UNDERSTANDING FACTORS ASSOCIATED WITH INTENTION TO GO TO YOUR DOCTOR TO ASK FOR SICKLE CELL TRAIT SCREENING AMONG AFRICAN AMERICANS WITHIN MIDDLE REPRODUCTIVE AGE

Tilicia L. Mayo-Gamble

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Doctoral Committee

_____
Susan E. Middlestadt, Ph.D., Chair

_____
Hsien-Chang Lin, Ph.D.

_____
Priscilla Barnes, PhD.

_____
Pamela Braboy Jackson, Ph.D.

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Tilicia L. Mayo-Gamble

I dedicate my dissertation to two people who supported and desired to see this project through to the end, but left us way too soon, Shirley Jo Adams and Larry Gamble. I know you both are looking down on me and smiling. I also dedicate this dissertation to Larry D. Hobbs Jr. for reminding that the grade is not as important as the work I put into it. I hope I've made you all proud.

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UNDERSTANDING FACTORS ASSOCIATED WITH INTENTION TO GO TO YOUR DOCTOR TO ASK FOR SICKLE CELL TRAIT SCREENING AMONG AFRICAN AMERICANS WITHIN MIDDLE REPRODUCTIVE AGE

Background: Current guidelines recommend that African Americans (AA) know their sickle cell trait status to inform their reproductive decisions. Two studies based on the Reasoned Action Approach (RAA) and the Extended Parallel Process Model were conducted with AA between 18 and 35 to understand their intention to get screened to determine their status. The aim of the *main study* was to identify factors underlying intention to go to their doctor to ask for sickle cell screening in the next 12 months. The aim of the *secondary study* was to identify how exposure to a brochure with information about sickle cell trait screening might influence knowledge and beliefs.

Methods: Data were collected during March through May 2015 from community sites and via referral to Qualtrics from 300 AA residing in three cities in Indiana. After participants answered eligibility and knowledge questions, they were randomly exposed to one of two brochures. The control brochure had two boxes of information on sickle cell trait susceptibility, severity, and screening; the intervention brochure was identical to the control brochure with the recommended response (e.g., "Go to your doctor to ask for sickle cell trait screening.") inserted between the two boxes. Then the participants completed a 45-item questionnaire.

Results: In the main study sequential regression was used to predict intention. Adding the three RAA constructs of perceived behavioral control ($\beta = .579$, $p<.001$), attitude ($\beta =$

.354, $p<.001$), and perceived norm ($\beta = .177$, $p<.001$) significantly increased the adjusted R^2 from .173 to .639 ($F=34.136$, df, 16, 283 $p<.001$) over the model with four demographic variables and three knowledge and belief variables. In the secondary study, the multivariate t-test comparing those exposed to the control brochure to those exposed to the intervention brochure with the recommended response revealed no significant multivariate effects. However, a paired sample t-test comparing knowledge and beliefs before and after the brochures revealed that exposure to the brochure improved knowledge and beliefs about sickle cell trait screening.

Conclusion: RAA was demonstrated to be a useful behavioral theory to understand factors underlying this genetic screening decision. Implications for interventions and research were discussed.

INDEX WORDS: sickle cell trait, screening, reasoned action approach, intention

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Susan E. Middlestadt, Ph.D., Chair

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Hsien-Chang Lin, Ph.D.

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Priscilla Barnes, PhD.

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Pamela Braboy Jackson, Ph.D.

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CHAPTER 1: INTRODUCTION

Demographic

Sickle cell trait is the carrier state for a genetic blood disorder called sickle cell disease (MCSI, 2012). In the United States, sickle cell trait affects1 in 12 Blacks or African Americans (CDC, 2010; NHLBI, 2009). Individuals with sickle cell trait (SCT) are known as carriers of sickle cell disease. While most individuals with SCT are asymptomatic, this condition has been linked with increased risk of hyposthenuria, hematuria, sickling under extreme conditions (e.g., excessive exertion and high altitudes), eye abnormalities, and an increase in the expression of microvascular diabetic complications (SCDAA, CDC, 2011; Motulsky A.G., 1973; Kark, J.A., Posey, D.M., Schumacher, H.R., Ruehle, C.J., 1987). Sickle cell trait is identified in the course of newborn screening; however, there is no universal method of notification (Pass et al., 2000; Gustafson, S.L., Gettig, E.A., Watt-Morse, M., Krishnamurti, L., 2007). As a result, many carriers are unaware of their sickle cell trait status (Pass et al., 2000).

It is particularly important for individuals with SCT to understand the implications for reproduction. Previous literature on SCT screening reflects a need to develop strategies to educate African Americans about the genetics associated with having a child with sickle cell disease (Acharya *et al*., 2009; Asgharian & Anie, 2003). Such education would allow this population to make informed reproductive decisions. Unfortunately, SCT is a concept in which African Americans are often misinformed and poorly understand. In order to inform interventions geared toward increasing the number of African Americans within reproductive age who know their SCT status, it would be

beneficial to apply a health behavior model to understand factors influencing the decision to go to the doctor to ask for SCT screening.

Furthermore, in order to influence behavior change, a need exists to design effective persuasive health messages. Persuasive health messages have been used to promote health behavior associated with several health conditions, including: mammography, colon cancer screening, and diabetes control (Bunn, *et al.,* 2002; Williams-Piehota, Schneider, T.R., Pizarro, J., Mowad, L., & Salovey, P., 2003). In these areas, effective methods of communication that are necessary to increase behavior change have been identified. However, there are several health behaviors in which the appropriate method of communication is unclear. For these behaviors a persuasive health message that communicates an explicit recommended response might be effective. Persuasive health messages are often used to communicate information, in the form of brochures, regarding SCT. Therefore, in order to develop educational strategies geared toward educating African Americans regarding the inheritance pattern of sickle cell trait and the methods for learning one's SCT status, it would be beneficial to assess the effect of a persuasive health message in the form of a brochure on attitude, perceived norm, perceived behavioral control, and sickle cell trait knowledge/sickle cell trait screening knowledge.

Statement of the Problem

Previous studies on SCT screening have focused on attitude and beliefs as potential barriers to screening (Acharya *et al*., 2009; Gustafson *et al.*, 2007; Treadwell *et al*., 2006). However, these studies indicate that despite having positive attitudes towards SCT screening, African Americans are not likely to follow through with screening. This suggests that there may be other determinants underlying this specific screening behavior.

In addition, there is no evidence of studies within the U.S. that focus on the strongest predictor of behavior, intention. Therefore, this two-fold study seeks to utilize the Reasoned Action Approach to identify and understand factors (demographic, knowledge and fear beliefs, and RAA determinants) influencing the intention to go to the doctor to ask for SCT screening as well as to determine the effects of exposure to a communication with an explicit recommended response (in the form of a verbal statement) on understanding of brochure, knowledge and fear beliefs, and RAA determinants.

Aims and Research Questions

The aims and research questions this study attempts to address are as follows:

Main Study Aim (Aim 1)

To utilize the Reasoned Action Approach to identify and understand factors (demographics, knowledge and fear beliefs, and RAA determinants) influencing the intention to go to the doctor to ask for sickle cell trait screening.

Main Study Question

1) What are the factors (demographic factors, fear and knowledge beliefs, and RAA constructs) influencing the intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?

Secondary Study Aim (Aim 2)

To determine if including a recommended response in a brochure influences understanding of brochure, knowledge and fear beliefs, and RAA determinants

Secondary Study Questions (Experimental Design)

1) What is the effect effect of including an explicit recommended response (in the form of a verbal statement) in a brochure on intention, attitude, perceived norm, perceived

behavioral control, response efficacy, perceived threat, sickle cell trait/sickle cell trait screening awareness, sickle cell trait knowledge and sickle cell trait screening knowledge?

2) What is the effect of including an explicit recommended response (in the form of a verbal statement) in a brochure on the relative weight (attitude, perceived norm, perceived behavioral control; sickle cell trait knowledge, sickle cell trait screening knowledge) predicting intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?

Secondary Study Sub-Questions (Pre-Test/Post-Test Design)

1) What is the effect of exposure to a communication in the form of brochure on sickle cell trait knowledge and sickle cell trait screening knowledge?
2) What is the to effect of exposure to a communication in the form of a brochure on sickle cell trait and sickle cell trait screening beliefs?

Delimitations

1) The main study uses a non-experimental, cross-sectional research design.
2) The target population for the main study and the secondary study comprised the following: Individuals who self-identified as “Black” or mixed with “Black,” all between the ages 18-35, and residents of Gary, Indiana; Indianapolis, Indiana, and Bloomington, Indiana.
3) A 44-item questionnaire was administered to volunteer study participants to measure variables of interest. The questionnaire contained items on demographics, knowledge, constructs from the Extended Parallel Process Model (perceived threat, response efficacy), and various measures based on the

Reasoned Action Approach (RAA). Constructs from both theories had been previously validated in national surveys. In addition, the secondary study included a brochure with an explicit recommended response.

Limitations

1) A salient belief elicitation study was not conducted prior to implementing the current study.
2) The study contains self-reported data.
3) Findings may not be generalizable to the larger African American population or to all African Americans within the state of Indiana.

Study Assumptions

1) All participants responded truthfully.
2) All items within the survey instrument are reliable and valid.

Implications

This study will serve as a precursor to understanding factors that influence screening in the African American population. The findings of this study will provide greater understanding of the factors associated with asking for sickle cell trait screening among African Americans within reproductive age. Findings will inform interventions designed specifically to motivate Africans Americans within reproductive ages 18-35 to go to their doctor to ask for sickle cell trait screening.

This study will fill an important gap in the literature. It is the first study of its kind to examine the effects of exposure to a communication with explicit recommended responses on behavioral intention. Furthermore, it will also add to the body of knowledge on theory-based health communication and behavior change interventions in a minority population. Additionally, the results of this study can be readily applied and should be of

great interest to health promotion professionals. Understanding effective methods of communicating health messages, particularly a recommended response, could have an immediate impact on behavior and change.

Results from the study will be disseminated in various forums. First and foremost, the results will be shared with the individuals and agencies that provide Sickle Cell education throughout the state of Indiana. This includes the Martin Center Sickle Cell Initiative and the Indiana Hemophilia and Thrombosis Center. The study results will also be developed into two manuscripts and submitted to peer-reviewed journals within the fields of public health, health education, health communication, and health behavior. Particular journals of interest include: *Journal of the National Medical Association*; *American Journal of Health Behavior*; the *Journal of Genetic Counseling*; and the *Journal of Health Communication*. The publication submission order will be based on the highest impact factor ranking. Abstracts will also be submitted for oral presentations and poster sessions at several national conferences. These may include the American Public Health Association Annual Meeting; the Society for Public Health Education Annual Meeting; and the National Conference on Health Communication, Marketing, and Media Annual Meeting.

