCN), unaffected at-risk patients will require cancer screening at a much earlier age and may require more frequent and different screening tests than average risk patients. Despite the importance of GCRA in improving survival and quality of life and the level B recommendation by the USPSTF, genetic risk assessment is still underutilized in primary care (Collins et al., 2014)). Additionally, there are still sizable ethnic disparities in the use of genetic testing and counseling and very few studies that assess risk and the perception of risk in unaffected African Americans (Allford et al., 2013)

# **GENETIC RISK ASSESSMENT AND FOLLOW-UP**

To address many of the above concerns, my colleagues and I at the Matilda Theiss Health Care Center developed a questionnaire exploring patient barriers to genetic risk assessment and follow-up genetic services. Our quality improvement project has several purposes. Our main objective is to gain an understanding of current patient-specific barriers to genetic cancer risk assessment and follow-up services. Our long-term goal is that results from our project will enable us to identify strategies to diminish the health disparities regarding breast cancer in the African-American community. We wanted to develop a questionnaire that could be a model for other primary care providers who want to explore patient barriers to care in their own clinic or patient care environment. We recognize that answering the questions in the developed questionnaire can give care providers a more holistic view of the patient and the current health disparities. This holistic view should allow providers to provide care that is appropriate, culturally sensitive, culturally competent and well received by the community. Furthermore, this quality improvement project will enable us to identify individuals at greater risk before they develop cancer and while they still have the option of using highly effective preventative measures. We wanted to give these patients more opportunity for risk assessment, agency, and, subsequently increased quality of life. We also wanted to make these patients more comfortable having these conversations about health in their community and among their family members, especially family members with whom they share genetic health history.

The overall intervention used a multi-survey approach. We developed 3 surveys to be distributed at different points during the patient’s care and risk assessment process. This paper will focus on the results of the initial survey. The main research question is “what perceptions and barriers do African Americans who come in for annual new patient appointment, physicals or annual gynecological exams have towards initial genetic risk assessment?” The survey questions were organized by themes including family and /or community stigma, medical mistrust, religion, and education about genetics. We used a Likert scale and assigned a score to each survey response.

Table 1. Survey Response

|  |  |
| --- | --- |
| Response | Score |
| Strongly disagree | 1 |
| Disagree | 2 |
| Neither agree nor disagree | 3 |
| Agree | 4 |
| Strongly agree | 5 |

Our null hypotheses were:

1. There is no difference between the percentage of African Americans who agree with questions categorizing Religion as a barrier to genetic services and the percentage of Caucasians who do

2. There is no difference between the percentage of African Americans who agree with questions categorizing Education as a barrier to genetic services and the percentage of Caucasians who do

3. There is no difference between the percentage of African Americans who agree with questions categorizing Stigma as a barrier to genetic services and the percentage of Caucasians who do

4. There is no difference between the percentage of African Americans who agree with questions categorizing Medical Mistrust as a barrier to genetic services and the percentage of Caucasians who do

We used a cross-sectional design for our survey. We asked a combination of demographic and Likert (scaled answers ranging from strongly disagree to strongly agree) scale questions about medical mistrust, religion, stigma, and education regarding genetic cancer risk assessment because we thought it was the most appropriate way to measure the variables of interest. We knew that the answers to the questions were ordinal in nature and that using a Likert scale format would be the easiest way for the patients to answer. We decided to use Likert scale questions instead of open-ended questions for several reasons. First, we thought the survey burden would be too high if we used open-ended questions. We posited that many patients would not be willing to answer questions of this type because the survey was being given in a clinic and patients were not receiving an incentive for completing it. Patients may not have enough time to answer the questions for an open-ended survey while waiting to see the doctor, and thus we would likely receive many incomplete surveys. Open-ended questions are more appropriate for a one-on-one interview process or focus-groups to provide insights regarding the concerns of the population of interest. Results from these focus group studies will facilitate the development of a questionnaire for a larger survey. Likert items are easy for the patients to use to describe their feelings, efficient in terms of completing the survey, and relatively simple analyze. We also thought that the Likert scales would be a better fit for our population’s needs for several reasons. First, our patient population included a substantial number of patients who lack computer literacy. These patients may not know how to type or write out detailed explanations on the computer, or they may be able to complete the task but would need much more time to do so. Using Likert scale questions allowed the patients to answer quickly and honestly regardless of their computer literacy. Thus, we obtained a complete representation of our population because we did not lose people due to lack of computer literacy.

Our study population comprised adults who used the Matilda Theiss Health Center for annual physicals, new patients and annual women’s health exams. Our total patient population is estimated to be 1000 patients, but may be smaller given that some patients may be lost to follow-up and it is unlikely that we will recruit new patients. Our goal was to survey 370 participants by the end of summer of 2017.

We used Qualtrics (Oppenheimer A, Panucci CJ, Kasten S, 2012) to develop the survey tool. Developing our survey tool took several months as we were learning how to develop the survey and to use Qualtrics. Our survey was self-administered and given in clinic while patients waited to be seen for their annual or women’s health exam. The patients completed the surveys in the exam rooms and could do so in privacy if they chose to. They used the exam room computers or the tablets in the clinic to complete the survey.

As part of this quality improvement project, we will confirm the percentage of primary care patients who meet criteria for high-risk cancer syndromes based on family health history and focus on assessing the patient perceived barriers to this process. We will identify patients who are at risk for specific hereditary cancer syndromes by taking family cancer histories. Once an at-risk patient is identified, additional counseling sessions will be provided to educate the patient about their risk status and about important health risk reduction strategies that apply to them. Upon conclusion of the first survey and counseling, we will then assess the same patients regarding barriers and perceptions that they encountered or developed regarding their risk assessment or the subsequently advised risk reduction recommendations. The target patient population will comprise all patients 18 or older who present for annual wellness and women’s health exams at Matilda Theiss Health Clinic.

### Intervention in practice

The first step in the quality improvement project was the development of three surveys using Qualtrics software. We used a five-point Likert scale as the model for our questionnaire. Each survey represented a different step in the risk assessment process. Survey One asked questions regarding patient’s attitudes about initial genetic cancer risk assessment. The second survey focused on perceptions and barriers leading to opt out or failure to follow up. The third survey focused on barriers and perceptions of genetic counseling and shared decision making. Patients received the surveys after being checked in for appointments. Each survey has an informed consent section with the option to discontinue at any time. Given the design of the project, all patients will not receive all three surveys. Patients receive survey one right after completing the genetic cancer risk assessment. Patients receive Survey Two if at any time they decide to opt out the genetic services, if they do not want to be tracked, or if they do not follow up with the initial genetic risk assessment appointment. Survey three is given after patients receive genetic counseling and recommendations for testing or additional genetic services. Patients may opt out of the surveys without opting out of the genetic services. We are still trying to figure out how to identify reasons patients might do this, because if a patient declines the survey it may be difficult to obtain this information.

The first survey is the initial risk assessment survey. This survey was self-administered and given after patients completed a Genetic Cancer Risk Assessment Tool. Patients completed the survey in the patient exams rooms in private, prior to seeing the doctor. In the clinic, we used the Family Referral tool to complete the risk assessment stage because the United States Task Force identified all tools as being equal in usability and quality. The Genetic Cancer Risk Assessment Tool was administered by staff at Matilda Theiss Health Center who received training on how to complete the assessment with patients. Once the risk assessment tool was completed, it was marked as positive or negative and scanned into the patient’s electronic health record. Patients who screened positive have been contacted and will complete step 2 of the process in early 2017. These patients will complete step two by coming for a genetic counseling follow-up appointment. If they do not show up to the appointment or they decline this type of appointment, they will be given the opt out survey. Patients who complete Survey One and return for follow-up and genetic counseling will receive Survey Three which focuses on genetic counseling and shared decision making.

In addition to demographic information including race, sex, age education, living arrangements and income, the limited amount of literature on the topic of patient-specific barriers indicated that the following categories were also likely causes of patient-specific barriers: medical mistrust, religious beliefs, cultural beliefs, and knowledge of medical services ((Allford et al., 2013; Jagsi et al., 2015; Lewis, 2014; Sheppard, Mays, LaVeist, & Tercyak, 2013). Therefore, our questionnaires included questions on all of the above categories; furthermore the specific questions were developed based on information about similar questions used to measure the above categories (such as medical mistrust) in other studies (Buseh, Kelber, Millon-Underwood, Stevens, & Townsend, 2014a; Opez-Cevallos, Harvey, Warren, & Opez-Cevallos, n.d.; Sheppard, Mays, Laveist, & Tercyak, n.d.).