Key Definitions

Sickle Cell Disease: Sickle cell **disease** is a group of inherited blood disorders that cause the body to make sickle-shaped red blood cells (CDC, 2011; NHLBI, 2009).

Sickle Cell Trait: Sickle cell **trait** is the carrier state for sickle cell **disease** (MCSI, 2012).

Persuasive Health Message: A message that attempts to convince an individual or group to take certain specific health actions (Lombardo, 2014; Witte, Meyer, and Martell, 2001).

Fear Appeal: A fear appeal is a persuasive message that arouses fear by outlining the consequences that occur if a certain action is not taken (Witte, Meyer, and Martell, 2001).

Perceived Threat: A threat is the negative consequences that occur if you don't do what is advocated (Witte, Meyer, and Martell, 2001).

Recommended Response: A recommended response is the action that should be taken to avoid experiencing the threat (Witte, Meyer, and Martell, 2001).

Implicit Recommended Response: An implicit recommended response is a recommendation that is not clearly expressed. The recommended response is thought to be understood from the context, such as a picture, within the message (Witte, Meyer, and Martell, 2001).

Explicit Recommended Response: An explicit recommended response is a specific recommendation about what to do to avoid a health threat (Witte, Meyer, and Martell, 2001).

Intention: Indications of a person's readiness to perform a behavior (Fishbein & Azjen, 2010).

Attitude: Tendency to respond with some degree of favorableness or unfavorableness to a psychological object (Fishbein & Ajzen, 2010).

Perceived Norm: The more one believes that important others think one should (or should not) perform the behavior and/or that important others or "others like me" are themselves performing the behavior (Fishbein & Middlestadt, 2011).

Perceived Behavioral Control: People's perceptions of the degree to which they are capable of, or have control over, performing a given behavior (Fishbein & Ajzen, 2010).

Perceived Susceptibility: Beliefs about one's risk of experiencing the threat (Witte, Meyer, and Martell, 2001).

Perceived Severity: Beliefs about the significance or magnitude of the threat (Witte, Meyer, and Martell, 2001).

Response Efficacy: Beliefs about the effectiveness of the recommended response to avert the threat (Witte, Meyer, and Martell, 2001).

Theoretical Orientation

Reasoned Action Approach

The present study employs a Reasoned Action Approach (RAA) framework. The RAA is the current formulation of Theory of Reasoned Action, Theory of Planned Behavior, and the Integrated Model. The RAA was selected because it has been used successfully in a number of domains (dark green leafy vegetable consumption; asking parents for fruits and vegetables, etc.) to understand the psychosocial factors underlying people's decisions to engage in health behaviors with the goal of improving health (Sheats *et al.*, 2013; Middlestadt *et al.*, 2013; Fishbein & Ajzen, 2010). For the purposes of the present study, the RAA framework was used to identify determinants influencing intention to go to your doctor to ask for sickle cell trait screening.

The RAA asserts that intention is the best predictor of behavior. Intention is defined as an individual's readiness to perform the behavior (Fishbein & Ajzen, 2010). According to the theory, any given behavior is likely to occur if one has a strong intention to perform the behavior, has the necessary skills and abilities required to perform the behavior, and there are no environmental constraints preventing behavioral performance (Fishbein & Ajzen, 2010).

When applying the Reasoned Action Approach, it is imperative to first clearly define the behavior of interest. Fishbein (2008) recommends defining (and describing) a behavior using the following four elements: action, target, context, and time. In this study, *going to your doctor to ask for* was selected as the action element; *sickle cell trait screening* as the target; *within the next 12 months* as the time element; and Indiana (Gary, Indianapolis, and Bloomington) as the context. These elements were based on the premises that: 1) in order for an individual to learn their sickle cell trait status, sickle cell

trait screening is required; and 2) in order to be screened for sickle cell trait a doctor must ask for the order from a laboratory. The time frame was selected after weighing options for going to the doctor. Additional time frames were considered in one of the intention items. Indiana, was selected because the investigator volunteers with a community agency seeking data to develop programs and interventions with goals consistent with this study. All cities were selected because they fall within service boundaries of partnering organizations (Martin Center Sickle Cell Initiative and the Indiana Hemophilia) and/or due to the increased sickle cell population in these cities. Bloomington was selected due to access to the target population.

The RAA predicts intention from a weighted combination of three global components: attitude toward the act (behavioral beliefs), perceived norm (normative beliefs), and perceived behavioral control (control beliefs) (Fishbein, 2008; Fishbein & Ajzen, 2010). These components guide the decision to perform or not to perform a specific behavior. The first component, attitude toward the act, determines people's attitude toward performing the behavior. These attitudes are a positive or negative evaluation of performing the behavior. The second global component, perceived norm, are the perceived pressure from referents (people who approve or disapprove of the individual performing the behavior) to engage or not to engage in the behavior. The final component, perceived behavioral control, is a sense of low or high self-efficacy with regard to performing the behavior. Each of these components is influenced by a set of beliefs individuals hold as a result of external or demographic factors. These beliefs are reflected in the extended version of the conceptual (See appendix B) framework guiding the study. As a result, the study collected data regarding these beliefs, but this

information will not be included in the results of the study, but will be included in future studies.

Persuasive Health Message Framework

The study was also guided by Witte's Persuasive Health Message Framework (PHMF). The PHMF was used to develop the persuasive health messages (brochures) that were used in the Part I of the study. This framework was selected to justify the content within the brochures. The PHMF is a combination of parts of successful theories (Theory of Reasoned Action, Elaboration Likelihood Model, and Protection Motivation Theory) into a single framework. As opposed to explaining human behavior, the PHMF outlines what one should do to develop the most effective persuasive messages. According to Witte, there are three steps developing effective persuasive health messages: 1) Determine information about threat and efficacy; 2) Develop audience profile; and 3) Construct the persuasive health message.

Extended Parallel Process Model

The theoretical basis for the study is also rooted in a communication approach called fear appeals. Fear appeals have been used successfully to distribute health information to the general public. Fear appeals can be found in drinking and driving advertisements, AIDS awareness posters, seatbelt compliance laws, antismoking campaigns, antidrug messages, and even dentists' offices (Perloff, 2003; Gore, 2005).The most recent fear appeal theory, the Extended Parallel Process Model (EPPM) (Witte, 1992), attempts to explain when and why persuasive messages may work or fail (Witte & Allen, 2000; Gore, 2005). The EPPM was selected because the framework used to

develop the brochures is grounded in this theory. In addition, the EPPM provides constructs that are useful for understanding the behavior.

According to the main principles of the EPPM, when an individual is exposed to a fear appeal, two cognitive appraisals of the message will occur, "appraisal of the threat" and, the "appraisal of the efficacy of the message's recommended response" (Witte, Meyer, & Martell, 2001, p. 24). The construct for the appraisal of threat in the EPPM is perceived threat. Perceived threat is comprised of two sub-constructs called perceived susceptibility and perceived severity. Perceived susceptibility is known as the possibility of the threat, while perceived severity is known as the magnitude of the threat.

Next is the appraisal of the efficacy of the message's recommended response. Efficacy consists of two sub-constructs, self-efficacy and response efficacy. Instead of using the self-efficacy construct from the EPPM, the investigator has elected to use the "perceived behavioral control" construct from the Reasoned Action Approach. This construct was explained in subsequent paragraphs. Response efficacy is the belief that the recommend response will prevent or avoid the threat. According to Witte, *et al.*, there are two types of recommended responses, implicit and explicit. An implicit recommended response is a recommendation that is thought to be understood from the context, such as a picture, within the message (Witte, *et al*., 2001). An explicit recommended response is a specific recommendation about what to do to avoid the threat (Witte, *et al*., 2001). For the purpose of this study, the explicit recommended response will be used.

The EPPM posits that if a perceived threat is high, meaning it elicits some level of fear, and depending on the level of efficacy, individuals will follow one of two separate pathways: danger control processes or fear control processes (Witte *et al*., 2001). When

perceived threat and efficacy are high, individuals will follow the course of danger control, meaning they will focus cognitively on dealing with the threat and accept the recommended response (Gore, 2005; Witte *et al*., 2001). When perceived threat is high, but self-efficacy and/or response efficacy is low, individuals will follow the course of fear control, meaning they are less likely to accept the recommended response (Witte, 1992, 1994, 1998; Witte et al., 2001).

The next section will discuss a more precise framework illustrating only constructs that were used in the results of the study.

Conceptual Framework

The conceptual framework (See Appendix B) for the study suggests that in order to increase the number of African Americans who go to their doctor to ask for sickle cell trait screening within the next 12 months, it is first important to determine the various factors influencing their intention to perform the behavior. The RAA has been adapted to posit that intention to go to your doctor to ask for sickle cell trait screening as the immediate determinant of behavior performance. According to this framework, if an individual has high intention to go to their doctor to ask for sickle cell trait screening, then s/he will perform the behavior. The framework also posits that the RAA global constructs (attitude, perceived norm, and perceived behavioral control) and constructs from the EPPM (perceived threat and response efficacy) predict intention to go to your doctor to ask for sickle cell trait screening. The conceptual framework also proposes that through the use of a communication with an explicit recommended response, the determinants attitude, perceived norm, perceived behavioral control, perceived threat, and response efficacy are influenced.

Based on the research questions, the conceptual framework suggests individuals who are exposed to an explicit recommended response will have stronger intentions to go to a doctor to ask for screening for sickle cell trait than those who are not exposed to a recommended response. It also suggests: individuals who have strong intentions to go to a doctor to ask for sickle cell trait screening believe that going to their doctor to ask for sickle cell trait screening will lead to positive outcomes rather than negative outcomes; believe those who are most important to them think they should go to their doctor to ask for screening for sickle cell trait; and have the perceived behavioral control/self-efficacy to go to their doctor to ask for screening for sickle cell trait. Third, the conceptual framework suggests individuals who have strong intentions to go to their doctor to ask for sickle cell trait screening believe that sickle cell trait is a serious condition in which they are predisposed, and that going to their doctor to ask for screening for sickle trait is an effective response to avoid complications associated with sickle cell trait. Lastly, the conceptual framework proposes that demographic factors (age, sex, partner status, education, employment status) are essential to influencing an individual's intention to go their doctor to ask for screening for sickle cell trait.

CHAPTER 2: SUMMARY OF THE LITERATURE

Introduction

This section presents a summary of the reviewed literature. An outline of the information presented can be found in the evidence tables (See Appendix F). This review provides details of previous work on the scope and significance of sickle cell disease and sickle cell trait; addressing sickle cell trait among African Americans as a priority group; determinants of screening for African Americans; determinants of screening for sickle cell trait; theories/construct(s) that might be useful to understand why people would or would not be screened for sickle cell trait; and finally, gaps in the literature. For the purposes of this review the terms "Blacks" and "African Americans" will be used interchangeably. The literature reflects studies which select the use of each term both distinctively and interchangeably, thereby supporting the use of the terms interchangeably for the purposes of this review.

Scope and Significance of Sickle Cell Disease and Sickle Cell Trait

Genomics plays an integral role in nine of the ten leading causes of death in the United States. Sickle cell disease accounts for one of these disorders. Sickle cell disease is a group of inherited blood disorders that cause the body to make sickle-shaped red blood cells (CDC, 2011; NHLBI, 2009). It is the most prevalent genetic blood disorder in the United States, primarily affecting individuals of African descent (NHLBI, 2009). Sickle cell trait is the carrier state of sickle cell disease (MCSI, 2012). Individuals with sickle cell trait are known as carriers of sickle cell disease. Many carriers, despite being screened at birth, are often unaware of their carrier status (Pass et al., 2000).

Sickle cell trait (SCT) occurs among about 1 in 12 Blacks or African Americans., 8.3% of African Americans (CDC, 2010; NHLBI, 2009). Although most individuals with SCT are asymptomatic, there have been several studies that document complications resulting from sickle cell trait. Examples of areas in which these complications occur are athletic training and pregnancy (Kark *et al*., 1987; Kark *et al*., 1994; NATA, 2013; Larrabee &, Monga, 1997; Austin *et al*., 2007). Military recruits in basic training with sickle-cell trait have a substantially increased, age-dependent risk of exercise-related sudden death unexplained by any known preexisting cause (Kark *et al*., 1987; Kark *et al*., 1994). During intense exertion red blood cells can sickle, blocking blood vessels and posing a grave risk for athletes with sickle cell trait (NATA, 2013). SCT is also an issue in the area of reproduction. SCT positive women are at significantly higher risk for development of perinatal complications (Larrabee &, Monga, 1997). In addition, individuals with SCT are at an increased risk of venous thromboembolism (Austin *et al*., 2007).

SCT is particularly an issue for African Americans within reproductive age (Table 3b). It is important for members of the African American community to know their SCT status so that they are aware of their risk of having a child with the disease. Increasing the proportion of sickle cell carriers who know their own carrier status has important public health implications in that it will prevent illness and disability attributed to sickle cell disease (HP2020, 2012; WHO, 2006; Modell & Darlison, 2008). This occurs through a reduction in the number children born with sickle cell disorders. The majority of the estimated reduction is attributed to reduced reproduction by individuals who are informed

of their risk of having a child with sickle cell disease (WHO, 2006; Modell & Darlison, 2008).

Genetic Screening

Racial disparities exist in a multitude of health disorders, including diabetes and cardiovascular disease (IOM, 2013). However, they also occur with use of health care services such as screening (IOM, 2013). Research suggests that while genetic testing is a useful screening tool that can help identify risks for illness or disease, African Americans are less likely than other racial groups to get genetic testing (Singer, Antonucci, Van Hoewyk, 2004). In fact, Blacks are less likely to use genetic testing than non-Hispanic whites (Singer, Antonucci, Van Hoewyk, 2004). Furthermore, African Americans are less likely to undergo genetic counseling even when there is a family history (Singer, Antonucci, Van Hoewyk, 2004).

Determinants of Genetic Screening

There have been several studies conducted to explore and identify barriers to genetic screening. These studies have identified both non-modifiable and modifiable determinants of screening. Modifiable determinants of genetic screening, such as sickle cell screening, among African Americans include beliefs, attitude, knowledge, and awareness (Armstrong, Micco, Carney, Stopfer, Putt, 2005; Singer, Antonucci, Van Hoewyk, 2004). Both blacks and Latinos had significantly lower knowledge of genetic testing compared with non-Hispanic whites. Knowledge or lack of adequate information provided by their physicians about genetic testing and health insurance coverage were found to be determinants of genetic screening. In the 2005 National Health Interview Survey, 30.8% of blacks reported that they had heard about genetic testing. Some studies

indicate racial differences in beliefs about genetic testing and racial disparities in the actual uptake of genetic testing.

Non-modifiable determinants to genetic screening, including sickle cell screening, among African Americans include race, ethnicity, gender, and age (Leach, 2010; Zimmerman, Tabbarah, Nowalk, Raymund, Jewell, Wilson, Ricci, 2006; Antonucci, Van Hoewyk, 2004; Peters, Rose, Armstrong, 2004; Aro, Hakonen, Hietala, Lönnqvist, Niemelä, Peltonen, Aula, 1997). According to Singer *et al*., African Americans are more likely to have a negative attitude towards genetic screening (2004). In addition, women are more likely to be concerned with genetic testing compared to men (Leach, 2010). Despite this finding, other studies have shown that African American women are less likely to participate in genetic counseling and testing (Halbert, Kessler, Mitchell, 2005). In a study conducted by Aro *et al.* (1997), individuals aged 15-24 were more likely to undergo genetic testing than other age groups.

Use of Theory

Theories from communication and health behavior disciplines would be useful for understanding the determinants to SCT screening. One of these theories is the Reasoned Action Approach (RAA). The RAA has been used successfully in a number of domains to understand the psychosocial factors underlying people's decisions to engage in health behaviors with the goal of improving health (Middlestadt *et al*., 2013; Sheats *et al*., 2013). A second theory that would be useful in understanding the determinants of sickle cell trait screening is the Extended Parallel Process Model (EPPM). The Extended Parallel Process Model is the most recent fear appeal theory. It attempts to explain when and why persuasive messages may work or fail (Witte & Allen, 2000; Gore, 2005). Fear

appeals can be effective in changing attitude, intentions and behaviors under very specific conditions (Witte, 2000). Fear appeals are most likely to be successful if an individual perceives a high threat and has a high degree of self-efficacy about being able to do something to improve the behavior (Gore, 2005; Witte, 2000).

Gaps in the Literature

The literature consisted of several studies that focused on understanding attitude and beliefs about SCT screening. However, there was no evidence of studies within the U.S. that assess intention to be screened for SCT. In addition, there is no evidence in the literature that reflects the number of individuals who are unaware of their SCT status nor the level of knowledge Africans Americans have of sickle cell trait. Few studies have used the Reasoned Action Approach to address SCT screening in African Americans. There are few studies focusing on SCT screening that measure an individual's strongest predictor of behavior, intention to perform the behavior. In addition, there is little research on the underlying factors influencing the intention to ask for genetic SCT screening in the African Americans. The behavior "sickle cell trait screening" has not been stated in terms of action, target, context and time which would make operationalization and measurement more practical. While the persuasive health framework has been applied to several health domains, it has not been used to understand SCT screening.

This study is novel in that it is the first to use the three global components of the RAA within the context of SCT screening. Therefore, the goals of this research study are: The goals of the study is: 1) to determine if the Reasoned Action Approach (RAA) is an appropriate framework to apply within the context of SCT screening; 2) identify factors

(demographic factors, fear and knowledge beliefs, and RAA constructs) influencing intention to go to your doctor to ask for SCT screening; 3) to determine if exposure to a communication with an explicit recommended response (in the form of a verbal statement) influences mean attitude, perceived norm, and perceived behavioral control, and intention; and 4) to determine if exposure to a communication with an explicit recommended response (in the form of a verbal statement) influences the relative weight (attitude, perceived norm, perceived behavioral control) predicting intention.

CHAPTER 3: METHODOLOGY

The function of this chapter is to explain the methodology implemented for the present research study. In addition to content traditionally included in a methods chapter, this chapter will also include a discussion of analyses conducted and rationale for implementing these analyses. The main study quantitatively examines and analyzes data to answer the question, "What are the factors (demographic factors, fear and knowledge beliefs, and RAA constructs) influencing the intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?" The secondary study part I quantitatively analyzes data to answer the following research questions, "What is the effect of including an explicit recommended response (in the form of a verbal statement) in a brochure, on understanding of brochure, fear beliefs, knowledge beliefs, and reasoned action approach determinants of intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?"; "What is the effect of including an explicit recommended response (in the form of a verbal statement) in a brochure on the relative weight (attitude, perceived norm, perceived behavioral control) predicting intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?" The secondary study part II quantitatively and qualitatively analyses data to answer the follow research questions, "What is the effect of exposure to a brochure sickle cell trait knowledge and sickle cell trait screening knowledge?" and "What is the effect of exposure to a brochure on sickle cell trait and sickle cell trait screening beliefs?"

Development of Brochures

Content Analysis

In preparation for the present study, an analysis of sickle cell brochure content from national and local research institutes and sickle cell agencies (N=10) was conducted to explore how often a recommended response was used to persuade African Americans to get screened for sickle cell trait. None of the brochures explicitly stated a recommended response. However, all of the brochures contained health risk information. Based on the principles of fear appeal, if a communication contains health risk information (threat), it should also contain a recommended response. Therefore, it would be beneficial to not only develop a communication (in the form of a brochure) that includes a recommended response, but also to evaluate the message within the context of sickle cell trait.

Advisory Committee

An advisory committee was assembled to provide the researcher with feedback throughout the development of the brochures. The advisory committee consisted of doctoral students and a full faculty member who is also an applied behavioral scientist who specializes in the design and evaluation of social and behavioral interventions. The faculty member is also a member of the research team for the study. The purpose of the advisory committee was to get input on the brochures to be used in the study. Input included evaluating whether the content (pictures and text) matched the intent of the brochures and evaluating the overall look of the brochures.

Interviews

In addition to utilizing an advisory committee, interviews were conducted with a small sample of participants from members of the target population (N=6). Interviewees

were asked to review the combined implicit and explicit brochure. Interviewees were then asked the following questions: What message does this brochure convey? What characteristics of the brochure helped you to determine the overarching message? The investigator then pointed to the implicit picture and asked, "What message does this picture convey to you?" The investigator also pointed to the explicit text and asked, "What message does this picture/ text convey to you?

Final Decision

After completion of the interviews and additional feedback from the advisory committee, it was decided that the brochure should be simplified to two boxes with basic information and the brochure would include a recommended response in the form of a textual statement but would not include a picture.

Research Design

Main Study

The study was implemented in two parts, a main study (determinants of intention) and a secondary study (effect of brochure). Data for both studies was collected through the use of an online survey with a convenience sample. The main study employed a descriptive, non-experimental cross-sectional research design. The purpose of the main study was to identify and understand factors (attitude, perceived norm, perceived behavioral control) influencing the intention to go to the doctor to ask for sickle cell trait screening. This study measured the Reasoned Action Approach global constructs attitude, perceived norm, and perceived behavioral control as independent variables and intention as the outcome variable. Demographic factors were measured, including age, sex, employment, education level, health care provider status, and partner status (See Appendix B; Conceptual Framework). Knowledge and fear beliefs were measured, including health status awareness, sickle cell trait knowledge, sickle cell trait screening knowledge, perceived threat (perceived susceptibility and perceived severity), and response efficacy.