### Challenges

We faced many challenges while administering the survey. One major challenge we had was provider buy-in. One clinician was very supportive of the quality improvement project and had no problem administering it to their patients. Matilda Theiss is a very busy clinic, and some providers felt the surveys were a waste of time and took time they could be spending with their patients. This attitude was unexpected because the clinicians initially agreed to participate in the project before it was launched. Several challenges arose from the nursing staff and graduate student who were administering the questionnaires. Some staff forgot to administer the questionnaires and some did not understand who the questionnaires were supposed to be given to. Therefore, data collection was inconsistent. One result of these problems was that many of patients taking the survey were patients who had the same doctor. Thus, the study results may be biased because people who chose the same care provider may be more similar than people who chose a different doctor. We also had some people refuse the genetic risk assessment tool as well as the survey regarding their feelings about the tools. Unfortunately, these individuals are the ones from whom we need information.

# RESULTS

To date 94 patients have completed initial risk assessment. Of these patients, 77 of them have completed our initial survey and we had a response rate of 81.91%. Among the patients that completed the initial risk assessment, 31.91% (30/94) screened positive and would be considered for additional follow-up and genetic services. We are still in the process of following up with these patients and bringing them back for additional counseling and services.

The patients surveyed were women and men ages 18 and older. Most of our patients were African American (71.83%), between 26-35 years of age (34.78%) with some college education (27.54%) and an annual household income of under $25,000 (37.31%). The initial results of our first survey regarding patient attitudes on genetic risk assessment among these individuals are presented in Table 1.

Table 2. Mean Responses of the First Survey: Patient Attitudes on Genetic Risk Assessment

|  |  |  |
| --- | --- | --- |
| Measured Concept | # of questions | Response average |
| Religion and views on genetics/genetic services | 3 | Strongly disagree: 42.22%  Somewhat disagree: 11.11%  Neither agree nor disagree: 28.33%  Somewhat agree: 10.00%  Strongly agree: 8.33% |
| Education about genetics/genetic services | 9 | Strongly disagree: 16.38%  Somewhat disagree: 16.94%  Neither agree nor disagree: 22.78%  Somewhat agree: 30.56%  Strongly agree: 11.67% |
| Family/Community Stigma | 3 | Strongly disagree: 42.22%  Somewhat disagree: 10.00%  Neither agree nor disagree: 36.11%  Somewhat agree: 9.44%  Strongly agree: 3.89% |
| Medical Mistrust | 8 | Strongly disagree: 14.33%  Somewhat disagree: 16.99%  Neither agree nor disagree: 29.83%  Somewhat agree: 25.83%  Strongly agree: 13% |

Table 3. Results of the First Survey: African American Patient's Attitudes on Genetic Risk Assessment

|  |  |
| --- | --- |
| Measured Concept | Mean responses |
| Education | Strongly agree or agree mean 37.93%  Neither agree nor disagree 25.03%  Strongly disagree or disagree 37.05% |
| Religion | Strongly agree or agree mean 19.28%  Neither agree nor disagree mean 34.96%  Strongly disagree or disagree mean 45.75% |
| Stigma | Strongly agree or agree mean 12.32%  Neither agree nor disagree mean 36.46%  Strongly disagree or disagree 36.46% |
| Medical Mistrust | Strongly agree or agree mean 41.42%  Neither agree nor disagree mean 34.24%  Strongly disagree or disagree mean 24.33% |

Table 4. Results of the First Survey: Caucasian Patient Attitudes on Genetic Risk Assessment

|  |  |
| --- | --- |
| Measured Concept | Mean responses |
| Education | Strongly agree or agree mean 37.14%  Neither agree nor disagree 21.64%  Strongly disagree or disagree 47.22% |
| Religion | Strongly agree or agree mean 15.79%  Neither agree nor disagree mean 7.02%  Strongly disagree or disagree mean 77.19% |
| Stigma | Strongly agree or agree mean 8.77%%  Neither agree nor disagree mean 19.30%  Strongly disagree or disagree 71.93% |
| Medical Mistrust | Strongly agree or agree mean 40.81%  Neither agree nor disagree mean 16.93%  Strongly disagree or disagree mean 42.26% |

Figure 1. Gender of Patients who Participated in Initial Survey

Figure 2. Race of Patients who Participated in Initial Survey

The percentage of African American versus Caucasian patients who selected Education as a barrier were similar, 37.93% versus 37.14%, respectively . With Religion as a barrier 19.28% of African Americans selected Agreed or Strongly Agreed, while only 15.79% of Caucasian patients did. For the category of Stigma as a possible barrier, 12.32% of African Americans selected Agreed or Strongly Agreed, while only 8.77% of Caucasian patients did. Both African Americans and Caucasians selected Agreed or Strongly Agreed that Medical Mistrust was a barrier, 41.42% versus 40.81%, respectively. Although the difference between the values for each group is small, percentages for African Americans are higher.