Secondary Study Part I (Experimental Design)

The secondary study consisted of two designs: (1) a two-group experimental design (brochure without an explicit recommend response vs. brochure plus a recommended response) and (2) a pretest posttest design with before and after a brochure. The purpose of the two-group experimental design was to determine if exposure to a communication with an explicit recommended response (in the form of a verbal statement) influences mean attitude, perceived norm, and perceived behavioral control,

and intention and to determine if exposure to a communication with an explicit recommended response (in the form of a verbal statement) influences the relative weight (attitude, perceived norm, perceived behavioral control) predicting intention. For the purposes of this study, the explicit recommended response was indicated as, "Go to your doctor to ask for sickle cell trait screening."

In the experimental design, Group 1 (control) was exposed to a brochure that contained standard information on sickle cell trait and sickle cell trait screening (Appendix R). Group 2 (intervention) was exposed to a brochure that contains standard information on sickle cell trait and sickle cell screening PLUS an explicit recommended response in the form of a verbal statement (Appendix R). Each participant was randomly assigned to one of the two conditions (control or intervention).

Secondary Study Part II (Pre-Test Post-Test Design)

The purpose of the pre-post design was to determine the effect of exposure to a communication on sickle cell trait knowledge and sickle cell trait screening knowledge. In this design, participants were asked questions to elicit their sickle cell trait and sickle cell trait screening knowledge before and after exposure to a brochure.

For both designs, all participants were shown their assigned brochures for a minimum of ten seconds and then completed an online survey instrument. Viewing of brochures and survey administration were completed via Qualtrics ©2015 survey software. Participants responded to eligibility and consent questions and then reviewed their randomly assigned brochure and then completed a survey instrument. The control brochure (Brochure 1) contained severity, susceptibility, and screening information pertaining to sickle cell trait. The intervention brochure (Brochure 2) contained the same

information in addition to an explicit recommended response, in the form of verbal statement (See Appendix R).

Selection of Behavior Main Study and Secondary Study

When applying the Reasoned Action Approach, it is imperative to first clearly define the behavior of interest. Fishbein (2008) recommends defining (and describing) a behavior using the following four elements: action, target, context, and time. In this study, *going to your doctor to ask for* was selected as the action element; *sickle cell trait screening* as the target; *within the next 12 months* as the time element; and Indiana (Gary, Indianapolis, and Bloomington) as the context. The target, *sickle cell trait screening*, was selected first. One of the outcomes of this study is to inform interventions geared toward increasing the number of African Americans who know their sickle cell trait status. In order for an individual to learn their sickle cell trait status, sickle cell trait screening is required. The action element, *going to your doctor to ask for* was determined second. In order to be screened for sickle cell trait a doctor must ask for the order from a laboratory. The context, Indiana, was selected because the investigator volunteers with a community agency seeking data to develop programs and interventions with goals consistent with this study. Specifically, Gary, Indianapolis, and Bloomington, were selected, in part, due to the investigator's access to the target population within these cities.

Selection of and Participants for Main Study and Secondary Study

Study participants included the following:

1) 18 years of age or older

2) African American

3) Do not know their sickle cell trait status

4) Residents of Indianapolis, Gary, or Bloomington, Indiana (Verified through self- reported zip code)

Sample Size

Main Study and Secondary Study

The study has a desired sample size of 300. G* Power and Cohen (1998) Statistical Power Analysis were used to calculate the most appropriate sample to perform the Multivariate Analysis of Variance (MANOVA) and Linear Multiple Regression. The statistical level of significance, effect size, power, and estimated variance were all predetermined in calculating the power analysis. In an effort to be conservative in determining the sample size, a small effect size was used in the MANOVA calculation and a medium effect size was in the regression. An alpha level of .05 was used to calculate the sample size for both analyses. All levels and effect sizes were supported by the literature on predicting intention for various health screenings (mammography, colorectal cancer, HIV). A total of twenty-two predictors were used to calculate the sample size for the regression analysis. This was the maximum number of predictors that could be used based on the constructs within the survey instrument. However, not all constructs were used in the analysis.

G*Power indicated sample sizes lower than the sample size selected for the secondary study. However, if variables were to be added in the analyses at a later stage, it would be beneficial to have a sample size that exceeds the requirement. Required sample size the regression analysis was 200 while the required sample size for the MANOVA was 130.

Sampling Frame

Main Study and Secondary Study

The present study utilized purposeful, voluntary sampling to identify participants for recruitment. Participants were recruited via email, word-of-mouth, and flyers in select locations throughout Indianapolis and Gary, IN.

To be eligible for this study, participants met the following criteria: 1) be aged 18-35; 2) self-identify as African American; 3) could not know their sickle cell trait status; and 4) reside in Indianapolis or Gary, Indiana. Individuals with sickle cell disease were excluded from this study because they inherently have sickle cell trait. Indianapolis and Gary were selected because they have the highest African American populations in Indiana (See Appendix G). Fort Wayne was a third option; however, the investigator was not familiar with the city and this could have made data collection challenging. The 18-35 age range was selected to capture a young reproductive population. While interested in the entire 18-35 age range, the investigator has a particular interest in participants who are in the beginning stages having children (i.e., having no children or one child). Individuals who are within this age range and do not know their sickle cell trait status, run the risk having a child with sickle cell disease without knowing it. In addition, this age was selected in an effort to increase the ability of individuals within reproductive age to make informed reproductive decisions. African Americans were selected due to the interest of the investigator and literature to support African Americans as being the population most impacted by sickle cell trait. The locations, Indianapolis and Gary, were selected due to the evidence shown that these cities have the highest rates of sickle cell trait throughout Indiana (See Appendix H).

An eligibility screening tool was developed and utilized to ensure participants meet the outlined eligibility requirements of the study. Eligibility screening was conducted through contact between the prospective participant and the investigator. All persons who met the eligibility criteria and volunteered to participate in the study were provided a link to an online version of the survey to complete. The survey also included two inclusion questions: 1) Do you self-identify as being Black/African American or mixed with Black/African American? and 2) Do you know your Sickle Cell *Trait* status?

Final Sample for Analysis

Qualtrics reported a 1% dropout rate, meaning participants started the survey but did not return to complete it within 72 hours. One survey was discarded due to age ineligibility (these surveys were actually completed); three surveys were discarded due to location ineligibility (these surveys were actually completed); and four surveys were discarded because participants only completed the eligibility questions prior to the closing of the survey. Qualtrics did not include this in the dropout rate because these were manually removed by the investigator. Final sample for analysis is 300 African Americans ages 18-35 who do not know their sickle cell trait status.

Measures

Main Study and Secondary Study

A 45-item online questionnaire was completed by all participants. Constructs within the survey instrument were based on the EPPM and the RAA. The study measured the RAA global constructs attitude, perceived norm, and perceived behavioral control as well as intention to go to your doctor to ask for sickle cell trait screening as the dependent variables. In addition, the constructs, response efficacy, and perceived threat (perceived

susceptibility and perceived severity) from Witte's Extended Parallel Process model was measured as fear beliefs (See Appendix C for Conceptual Framework). Other factors included knowledge beliefs (awareness of sickle cell trait/screening, pre sickle cell trait knowledge, pre sickle cell trait screening knowledge, post sickle cell trait knowledge, post sickle cell trait screening knowledge), understanding of brochure (brochure clarity and recognition of main point of the brochure). Basic demographics were measured, including age, gender, employment, education level, health care provider status, and health status. The questions used to measure each construct can be found in Appendix J.

RAA Items

Items assessed in the instrument from the RAA were intention, attitude toward going to the doctor to ask for sickle cell trait screening within the next 12 months, perceived norm, and perceived behavioral control (See Appendix L). Intention was assessed using four items. One 6-point item ranging from 0 to 5 and two 7-point items ranging from -3 to 3 were averaged to measure intention: "How LIKELY or UNLIKELY are you to go to your doctor to ask for sickle cell trait screening in the next 12 months? (*extremely unlikely* to *extremely likely*); "I intend to go to my doctor to ask for Sickle Cell *Trait* screening within the next 12 months." (*extremely disagree* to *extremely agree*); and "What statement best describes your intention when it comes going to your doctor to ask for screening for Sickle Cell *Trait*?" (Five statements listed) The 5-point item was rescaled prior to being averaged with the 7-point items. The new scale for the rescaled item ranged from -1 to 3. The Cronbach's α for a scale with four items was a moderate value of .763.

Attitude toward the act (attitude) was assessed using four items. Of these items two characterized the first component of attitude, instrumental, while two items represented the second component of attitude, experiential. Items representing instrumental included, "Would it be GOOD or BAD for you to go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely bad* scale to *extremely good*) and "Would it be WISE or FOOLISH for you to go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely foolish* to *extremely wise* scale). Items representing experiential included: "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is ___" (*extremely boring* to *extremely fun);* and "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is ___" (*extremely unenjoyable* to *extremely enjoyable* scale). All items were measured using 7-point scales ranging from -3 to 3 and were then averaged to assess mean attitude. The Cronbach's α for a scale with four items was a moderate value at .712.

Perceived norm was assessed using four items. Of these items two characterized the first component of perceived norm, descriptive, while two items represented the second component of perceived norm, injunctive. Items representing injuctive included: "How LIKELY or UNLIKELY is it that African Americans age 18-35, WHO ARE LIKE YOU would ask for Sickle Cell Trait screening from their doctor in the next 12 months?" (*extremely unlikely* to *extremely likely* scale) and "How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU think you should ask for Sickle Cell Trait screening from your doctor in the next 12 months?" (*extremely unlikely* to *extremely likely* scale). Items representing descriptive included: How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU would

approve of you going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely unlikely* to *extremely likely* scale) and "How many of the people whose opinion you value would go to their doctor to ask for Sickle Cell Trait screening from their doctor in the next 12 months?" (*virtually none* to *virtually all* scale). All items were measured using a 7-point scale ranging from -3 to 3 and averaged to assess mean perceived norm. The Cronbach's α for a scale measuring all four items was moderate at .700.

Perceived behavioral control was assessed using four items. Of these items two characterized the first component of perceived behavioral control, capacity, while two items represented the second component of perceived norm, autonomy. Items representing capacity included: "How SURE are you that you will go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*not at all sure* to *very sure* scale*)* and "I am CONFIDENT that I can go to the doctor to ask for Sickle Cell Trait screening in the next 12 months." (*extremely disagree* to *extremely agree* scale). Items representing autonomy included: "How much UNDER YOUR CONTROL is going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*not at all under my control* to *completely under my control* scale) and "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is UP TO ME." *(not at all up to me* to completely *up to me* scale). After review of the Cronbach's α if items were deleted, one item, "How much UNDER YOUR CONTROL is going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" was deleted. Thus, three 7-point items ranging from -3 to 3 were averaged to measure mean perceived behavioral control. The Cronbach's α the final three items was a low value at .460. The low Cronbach's

alpha value has been acknowledged as a limitation in the limitations section of this dissertation.

Knowledge and Fear Belief Items

Knowledge and fear beliefs consisted of five constructs: perceived threat, response efficacy, awareness of sickle cell trait/screening, sickle cell trait knowledge, and sickle cell trait screening knowledge. Perceived threat was assessed using four items. Of these items, two characterized the first component of perceived threat, severity, while two items characterized the second component, susceptibility. Items representing severity included: "I believe that sickle cell trait is severe." (*extremely disagree* to *extremely agree* scale) and "Sickle cell trait has serious negative consequences." (*extremely disagree* to *extremely agree* scale). Items representing susceptibility included: "I am at risk for having sickle cell trait." (*extremely disagree* to *extremely agree* scale) and "It is possible that I could have sickle cell trait." (*extremely disagree* to *extremely agree* scale). All items were measured on a 7-point scale ranging from -3 to 3 and were then averaged to assess perceived threat. The Cronbach's α for a scale with four items was low at .595.

Response efficacy was assessed using one item: "Going to your doctor to get screened for sickle cell trait is an effective method for learning your sickle cell trait status." (*extremely disagree* to *extremely agree* scale). This item was measured on a scale ranging from -3 to 3.

Awareness of sickle cell trait/screening was included as a score comprised of three items. All items were measured on a 3-point scale ranging from 0 to 2: "Have you personally known or know anyone who has Sickle Cell *Disease*?" (No/Unsure/Yes); "Prior to today, had you ever heard of *Sickle Cell Trait*?" (No/Unsure/Yes); and "Have

you personally known or know anyone who has *Sickle Cell Trait*?" (No/Unsure/Yes). Responses to these items were added to assess awareness of sickle cell trait/screening. The Cronbach's α for a scale with three items was a moderate value of .726.

Sickle cell trait pre-knowledge and sickle cell trait post-knowledge were assessed by coding responses to the following question: "In your own words, what does sickle cell trait mean to you?" This question was asked twice in the survey. If the question was asked prior to viewing the brochure, the variable was called "pre-knowledge." If the question was asked after the brochure was viewed, the variable was called "post-knowledge." Coding for sickle cell trait knowledge and sickle cell trait screening knowledge was adapted from a previous instrument by Treadwell, McClough, and Vichinsky (2006). Responses to this item were recoded as incorrect, partially correct, and completely correct. Partially Correct responses made reference to the hereditary nature of sickle cell trait or indicated the manifestation of sickle cell trait such as sickling of the red blood cells (Ex. "an inherited gene" "Having a sickle shaped cell.") Completely correct responses indicated that sickle cell trait means you are a carrier for sickle cell disease and made reference to the hereditary nature of the trait (Ex. "It means you are a carrier for sickle cell.").

Sickle cell trait screening pre-knowledge and sickle cell trait screening post-knowledge were assessed by coding responses to the following question: "In your own words, what does getting screened for Sickle Cell Trait mean to you?" This question was asked twice in the survey. If the question was asked prior to viewing the brochure, the variable was called "sickle cell trait screening pre-knowledge." If the question was asked after the brochure was viewed, the variable was called "sickle cell trait screening post-

knowledge." Coding for sickle cell trait knowledge and sickle cell trait screening knowledge was adapted from a previous instrument by Treadwell, McClough, and Vichinsky (2006). Partially correct made reference to finding out or being told if you have sickle cell trait (Ex. "To be notified if I have the trait.") Completely correct responses indicated testing or screening (genetic or blood) to determine if you have sickle trait (Ex. "It means that you will take a test to see if you have the sickle cell trait. A blood test.")

Responses to the questions, "In your own words, what does getting screened for Sickle Cell Trait mean to you?" and "In your own words, what does getting screened for Sickle Cell Trait mean to you?" were also analyzed for content and recoded as sickle cell trait beliefs and sickle cell trait screening beliefs, respectively. Please see Appendix M for a description of this analysis.

Understanding of Brochure Content

Recognition of intended main point was assessed as one open ended question, "What is the main point of the brochure?" Responses were then coded as "incorrect" or "correct" to create a binary variable. Perceived brochure clarity was assessed using one closed ended item "The information in the brochure was clear and easy to understand" (*extremely disagree* to *extremely agree* scale). This item measured on a 7-point scale ranging from -3 to 3.

Demographic Factors

Demographic variables included education level, employment, health care provider status, general health status, sex, and age (See Appendix A; Conceptual Framework). Education was coded as less than high school, some high school, high

school diploma or GED, some college, college degree, or graduate work or degree. Employment was coded as unemployed, employed part-time, employed full-time, and student. Income level was coded as <$10,000, $10,000-$19,999, $20,000-$29,999, $30,000-$39,999, $40,000-$49,999, ≥$50,000. Marital status was coded as single not in a relationship, single in a relationship, cohabitating, married, separated/divorced, and widowed. Health insurance status was coded as uninsured, employer paid insurance, and Medicaid/Medicare. General health status was coded as excellent, very good, good, fair, or poor. Sex was assessed as a binary variable. Age was included as a continuous variable.

Recoding of Demographic Variables

For the main study analysis, some demographic factors were recoded from dissertation format. These factors included employment, marital status, and health insurance status. Employment was recoded as unemployed/student, employed part-time, and employed full-time. Marital status was recoded to represent a new binary variable "Partner status" to reflect not in a relationship and in a relationship. Health insurance status was recoded as binary variable to represent uninsured and insured.

Additional Items

The instrument used to collect data for this study consisted on additional items: parity, future parity, athlete status, and military status. These items will not be analyzed within main or secondary study. For descriptions of how these items were measured please see the construct table in Appendix L.

Placement of Items

While most items were asked after viewing the brochure, there were items that were asked both before and after viewing the brochure and included as pre/post constructs for sickle cell trait and sickle cell trait screening knowledge. These items "In your own words, what does sickle cell trait mean to you?" and "In your own words, what does sickle cell trait screening mean to you?" In addition, some items were asked after viewing the brochure as manipulation checks for understanding of brochure content and were included in the constructs, recognition of intended main point and perceived brochure clarity. These items were: "What is the main point of the brochure?"; "What helped you to determine the main point of the brochure?" and "Please rate your level of agreement with the following statement, "The information in brochure was clear and easy to understand."

Procedures

Main Study and Secondary Study

Study protocol was approved by the Indiana University Institutional Review Board (See Appendix E).

Arrangements for Conducting the Study for Main Study and Secondary Study

Recruitment took place over a two-month period during April and May 2015. A convenience sampling technique was used to target a non-representative subgroup from the larger African American population. This sampling method was selected because it is based on preselected criteria according to the research of interest (Merriam, 2009). Locations for recruitment included: Indiana Hemophilia and Thrombosis Center, Martin Center Sickle Cell Initiative, Indianapolis Churches, Indiana University (minority sororities and fraternities), Indianapolis Public Library locations, churches located in

Gary, and Gary Community Organizations. These locations were selected to increase variation in participants in the following areas:

1) The locations are areas which are visited or congregated by individuals who do and do not fit the target demographic.
2) The variety of locations (public libraries, colleges, churches, clinics, community organizations) allow for a range of ages, employment status, income, and health status.
3) The investigator is from Gary and lived and worked in Indianapolis making it easier to track and modify recruitment.

Process of Recruiting Participants

The investigator sought permission to leave and post flyers for at each location. The survey link was located on the flyer. Individuals interested in participating could follow the link on the survey or directly contact the investigator to have the link sent to them or to set up a time to complete the survey in person. A sample of the flyers can be found in Appendix Q. In addition, the social network site, Facebook, was used to advertise the study to potential participants. The social media method was used to extend the investigator's reach to the target population. Facebook has been used in studies as an alternative recruitment method when participation rates are low (Tan, H., *et al.*, 2012; O'Shaughnessy P.K., *et. al*., 2013). The link was embedded into ten Facebook pages as opposed to using Facebook to advertise the survey. Use of Facebook employed a convenience sampling method as the investigator would increase participation by asking Facebook "friends" to share the link to the survey. For a complete list of all recruitment methods, please see Appendix I.

Survey Administration for Main Study and Secondary Study

Surveys were distributed through Qualtrics survey software. Online surveys were selected to allow participation in the study without requiring the investigator to be present. An online survey through Qualtrics allowed for random assignment to a condition (brochure). A paper version of the survey was available to participants who wish to participate but do not have access to technology. This version of the survey was completed in the presence of the investigator and returned to the investigator once the survey has been completed. Participants were provided an incentive of $15 in the form of a gift card for their contribution to the study.

Survey Administration Part II (Salient Belief Elicitation)

Participants were offered the opportunity to answer a set of survey questions that were not included either portion of the dissertation study. This opportunity was offered until twenty-five participants had completed the second set of questions. The second set of questions consisted 8 items. Of these 8 items, 2 assessed knowledge (sickle cell trait and sickle cell trait screening) and 6 items elicited salient beliefs (behavioral, normative, and control) about going to your doctor ask for sickle cell trait screening. In addition, twenty-five participants outside of the study were asked the same set of questions. These participants were not eligible for the either portion of the dissertation study because they were aware of their sickle cell trait status. However, these participants did fit the other characteristics of the study population (i.e. African American, aged 18-35, residents of Gary, Indianapolis, or Bloomington).

Data Validity and Reliability

1. To ensure that adequate data was obtained from the participants multiple strategies were used to minimize both unit and item response bias.
    a. To reduce item non-response, the researchers checked questionnaires for completeness. However, it is important to note that the IRB requirement to include "voluntary" clause in instructions/introduction gives respondents the choice to leave any questions they do not want to answer.
    b. To reduce non-response, facilities were visited multiple times to capture those working on different days or shifts.
2. For construct validity, the items in the survey were modeled on the theoretical framework to measure the theoretical constructs of interest for a specified behavior. Additional constructs that were not derived from previous theoretical frameworks had been used in instruments in related studies.
3. To address the risk of bias from answering questions in a socially desirable manner, participants were not required to provide any personally identifying information and the need to adequately and completely respond was communicated to them.
4. For reliability, clear questions and ease of navigating the survey were considered during instrument development. Additionally, the instrument was pre-tested before data collection commenced to ensure comprehension, ease of navigation and length, which were adjusted accordingly based on the feedback. This pre-testing consisted of having committee members, other doctoral students, and

members of the target population (n=2) either read or take the survey prior to the survey being implemented.