Though these results may not seem significant we must consider the big picture. Each possible question response was given a score between 1-5. Five was given when a participant chose strongly agree, 4 was given when a participant chose agree, 3 was given when a participant chose neither agree not disagree, 2 was chosen when a patient picked disagree and 1 was chosen when a patient chose strongly agree. Given how we structured the questions, a strongly agree choice would coincide with a stronger influence from that barrier. We assessed these barriers by comparing the scores for African Americans and Caucasian patients who completed the survey. We compared their scores to see if they were higher in African Americans.

Table 5. Religion as Barrier African Americans vs Caucasians

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | | | |
| RACE | | My religious beliefs are a strong factor in my feelings about genetic risk assessment. | I believe that wanting to know about my genetic risk for developing cancer shows a lack of faith in my religion. | I believe that if I am at risk of having a genetic disease I can do spiritual/religious practices to get rid of it. |
| CCA | N | 18 | 18 | 18 |
| Mean | 2.17 | 1.33 | 1.94 |
| Std. Deviation | 1.581 | .840 | 1.211 |
|  |  |  |  |
| AAA | N | 56 | 56 | 56 |
| Mean | 3.00 | 2.34 | 2.54 |
| Std. Deviation | 1.062 | 1.195 | 1.175 |
|  |  |  |  |

In Table 5, the mean scores for African American patients are higher than those for Caucasian patients for each question about religion. This result is consistent with the hypothesis that African American patients view religion as a stronger barrier than Caucasian patients. We then calculated the average scores for Education and found the following results.

Table 6. Report Caucasians vs African Americans Education Barrier

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | | | | | | | | | |
| RACE | | Our genetic risk information will be stored in computers (data banks). | There will be a division or split in our society: People with a ‘good’ and people with a ‘bad’ genetic predisposition. | The government will not be able to protect citizens against negative aspects of genetic risk assessment. | Insurance companies will ask my genetic risk status before giving me a plan. | Future employees will have to have a genetic test before they are hired. | I would prefer to discuss my genetic history and health with my regular doctor and not a genetic counselor or specialist. | I know what a genetic counselor is and what type of medical services they provide. | I think that having an evaluation using a genetic risk assessment tool is the same as a diagnosis of a genetic disease. | Having the initial genetic risk assessment tool done caused or increased anxiety and/or fear about my own health. |
|  | Mean | 4.67 | 2.83 | 3.06 | 3.67 | 2.22 | 2.83 | 2.61 | 2.17 | 2.56 |
| N | 18 | 18 | 18 | 18 | 18 | 18 | 18 | 18 | 18 |
| Std. Deviation | .594 | 1.043 | .938 | 1.455 | 1.003 | 1.150 | 1.037 | 1.098 | 1.042 |
| Mean | 3.63 | 3.07 | 3.02 | 3.23 | 2.64 | 3.23 | 2.41 | 2.70 | 2.86 |
| N | 56 | 56 | 56 | 56 | 56 | 56 | 56 | 56 | 56 |
| Std. Deviation | 1.214 | 1.006 | 1.053 | 1.144 | 1.167 | 1.027 | 1.108 | .872 | 1.017 |

In Table 6, when compared to Caucasian patients, the mean scores for African American patients were higher in 5 out of 9 questions regarding education about genetic services. This result is also consistent with stronger barriers in education among the African American patients.

The next barrier we assessed in detail was stigma.

Table Caucasians vs African Americans Sigma

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Report Caucasians vs African Americans Stigma** | | | | |
| RACE | | My family and friends will feel uncomfortable with me doing genetic risk assessment. | My friends and family worry about their own privacy when I do genetic risk assessment. | People from my community have/will pressure me to find other options besides genetic risk assessment. |
| CCA  aAA | N | 18 | 18 | 18 |
| Mean | 1.94 | 1.94 | 1.72 |
| Std. Deviation | 1.110 | 1.162 | 1.018 |
| Mean | 2.43 | 2.55 | 2.38 |
| N | 56 | 56 | 56 |
| Std. Deviation | 1.042 | 1.043 | 1.121 |

For all 3 questions on stigma, African American patients had higher scores than their Caucasian patients, and supports the idea that that African American patients view stigma as a more prominent barrier than do Caucasia patients. We then assessed the category of medical mistrust. African American patients scored higher in 6 out of 9 questions regarding medical mistrust.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Table Caucasians vs African Americans Medical Mistrust Barrier   |  | | --- | | **Report Caucasians vs African Americans medical Mistrust Barrier** | | | | | | | | | | |
| RACE | | You’d better be cautious when dealing with health care organizations. | Mistakes are common in health care organizations. | Sometimes I wonder if health care organizations really know what they are doing. | They know what they are doing at health care organizations. | Health care organizations don’t always keep your information totally private. | Health care organizations have sometimes done harmful experiments on patients without their knowledge. | Patients have sometimes been deceived or mislead by health care organizations. | When health care organizations make mistakes they usually cover it up. |
| CA  AA | Mean | 2.39 | 3.33 | 2.78 | 3.61 | 2.89 | 2.50 | 3.00 | 2.83 |
| N | 18 | 18 | 18 | 18 | 18 | 18 | 18 | 18 |
| Std. Deviation | 1.290 | 1.188 | 1.309 | 1.145 | 1.278 | 1.465 | 1.372 | 1.043 |
| Mean | 3.39 | 3.23 | 2.88 | 3.73 | 2.86 | 2.91 | 3.09 | 3.32 |
| N | 56 | 56 | 56 | 56 | 56 | 56 | 56 | 56 |
| Std. Deviation | 1.021 | 1.044 | .974 | .820 | 1.103 | 1.032 | .959 | .897 |

We then did a t-test comparing the difference between the perception of the barriers in African American and Caucasian patients

Table African Americans vs Caucasians T-test Group Statistics and Independent Sample Test

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **African Americans vs. Caucasians T-test Group Statistics** | | | | | |
|  | AAA vs CA | N | Mean | Std. Deviation | Std. Error Mean |
| Religion | .CA | 18 | 4.9444 | 2.99946 | .70698 |
| 1AA | 50 | 6.9600 | 3.32560 | .47031 |
| Education | .CA | 18 | 24.4444 | 7.03957 | 1.65924 |
| 1AA | 50 | 23.7600 | 9.31875 | 1.31787 |
| Stigma | .CA | 18 | 5.1111 | 3.00762 | .70890 |
| 1AA | 50 | 6.2600 | 3.53299 | .49964 |
| Medical Mistrust | .CA | 18 | 21.3333 | 8.48528 | 2.00000 |
| 1AA | 50 | 22.7000 | 9.41828 | 1.33195 |

**African Americans vs. Caucasians T-test Independent Samples Test**

**Table 9 Continued**

|  |  |  |  |
| --- | --- | --- | --- |
|  | | Levene's Test for Equality of Variances | |
| F | Sig. | t | df | Sig. (2-tailed) | Mean Difference |
| Religion | Equal variances assumed | .020 | .887 | -2.260 | 66 | .027 | -2.01556 |
| Equal variances not assumed |  |  | -2.374 | 33.125 | .024 | -2.01556 |
| Education | Equal variances assumed | 2.106 | .151 | .283 | 66 | .778 | .68444 |
| Equal variances not assumed |  |  | .323 | 39.729 | .748 | .68444 |
| Stigma | Equal variances assumed | 1.077 | .303 | -1.227 | 66 | .224 | -1.14889 |
| Equal variances not assumed |  |  | -1.325 | 35.081 | .194 | -1.14889 |
| Medical Mistrust | Equal variances assumed | .104 | .748 | -.541 | 66 | .590 | -1.36667 |
| Equal variances not assumed |  |  | -.569 | 33.161 | .573 | -1.36667 |

Looking at the above tables all the values in the Sig column are greater than .05 we can assume that variability between African Americans and Caucasians are the same when it comes to perception of barriers. We know look at the Sig 2 tailed to get the p-value. The only barrier which had a p-value less than .05 was Religion. The Religion p-value was .027 which shows that there is a significant difference between African American patients and Caucasian patients when it comes to Religion as a perceived barrier for genetic services. Since African American patients had a mean Religion score of 6.96 and Caucasian patients had a mean score of 4.94 and we found that these groups were significantly different when it came to this barrier we can conclude that African Americans are more likely to perceive Religion as a barrier to genetic services.

We then did a linear model for each barrier and adjusted for education, age and income. Our results are shown in the tables below.