5. Cronbach's alpha was used to test internal consistency reliability of multiple items used to measure single variables such as underlying beliefs used to estimate the global theoretical constructs or items used to measure intention and other global construct

Missing Data Statement

There were no missing data to report on this study. This was confirmed through frequency analysis of all variables.

Statistical Analysis

Main Study (Determinants of Intention)

All statistical analyses were conducted using IBM version 22.0 Statistical Package for the Social Sciences (SPSS). There were other options for statistical software. However, the investigator has the most experience using SPSS and would like to use the option in which she is most knowledgeable. Descriptive statistics on all outcome variables were obtained (See Appendix N Tables 1 &12). Three step sequential ordinary least squares regression was used to predict intention using the independent variables, demographic factors, knowledge and fear beliefs, and the three RAA global constructs (Appendix N, Table 6). Reliability analysis was used to measure internal consistency of constructs (See Appendix N, Table 3). Pearson correlation analysis was used to determine which variables to include in the regression analysis (See Appendix N, Table 4).

Regression Assumption Diagnosis

Visual displays and statistical tests were used to check for violations of the regression assumptions in a preliminary model. The plots and test results indicated that the data met all the assumptions except for the normality assumption. Below are the summary results of regression assumption diagnostics:

- Normality: Shapiro-Wilk *W* test for normal data was statistically significant at p=.01. QQ-plots also reflected deviation from normality. Therefore, the normality assumption was violated. Before correcting this violation via variable transformation, the pattern of the residuals was checked for patterns.
- Independence of residuals was checked using the residual-fitted values plot and no patterns were observed. Since there were no patterns in the residuals, the outcome variable was not transformed.
- The multicollinearity assumption was met with all variance inflation factor statistics below 2.0. The overall VIF means was 1.42 and ranged from 1.138-1.931.
- In a cross sectional study, OLS regression assumes a random sample. The sample for the main study employing OLS regression did not use a randomized sample. This is a limitation of the study and is acknowledged in the limitations section.

Secondary Study Part I (Experimental Design)

All statistical analyses were conducted using IBM version 22.0 Statistical Package for the Social Sciences (SPSS). Descriptive statistics on all independent and outcome variables were obtained (See Appendix O, Table 1).

Chi Square analysis was conducted on all demographic variables to determine if there were differences in the sample characteristics between brochure groups (See Appendix O, Table 4). Results of this analysis indicated that brochure groups were different in their education. No other differences were observed.

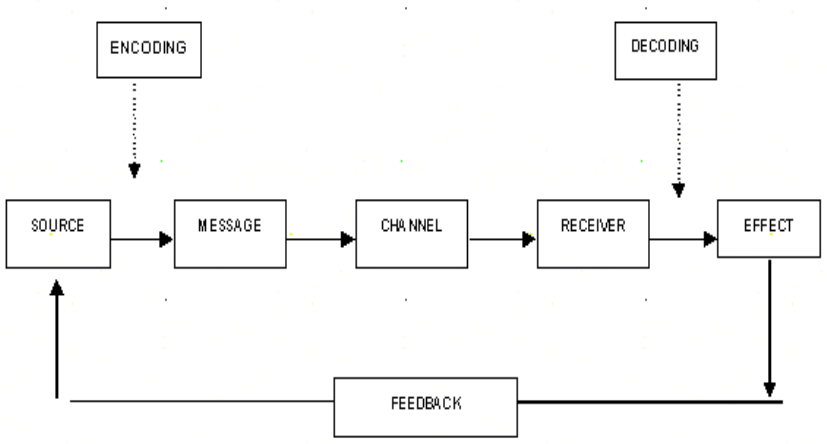
The first research question for secondary study part I was, "What is the effect of exposure to a communication with an explicit recommended response (in the form of a verbal statement) on fear beliefs, knowledge beliefs, and reasoned action approach determinants? A two-group experimental design with post-test measurements was conducted to determine the effect of exposure to a communication with an explicit recommended response (in the form of a verbal statement) on knowledge and fear beliefs, and reasoned action approach factors.

Tests Conducted to Answer Secondary Study Part I (Experimental Design)

A Multivariate Analysis of Variance (Manova) examined the effect of brochure group as the independent variable and recognition of the intended main point, perceived clarity of the brochure, sickle cell trait knowledge, sickle cell trait screening knowledge, perceived threat, response efficacy, attitude, perceived norm, perceived behavioral control, and intention as dependent variables (See Appendix O Table, 5). The results of the MANOVA indicated the multivariate F test was not significant. Univariate *F* tests showed there was a significant difference between brochures groups on recognition of the

intended main point and awareness of sickle cell trait/screening. However, there were no additional differential effects of the brochure. Therefore, a second MANOVA was conducted using brochure group as in the independent variable and recognition of the intended main point as a covariate.

The rationale for using recognition of intended main point as a covariate was due to the communicative nature of the study. The study is grounded in communication theory. According to the basic communication process model, a sender conveys messages to one or more receivers with the purpose of establishing a change in the knowledge, attitude and, ultimately, the behavior (See image below) (Foulger, 2004). If behavior



change is to occur, the message recipient must be able to decode the message, i.e. recognize the main point of the brochure.

The MANCOVA was conducted to examine the effect of brochure group as the independent variable and perceived clarity of the brochure, sickle cell trait knowledge, sickle cell trait screening knowledge, perceived threat, response efficacy, attitude, perceived norm, perceived behavioral control, and intention as dependent variables, using recognition of the intended main point as the covariate (See Appendix O, Table 6).

When using recognition of the main point as a covariate the results of the MANOVA indicated the multivariate F test was not significant. The univariate *F* tests indicated there was a significant difference between brochures groups on participants' awareness of sickle cell trait/screening and perceived norm. There were no other differential effects of the brochure. As a result of finding non-significant results the investigator elected to explore other areas in which the brochure groups might have been different. One of these areas was beliefs.

Introduction of a New Research Question to the Secondary Study Part I (Experimental Design)

At this point, the investigator introduced a new question, "What is the effect of exposure a communication with an explicit recommended response on sickle cell trait and sickle cell trait screening beliefs. As previously indicated, responses to the questions, "In your own words, what does sickle cell trait mean to you?" and "In your own words, what does sickle cell trait screening mean to you?" were coded as sickle cell trait and sickle cell trait screening beliefs. Since these questions were asked before and after viewing the brochure, pre and post beliefs were coded. For full coding of these beliefs, please see Appendix M. The codes sorted into general categories. There were 12 categories of post sickle cell trait beliefs and 11 categories of post sickle cell trait beliefs. A MANOVA was conducted to examine the effect of brochure group as the independent variable and sickle cell trait beliefs and sickle cell trait screening beliefs as dependent variables (See Appendix P, Table 2). Neither the multivariate F nor univariate tests yielded significant results.

MANOVA to Assess the Effect of the Brochure on Beliefs

Similar to the steps in the analysis for research question 1, the covariate effect of recognition of the main point was also examined through MANOVA for the beliefs. MANOVA was conducted to examine the effect of brochure group as the independent variable and sickle cell trait beliefs and sickle cell trait screening beliefs as dependent variables (See Appendix P, Table 3). Neither the multivariate F nor univariate tests yielded significant results. After obtaining these results further consultation with dissertation committee members was sought. One of these consultations resulted in the option of a new test, the Kruskal Wallis test.

Kruskal Wallis to Assess the Effect of the Brochure on Beliefs (Experimental Design)

The Kruskal Wallis test is a non-parametric test that should be used to analyze data in which the independent variable represents independent sample data and the dependent variables represent binary data. Therefore, the Kruskal Wallis test was an option to re-conduct the analysis in the previous paragraph. The Kruskal Wallis test of independent samples was conducted to determine the effect of brochure group as the independent variable and sickle cell trait beliefs and sickle cell trait screening beliefs as dependent variables (See Appendix P, Table 4). This test did not yield any significant results. At this point, it was decided that the results would be reported and analysis would continue by moving on to secondary study research question 2.

Tests Conducted to Answer Secondary Study Part I (Experimental Design)Research Question II

Secondary study part I, research question 2 was, "What is the effect of including an explicit recommended response (in the form of a verbal statement) in a brochure on the relative weight (attitude, perceived norm, perceived behavioral control) predicting

intention to go to the doctor to ask for sickle cell trait screening within the next 12 months?" Regression analysis was used to determine of the effect of exposure to a recommended response (in the form of a verbal statement) on the relative weight (attitude, perceived norm, perceived behavioral control) predicting intention to go to the doctor to ask for sickle cell trait screening (See Appendix P, Table 1). The interaction effect of the binary variable, "brochure group," and the independent variables (attitude, perceived norm, and perceived behavioral control) on intention was tested. Results of regression analysis were not significant for all interaction terms.

After reviewing the results of the regression analysis, the investigator consulted with members of the dissertation committee to reassess the research questions and to explore areas in which the brochure may have had an effect. As discussed in the instrument development section, sickle cell trait and sickle cell trait screening knowledge were assessed before and after the brochure was viewed. By collecting the data in this manner, it was determined that a pre/post design had been conducted. Therefore, the next step was to introduce a new research question to the secondary study.

Secondary Study (Effect of Brochure/Pre-Test Post-Test Design) Part II

Research question four of the secondary study was, "What is the effect of exposure to any brochure on sickle cell trait and sickle cell trait screening knowledge?" A pretest-posttest design was conducted to determine the effect of exposure to a brochure on sickle cell trait knowledge and sickle cell trait screening knowledge. T-Test compared pre and post knowledge scores for sickle cell trait knowledge and sickle cell trait screening knowledge to determine the effect of exposure to a brochure (See Appendix O,

Table 7). Results indicated a significant difference in the mean of sickle cell trait knowledge but not sickle cell trait screening knowledge.

A pretest-posttest design was implemented to determine the effect of exposure to any brochure on sickle cell trait beliefs and sickle cell trait screening beliefs. Initially t-tests and chi square tests were explored as options for detecting difference in pre/post beliefs. However, these tests are most appropriately used for detecting differences in paired samples using continuous data. The belief constructs are binary variables. Therefore, a test that can detect differences in paired samples using categorical data would be most appropriate. Therefore, a McNemar Test (See Appendix O, Tables 8 & 9) was used to compare differences in the frequency of sickle cell trait and sickle cell trait screening beliefs. Recall, there were 12 categories of beliefs for sickle cell trait and 11 categories of beliefs for sickle cell trait screening. All categories were used in the analysis. The analysis yielded several significant results. Please see Appendix O for details of the results.