Table Linear Regression Religion

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Linear Regression Religion** | | | | | | |
| Model | | Unstandardized Coefficients | | Standardized Coefficients | t | Sig. |
| B | Std. Error | Beta |
| 1 | (Constant) | 7.325 | 1.927 |  | 3.802 | .000 |
| AA and CA | 1.997 | 1.026 | .289 | 1.945 | .056 |
| As of today, what is your age | -.166 | .270 | -.077 | -.617 | .540 |
| Highest level of education you have completed as to date | -.195 | .230 | -.134 | -.847 | .400 |
| Indicate total household income | -.017 | .088 | -.032 | -.195 | .846 |
| a. Dependent Variable: Religion | | | | | | |

Table Linear Regression Stigma

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Linear Regression Stigma** | | | | | | |
| Model | | Unstandardized Coefficients | | Standardized Coefficients | t | Sig. |
| B | Std. Error | Beta |
| 1 | (Constant) | 5.488 | 2.086 |  | 2.631 | .011 |
| AA and CA | 1.987 | 1.111 | .277 | 1.788 | .079 |
| As of today, what is your age | -.419 | .292 | -.188 | -1.436 | .156 |
| Highest level of education you have completed as to date | .023 | .250 | .015 | .093 | .927 |
| Indicate total household income | .029 | .095 | .053 | .309 | .759 |
| Dependent Variable: Stigma | | | | | | |
| Table Linear Regression Education and Medical Mistrust  **Linear Regression Education a** | | | | | | |
| Model | | Unstandardized Coefficients | | Standardized Coefficients | t | Sig. |
| B | Std. Error | Beta |
| 1 | (Constant) | 26.497 | 4.601 |  | 5.759 | .000 |
| AA and CA | .977 | 2.451 | .062 | .399 | .692 |
| As of today, what is your age | -1.160 | .644 | -.236 | -1.801 | .077 |
| Highest level of education you have completed as to date | .426 | .550 | .127 | .774 | .442 |
| Indicate total household income | -.195 | .210 | -.160 | -.929 | .357 |
| a. Dependent Variable: Education | | | | | | |
| **Linear Regression Medical Mistrust a** | | | | | | |
| Model | | Unstandardized Coefficients | | Standardized Coefficients | t | Sig. |
| B | Std. Error | Beta |
| 1 | (Constant) | 17.799 | 5.087 |  | 3.499 | .001 |
| AA and CA | 5.502 | 2.710 | .312 | 2.030 | .047 |
| As of today, what is your age | -1.279 | .712 | -.233 | -1.796 | .078 |
| Highest level of education you have completed as to date | .584 | .608 | .157 | .959 | .341 |
| Indicate total household income | .101 | .232 | .075 | .437 | .664 |
| a. Dependent Variable: Medical Mistrust | | | | | | |

Once we adjusted for these demographic factors the only significant barrier was Medical Mistrust with a p-value of .047. Religion was almost significant with a p-value of .056. This shows that these demographic measures effect perception of barriers.

# Conclusion

In conclusion, although our sample size is relatively small, these initial results indicate that religion may be a consistent barrier for African American patients who participated in our project, and thus we need to address this area. Our plan is to reach out to the local churches in the Hill district and educate the members about the importance of genetic services. We think this goal would best be achieved by reaching out to the leaders of the church and educating them about the benefits of these services. We are still brainstorming ways to combat the medical mistrust barrier seen from our data. We also recognize the limit of our data. Our sample size is relatively small, thus additional data needs to be obtained on the patient-specific barriers we examined. However, given our initial results, we also think assessment of structural barriers, such as transportation or poverty, should be included in future studies. Future steps will include a continuation of data collection for our quality improvement project and development of additional survey tools to assess additional hypotheses regarding the basis of health disparities in breast cancer mortality.