CHAPTER 4: MANUSCRIPT

Applying a behavioral theory to identify determinants of sickle cell trait screening: A Reasoned Action Approach

Tilicia L. Mayo-Gamble, MA, MPH, CHES, Susan E. Middlestadt, PhD, Hsien-Chang Lin, PhD, Priscilla Barnes, PhD, Pamela Braboy Jackson

Indiana University School of Public Health-Bloomington

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Applying a behavioral theory to identify determinants of sickle cell trait screening: A Reasoned Action Approach

Abstract

Background: In order to make informed reproductive decisions within the context of sickle cell disease, it is important for African Americans to know their sickle cell trait status. To develop interventions to increase sickle cell trait screening it would be beneficial to use a behavioral theory to identify determinants of this behavior. The Reasoned Action Approach (RAA) is a behavioral theory that has been successfully used to identify determinants of health behavior but has not been applied within this context. This study applies the RAA to identify determinants of intention to go to your doctor to ask screening for sickle cell trait.

Method: As part of a larger study, 300 African Americans ages 18-35 from three cities throughout Indiana completed an online cross-sectional survey assessing theory-based items on the behavior of interest. Sequential ordinary least squares regression analysis identified determinants of intention.

Results: In sequential regression analyses, RAA constructs influenced intention over and above demographic factors and knowledge and fear beliefs (R^2 = .644, p < .001). Perceived behavioral control had the highest relative weight (β = .579, p<.001). Attitude and perceived norm had significant weights (β = .354 and β = .177, p<.001, respectively).

Discussion: The RAA is an appropriate theory for identifying determinants of intention to go to your doctor to ask for sickle cell trait screening among this population. Interventions designed to increase intention should focus on positively influencing

attitude, perceived norm, and perceived behavioral control. Emphasis should be placed on increasing perceived behavioral control regarding sickle cell trait screening.

Keywords: sickle cell trait, screening, Reasoned Action Approach, intention

Abstract Word Count: 250

Applying a behavioral theory to identify determinants of sickle cell trait screening: A Reasoned Action Approach

Sickle cell disease is the most common genetic blood disorder in the United States. It primarily affects individuals of African descent (NHLBI, 2009). Sickle cell trait is the carrier state for sickle cell disease (MCSI, 2012). Individuals with sickle cell trait are known as carriers of sickle cell disease. Sickle cell trait occurs among about 1 in 12 Blacks or African Americans., 8.3% of African Americans (CDC, 2010; NHLBI, 2009). Although most individuals with sickle cell trait are asymptomatic, sickle cell trait has been associated with SCT status with health consequences, there is evidence of increased risk of several health conditions. These conditions include: hyposthenuria, hematuria, sickling under extreme conditions (e.g., excessive exertion and high altitudes), eye abnormalities and an increase in the expression of microvascular diabetic complications (SCDAA, CDC, 2011; Motulsky, 1973; Kark, Posey, Schumacher, Ruehle, 1987).

Despite the fact that sickle cell trait is identified in the course of newborn screening, there is no universal method of notification (Pass *et al*., 2000; Gustafson, Gettig, Watt-Morse, Krishnamurti, 2007). As a result, many carriers are unaware of their sickle cell trait status (Pass et al., 2000). It is important for individuals who have a predisposition for sickle cell trait to know their status so that they may take steps to reduce their risk for complications as well as understand the implications for reproduction. However, similar to other studies on genetic screening, research on screening for sickle cell trait reflect that African Americans have poor uptake of screening despite positive attitude towards the behavior (Gustafson *et al*., 2007; Long et al., 2010; Acharya *et al.,* 2009). As a result, there is a need to identify other factors

influencing this specific screening behavior. The Reasoned Action Approach (RAA) is a behavioral theory that has been successful used to understand factors influencing health behavior (Armitage & Connor, 2010; McEachan, Connor, Taylor, Lawton, 2011; Sheats, Middlestadt, Ona, Juarez, Kolbe, 2013; Lederer & Middlestadt, 2014). This theory posits that in addition to attitude, perceived norm and perceived behavioral control. The RAA has not been applied to understanding factors influencing screening for sickle cell trait. Therefore, the purpose of this study is to determine if the RAA can be applied to this behavior and to determine which of the three global components (attitude, perceived norm, and perceived behavioral control) is associated with the intention to go to your doctor to ask for sickle cell trait screening within the next 12 months.

Conceptual Framework

The conceptual framework for this study was guided by the Reasoned Action Approach (RAA). The RAA is the most recent formulation of the Theory of Reasoned Action, the Theory of Planned Behavior, and the Integrative Model (Fishbein & Ajzen, 2010). This framework has been used successfully in a number of domains (dark green leafy vegetable consumption; asking parents for fruits and vegetables, etc.) to understand the psychosocial factors underlying people's decisions to engage in health behaviors with the goal of improving health (Armitage & Connor, 2010; McEachan, Connor, Taylor, Lawton, 2011; Fishbein & Ajzen, 2010). The theory asserts that intention is the primary, immediate predictor of behavior. When applying the Reasoned Action Approach, it is imperative to first clearly define the behavior of interest. Fishbein (2008) recommends defining (and describing) a behavior using the following four elements: action, target, context, and time. In this study, *going to your doctor to ask* was selected as the action

element; *sickle cell trait screening* as the target; *within the next 12 months* as the time element; and Indiana (Gary, Indianapolis, and Bloomington) as the context. These elements were based on the premises that: 1) in order for an individual to learn their sickle cell trait status, sickle cell trait screening is required; and 2) in order to be screened for sickle cell trait a doctor must ask for the order from a laboratory.

Intention is defined as an individual's readiness to perform the behavior (Fishbein & Ajzen, 2010). According to the theory, any given behavior is likely to occur if one has a strong intention to perform the behavior, has the necessary skills and abilities required to perform the behavior, and there are no environmental constraints preventing behavioral performance. The RAA predicts intention from a weighted combination of three global components: attitude toward the act, perceived norm, and perceived behavioral control (Fishbein, 2008; Fishbein & Ajzen, 2010). The first component, attitude toward the act, determines people's attitude toward performing the behavior. These attitude are a positive or negative evaluation of performing the behavior (Fishbein & Ajzen, 2010). The second global component, perceived norm, are the perceived pressure from referents (people who approve or disapprove of the individual performing the behavior) to engage or not to engage in the behavior (Fishbein & Ajzen, 2010). The final component, perceived behavioral control, is a sense of low or high self-efficacy with regard to performing the behavior (Fishbein & Ajzen, 2010). These components guide the decision to perform or not to perform a specific behavior.

An adapted RAA framework was used to identify determinants of influencing intention to go to a doctor to ask sickle cell trait screening within the next 12 months. The framework suggests that in order to increase the number of African Americans who go to

their doctor to ask for sickle cell trait screening within the next 12 months, it is first important to determine which factors (demographics, knowledge and fear beliefs, or RAA factors) influence their intention to perform the behavior.

Constructs from the Extended Parallel Process Model (EPPM) were used within the conceptual framework as *fear beliefs* (perceived threat and response efficacy). The EPPM provides constructs that are useful for understanding behaviors or actions performed to avoid a threat (Witte & Allen 2000; Witte, Meyer, & Martell, 2001; Papova, 2012). According to the main principles of the EPPM, when an individual is exposed to a fear appeal, two cognitive appraisals of the message will occur, "appraisal of the threat" and, the "appraisal of the efficacy of the message's recommended response" (Witte, Meyer, & Martell, 2001, p. 24). The construct for the appraisal of threat in the EPPM is perceived threat. Perceived threat is comprised of two sub-constructs called perceived susceptibility and perceived severity. Perceived susceptibility is known as the possibility of the threat, while perceived severity is known as the magnitude of the threat.

[Insert Figure 1]

Methods

Data Collection

Data were collected from March through May 2015 in Indianapolis, Gary, and Bloomington, Indiana. All community members who agreed to participate in this study responded to the survey after consent was obtained. All study procedures were approved from the Institutional Review Boards of the authors' institution.

Study Design and Participants

As part of a larger study, a descriptive online cross-sectional survey of 300 African Americans between the ages 18-35 was conducted in three cities throughout Indiana was conducted between April and May 2015. Convenience sampling was implemented for recruitment from various locations throughout Indianapolis (n=93), Gary (n=181), and Bloomington (n=26) in Indiana including faith-based institutions, educational institutions, and libraries. Flyers and study informational sheets were provided to all recruitment sites and to key stakeholders. Participants were considered eligible if they were ages 18-35; self-identified as Black/African American or mixed race with Black/African American; did not know their sickle cell trait status; and resided in Indianapolis, Gary, or Bloomington, Indiana. Exclusion questions were asked at the beginning of the survey to eliminate anyone who did not meet the study's criteria. Upon completing the survey, participants were provided a $15 gift card to show appreciation for their contribution to the study.

Instrument

An online self-administered, open and closed ended questionnaire assessed demographic factors, fear and knowledge beliefs, and RAA constructs for intention to go to a doctor to ask screening for sickle cell trait. Constructs within the survey instrument were based on the RAA and the EPPM. The study measured the RAA global constructs attitude, perceived norm, and perceived behavioral control as well as intention to go to a doctor to ask for sickle cell trait screening as the dependent variables. In addition, the constructs, response efficacy, and perceived threat (perceived susceptibility and perceived severity) from Witte's Extended Parallel Process model was measured as demographic factors (See Appendix B for Conceptual Framework). Other demographic

factors included awareness, pre-knowledge, post-knowledge, brochure clarity, and main point. Basic demographics were measured, including age, gender, employment, education level, health care provider status, and health status.

Measures

Demographic Factors

Demographic factors included education level, employment, income level, health care provider status, perceived general health status, sex, and age (See Appendix A; Conceptual Framework). Education level was coded as less than high school, some high school, high school diploma or GED, some college, college degree, or graduate work or degree. Employment was coded as unemployed/student, employed part-time, and employed full-time. Income level was coded as <$10,000, $10,000-$19,999, $20,000-$29,999, $30,000-$39,999, $40,000-$49,999, ≥$50,000. Marital status was recoded to represent a new binary variable "Partner status" to reflect if a participant was not in a relationship or in a relationship. Health insurance status was recoded as binary variable to represent uninsured and insured. Perceived general health status was coded as excellent, very good, good, fair, or poor. Sex was assessed as a binary variable. Age was assessed as a continuous variable.

Knowledge and Fear Belief Items

Knowledge and fear beliefs consisted of five constructs: perceived threat, response efficacy, awareness of sickle cell trait/screening, sickle cell trait knowledge, and sickle cell trait screening knowledge.

Perceived threat was assessed using four items. Of these items, two characterized the first component of perceived threat, severity, while two items characterized the

second component, susceptibility. Items representing severity included: "I believe that sickle cell trait is severe." (*extremely disagree* to *extremely agree* scale) and "Sickle cell trait has serious negative consequences." (*extremely disagree* to *extremely agree* scale). Items representing susceptibility included: "I am at risk for having sickle cell trait." (*extremely disagree* to *extremely agree* scale) and "It is possible that I could have sickle cell trait." (*extremely disagree* to *extremely agree* scale). All items were measured on a 7-point scale ranging from -3 to 3 and were then averaged to assess perceived threat.