APPENDIX A: COMPLETE QUESTIONNAIre

|  |  |  |  |
| --- | --- | --- | --- |
| Question # | Question text | Measured Concept | Results |
| Q1 | Our genetic risk information will be stored in computers (data banks). | Education about genetics/genetic services | Extremely unlikely: 10%  Somewhat unlikely 5%  Neither likely nor unlikely 3.33%  Somewhat likely 35%  Extremely likely 46.67% |
| Q2 | There will be a division or split in our society: People with a ‘good’ and people with a ‘bad’ genetic predisposition. | Education about genetics/genetic services | Extremely unlikely: 10%  Somewhat unlikely 23.33%  Neither likely nor unlikely 26.67%  Somewhat likely 36.67%  Extremely likely 3.33%% |
| Q3 | The government will not be able to protect citizens against negative aspects of genetic risk assessment. | Education about genetics/genetic services | Strongly disagree: 10%  Somewhat disagree 21.67%  Neither agree nor disagree 28.33%  Somewhat agree 33.33%  Strongly agree 6.67%% |
| Q4 | My religious beliefs are a strong factor in my feelings about genetic risk assessment. | Religion and views on genetics/genetic services | Strongly disagree: 30%  Somewhat disagree 8.33%  Neither agree nor disagree 35.00%  Somewhat agree 16.67%  Strongly agree 10.00%% |
| Q5 | I believe that wanting to know about my genetic risk for developing cancer shows a lack of faith in my religion. | Religion and views on genetics/genetic services | Strongly disagree: 56.67%  Somewhat disagree 10.00%  Neither agree nor disagree 23.33%  Somewhat agree 3.33%  Strongly agree 6.67 %% |
| Q6 | Insurance companies will ask my genetic risk status before giving me a plan. | Education about genetics/genetic services | Extremely unbelievable 16.67%  Somewhat unbelievable 5.00%  Neither agree nor unbelievable 16.67%  Somewhat believable 43.33%  Extremely believable 18.33 %% |
| Q7 | Future employees will have to have a genetic test before they are hired | Education about genetics/genetic services | Strongly disagree: 28.33%  Somewhat disagree 23.33%  Neither agree nor disagree 26.67%  Somewhat agree 16.67%  Strongly agree 5.00%% |
| Q8 | I believe that if I am at risk of having a genetic disease I can do spiritual/religious practices to get rid of it. | Religion and views on genetics/genetic services | Extremely unbelievable 40.00%  Somewhat unbelievable 15.00%  Neither agree nor unbelievable 26.67%  Somewhat believable 10.00%  Extremely believable 8.33 %% |
| Q9 | My family and friends will feel uncomfortable with me doing genetic risk assessment. | Family/Community Stigma | Strongly disagree: 43.33%  Somewhat disagree 10.00%  Neither agree nor disagree 35.00%  Somewhat agree 11.67%  Strongly agree 5.00%% |
| Q10 | My friends and family worry about their own privacy when I do genetic risk assessment | Family/Community Stigma | Strongly disagree: 36.67%  Somewhat disagree 11.67%  Neither agree nor disagree 38.33%  Somewhat agree 10.00%  Strongly agree 3.33%% |
| Q11 | People from my community have/will pressure me to find other options besides genetic risk assessment. | Family/Community Stigma | Strongly disagree: 46.67%  Somewhat disagree 8.33%  Neither agree nor disagree 35.00%  Somewhat agree 6.67%  Strongly agree 3.33%% |
| Q12 | You’d better be cautious when dealing with health care organizations. | Medical Mistrust | Strongly disagree: 11.67%  Somewhat disagree 13.33%  Neither agree nor disagree 30.00%  Somewhat agree 28.33%  Strongly agree 16.67%% |
| Q13 | Mistakes are common in health care organizations. | Medical Mistrust | Strongly disagree: 6.67%  Somewhat disagree 18.33%  Neither agree nor disagree 28.33%  Somewhat agree 30.00%  Strongly agree 16.67%% |
| Q14 | Sometimes I wonder if health care organizations really know what they are doing. | Medical Mistrust | Strongly disagree: 16.67%  Somewhat disagree 23.33%  Neither agree nor disagree 28.33%  Somewhat agree 23.33%  Strongly agree 8.33%% |
| Q15 | They know what they are doing at health care organizations. | Medical Mistrust | Strongly disagree: 1.67%  Somewhat disagree 6.67%  Neither agree nor disagree 20.00%  Somewhat agree 46.67%  Strongly agree 25.00%% |
| Q16 | Healthcare organizations don’t always keep your information totally private | Medical Mistrust | Strongly disagree: 20.00%  Somewhat disagree 20.00%  Neither agree nor disagree 28.33%  Somewhat agree 20.00%  Strongly agree 11.67 %% |
| Q17 | Health care organizations have sometimes done harmful experiments on patients without their knowledge. | Medical Mistrust | Strongly disagree: 23.33%  Somewhat disagree 15.00%  Neither agree nor disagree 33.33%  Somewhat agree 20.00%  Strongly agree 8.33 %% |
| Q18 | Patients have sometimes been deceived or mislead by health care organizations. | Medical Mistrust | Strongly disagree: 13.33%  Somewhat disagree 18.33%  Neither agree nor disagree 31.67%  Somewhat agree 28.33%  Strongly agree 8.33 %% |
| Q19 | When health care organizations make mistakes they usually cover it up | Medical Mistrust | Strongly disagree: 8.33%  Somewhat disagree 11.67%  Neither agree nor disagree 40.00%  Somewhat agree 26.67%  Strongly agree 13.33 %% |
| Q20 | I would prefer to discuss my genetic history and health with my regular doctor and not a genetic counselor or specialist. | Medical Mistrust | Strongly disagree: 10.00%  Somewhat disagree 15.00%  Neither agree nor disagree 35.00%  Somewhat agree 23.33%  Strongly agree 16.67% |
| Q21 | I know what a genetic counselor is and what type of medical services they provide. | Medical Mistrust | Not knowledgeable at all: 31.67%  Slightly knowledgeable 28.33%  Moderately knowledgeable 23.33%  Very knowledgeable 11.67%  Extremely knowledgeable 5.00% |
| Q22 | I think that having an evaluation using a genetic risk assessment tool is the same as a diagnosis of a genetic disease. | Education about genetics/genetic services | Strongly disagree: 23.33%  Somewhat disagree 23.33%  Neither agree nor disagree 35.00%  Somewhat agree 18.33%  Strongly agree 0% |

APPENDIX B: QUESTIONNAIRE SOURCES

Measurement Matrix

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Question # | Measured Concept | Level of Measurement | Purpose in Analysis/Measurement Objective | Reference number |
| Q1 | Education about genetics/genetic services | ordinal | We will see if lack of education about services and genetic information is a barrier to uptake of genetic services in survey participants | (Buseh, Kelber, Millon-Underwood, Stevens, & Townsend, 2014b) |
| Q2 | Education about genetics/genetic services | ordinal | We will see if lack of education about services and genetic information is a barrier to uptake of genetic services in survey participants | (Buseh et al., 2014b) |
| Q3 | Education about genetics/genetic services | ordinal | We will see if lack of education about services and genetic information is a barrier to uptake of genetic services in survey participants | (Buseh et al., 2014b) |
| Q4 | Religion and views on genetics/genetic services | ordinal | We will see if survey participants consider religion when making decision about genetic services in survey participants | (Pargament et al., 1988) |
| Q5 | Religion and views on genetics/genetic services | Ordinal | We will see if survey participants consider religion when making decision about genetic services in survey participants | (Pargament et al., 1988) |
| Q6 | Education about genetics/genetic services | Ordinal | We will see if lack of education about services and genetic information is a barrier to uptake of genetic services in survey participants | (Buseh et al., 2014b) |
| Q7 | Education about genetics/genetic services | Ordinal | We will see if lack of education about services and genetic information is a barrier to uptake of genetic services in survey participants | (Buseh et al., 2014b) |
| Q8 | Religion and views on genetics/genetic services | Ordinal | We will see if survey participants consider religion when making decision about genetic services in survey participants | (Pargament et al., 1988) |
| Q9 | Family/Community Stigma | Ordinal | We will see if stigma in community or family is a factor in whether or not people uptake genetic services |  |
| Q10 | Family/Community Stigma | Ordinal | We will see if stigma in community or family is a factor in whether or not people uptake genetic services |  |
| Q11 | Family/Community Stigma | Ordinal | We will see if stigma in community or family is a factor in whether or not people uptake genetic services |  |
| Q12 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist, Isaac, & Williams, 2009) |
| Q13 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q14 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q15 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q16 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q17 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q18 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q19 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q20 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q21 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| Q22 | Medical Mistrust | Ordinal | We will see if most survey participants answer agree or strongly agree with at least 50% of the medical mistrust questions | (Laveist et al., 2009) |
| D1 | Demographic Info | Nominal | We will see if there is an association between gender and the other answers participants give |  |
| D2 | Demographic info | Nominal | We will see if there is an association between race and the other answers participants give |  |
| D3 | Demographic Info | Nominal | We will see if there is an association between ethnicity and the other answers participants give |  |
| D4 | Demographic Info | Nominal | We will see if there is an association between marital status and the other answers participants give |  |
| D5 | Demographic Info | Ordinal | We will see if there is an association between age and the other answers participants give |  |
| D6 | Demographic Info | Ordinal | We will see if there is an association between education and the other answers participants give |  |
| D7 | Demographic Info | Interval | We will see if there is an association between income and the other answers participants give |  |
| D8 | Demographic Info | Nominal | We will see if there is an association between industry type and the other answers participants give |  |

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