Response efficacy was assessed using one item: "Going to your doctor to get screened for sickle cell trait is an effective method for learning your sickle cell trait status." (*extremely disagree* to *extremely agree* scale). This item was measured on a scale ranging from -3 to 3.

Awareness of sickle cell trait/screening was included as a score comprised of three items. All items were measured on a 3-point scale ranging from 0 to 2: "Have you personally known or know anyone who has Sickle Cell *Disease*?" (No/Unsure/Yes); "Prior to today, had you ever heard of *Sickle Cell Trait*?" (No/Unsure/Yes); and "Have you personally known or know anyone who has *Sickle Cell Trait*?" (No/Unsure/Yes). Responses to these items were added to assess awareness of sickle cell trait/screening.

Sickle Cell Trait Knowledge was measured using one open ended item, "In your own words, what does sickle cell trait mean to you?" Responses to this item were recoded as incorrect, partially correct, and completely correct. Partially Correct responses made reference to the hereditary nature of sickle cell trait or indicated the manifestation of sickle cell trait such as sickling of the red blood cells (Ex. "an inherited gene" "Having a sickle shaped cell.") Completely correct responses indicated that sickle cell trait means

you are a carrier for sickle cell disease and made reference to the hereditary nature of the trait (Ex. “It means you are a carrier for sickle cell.”). *Sickle Cell Trait Screening Knowledge* was measured using one open ended item, “In your own words, what does screening for sickle cell trait mean to you?” Partially correct made reference to finding out or being told if you have sickle cell trait (Ex. “To be notified if I have the trait.”) Completely correct responses indicated testing or screening (genetic or blood) to determine if you have sickle trait (Ex. “It means that you will take a test to see if you have the sickle cell trait. A blood test.”) Coding for sickle cell trait knowledge and sickle cell trait screening knowledge was adapted from a previous instrument by Treadwell, McClough, and Vichinsky (2006).

Awareness of sickle cell trait/screening was included as a score comprised of three items. All items were measured on a 3-point scale ranging from 0 to 2: “Have you personally known or know anyone who has Sickle Cell ***Disease***?” (No/Unsure/Yes); “Prior to today, had you ever heard of *Sickle Cell* ***Trait***?” (No/Unsure/Yes); and “Have you personally known or know anyone who has *Sickle Cell* ***Trait***?” (No/Unsure/Yes). Responses to these items were added to assess awareness of sickle cell trait/screening.

RAA Items

Items assessed in the instrument from the RAA were intention, attitude toward going to the doctor to ask for sickle cell trait screening within the next 12 months, perceived norm, and perceived behavioral control (See Appendix L). Intention was assessed using four items. One 6-point item ranging from 0 to 5 and two 7-point items ranging from -3 to 3 were averaged to measure intention: “How LIKELY or UNLIKELY are you to go to your doctor to ask for sickle cell trait screening in the next 12 months?

(*extremely unlikely* to *extremely likely*); "I intend to go to my doctor to ask for Sickle Cell *Trait* screening within the next 12 months." (*extremely disagree* to *extremely agree*); and "What statement best describes your intention when it comes going to your doctor to ask for screening for Sickle Cell *Trait*?" (Five statements listed) The 5-point item was rescaled prior to being averaged with the 7-point items. The new scale for the rescaled item ranged from -1 to 3.

Attitude toward the act (attitude) was assessed using four items. Of these items two characterized the first component of attitude, instrumental, while two items represented the second component of attitude, experiential. Items representing instrumental included, "Would it be GOOD or BAD for you to go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely bad* scale to *extremely good*) and "Would it be WISE or FOOLISH for you to go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely foolish* to *extremely wise* scale). Items representing experiential included: "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is ___" (*extremely boring* to *extremely fun);* and "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is ___" (*extremely unenjoyable* to *extremely enjoyable* scale). All items were measured using 7-point scales ranging from -3 to 3 and were then averaged to assess mean attitude.

Perceived norm was assessed using four items. Of these items two characterized the first component of perceived norm, descriptive, while two items represented the second component of perceived norm, injunctive. Items representing injuctive included: "How LIKELY or UNLIKELY is it that African Americans age 18-35, WHO ARE LIKE YOU would ask for Sickle Cell Trait screening from their doctor in the next 12 months?"

(*extremely unlikely* to *extremely likely* scale) and "How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU think you should ask for Sickle Cell Trait screening from your doctor in the next 12 months?" (*extremely unlikely* to *extremely likely* scale). Items representing descriptive included: How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU would approve of you going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*extremely unlikely* to *extremely likely* scale) and "How many of the people whose opinion you value would go to their doctor to ask for Sickle Cell Trait screening from their doctor in the next 12 months?" (*virtually none* to *virtually all* scale). All items were measured using a 7-point scale ranging from -3 to 3 and averaged to assess mean perceived norm.

Perceived behavioral control was assessed using four items. Of these items two characterized the first component of perceived behavioral control, capacity, while two items represented the second component of perceived norm, autonomy. Items representing capacity included: "How SURE are you that you will go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*not at all sure* to *very sure* scale*)* and "I am CONFIDENT that I can go to the doctor to ask for Sickle Cell Trait screening in the next 12 months." (*extremely disagree* to *extremely agree* scale). Items representing autonomy included: "How much UNDER YOUR CONTROL is going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" (*not at all under my control* to *completely under my control* scale) and "My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is UP TO ME." *(not at all up to me* to completely *up to me* scale). After review of the Cronbach's α if items were deleted,

one item, “How much UNDER YOUR CONTROL is going to your doctor to ask for Sickle Cell Trait screening in the next 12 months?” was deleted. Thus, three 7-point items ranging from -3 to 3 were averaged to measure mean perceived behavioral control.

Analysis

All statistical analyses were conducted using IBM version 22.0 Statistical Package for the Social Sciences (SPSS), with α level .05. Descriptive statistics on all outcome variables were obtained. Reliability analysis was conducted to measure the internal consistency of the items used to assess intention, the three RAA constructs (attitude, perceived norm, and perceived behavioral control) and one EPPM construct (perceived threat). A three-step sequential linear regression was used to measure the influence on intention using the independent variables attitude, perceived norm, and perceived behavioral control. In step one, demographic variables were used to measure influence on intention. Demographic variables used in the model were identified, except for “sex,” using Pearson correlation analysis with intention. All statistically significant, ($p<.05$), demographic variables were included in the model. In step two EPPM constructs were added to capture the influence on intention. In the final step, constructs from the RAA were added to the model to capture the influence on intention.

Pearson correlation analysis was used to determine association between the dependent variable, intention, and the independent variables attitude, perceived norm, and perceived behavioral control. In addition, Pearson correlation analysis was used to determine which variables to include in the sequential regression analysis. Three demographic variables (age, education, income, sex, and partner status) were included in the first step of the sequential regression analysis, while knowledge and fear constructs

(sickle cell trait knowledge, sickle cell trait screening knowledge, awareness, response efficacy and perceived threat) were included in the step of the sequential regression analysis. All RAA constructs were included in the third step of the sequential regression analysis.

Results

Table 2 shows the characteristics of participants included in the study. The final study population used in the analyses consisted of 300 African Americans ages 18-35 with a mean age of 27.8 (*SD*=5.2). Sixty-three percent of participants were women; 57% were single/not in a relationship; 38.3% reported good health; 86.3% had insurance; 69.7% reported having a healthcare provider; 32.7% had "some college" education; 36.3% had an income of less than $10,000; and most participants, 48.0% were employed full time. Many participants had either heard of sickle cell trait and sickle cell trait screening or knew someone with sickle cell trait with average sickle cell sickle cell awareness score of 4.11. Nearly half of participants, 44.3%, had partially correct or completely correct responses to sickle cell trait knowledge while 42.6% had partially correct or completely correct responses to sickle cell trait screening knowledge.

[Insert Table 1]

Table 2 shows the descriptive characteristics of the main variables of interest. For fear and knowledge beliefs, the mean response efficacy was 1.93 (*SD*= 1.50), the mean perceived threat was 1.99 (*SD*= 3.93), mean awareness of sickle cell trait/screening was 4.11 (*SD*= 1.99), mean sickle cell trait knowledge was 0.72 (*SD*= 0.87), and mean sickle cell trait screening was 0.61 *(SD*= 0.78). For the RAA constructs, the mean attitude was

1.17 (*SD*= 0.86), mean perceived norm was 0.66 (*SD*= 1.27), mean perceived behavioral control was 1.66 (*SD*= 1.15), and mean intention was 1.00 (*SD*= 1.32).

[Insert Table 2]

Reasoned Action Approach Measures

Table 3 presents the results of the reliability analysis. Three items were used to measure the dependent variable, intention. Reliability for the 3-item measure of intention was moderate for the 3-item measure (Cronbach's $\alpha = .763$). Four items were used to measure two of the three global constructs, attitude and perceived norm. Reliability of for the 4-item measure of attitude was moderate (Cronbach's $\alpha = .712$). Reliability of for the 4-item measure of perceived norm was moderate (Cronbach's $\alpha = .700$). Three items were used or the final global construct perceived behavioral control. Reliability for perceived behavioral control was low (Cronbach's $\alpha = .515$).

[Insert Table 3]

Pearson Correlation Analysis

Table 4 displays the results from the Pearson correlation analysis for the RAA three global constructs with intention. As reflected in the table, all three behavioral predictor variables were significantly positively correlated with dependent variable, intention ($p<.001$). Perceived behavioral control had the highest correlation with intention, (Pearson $\rho=.705$, $p<.001$), followed by attitude (Pearson $\rho=.619$, $p<.001$), and perceived norm (Pearson $\rho=.547$, $p<.001$).

[Insert Table 4]

Pearson Correlation Analysis of Demographic Factors and Knowledge and Fear Beliefs

A Pearson correlation analysis was performed to identify which other demographic variables to include in the first step of the sequential regression analysis. Results revealed that out of the demographic variables, three were statistically significant: age, education, and partner status. Of the knowledge and fear beliefs, only sickle cell trait screening knowledge was significantly associated with intention.

[Insert Table 5]

Sequential Regression Analysis

Table 6 presents the results of three-step sequential regression analysis. In step 1 of the sequential regression analysis demographic variables (age, sex, education, and partner status) were used to capture the influence on intention. These variables accounted for 6.9% of the variation in intention ($F= 3.210$, $p<.001$). Results indicated that participants in the age groups 26-30 and 31-35 were more likely to intend on going to their doctor to ask for sickle cell trait screening compared to participants aged 18 to 20 ($\beta= .868$, $p<.01$ and $\beta=.987$, $p<.01$, respectively). No other demographic variables were found to be significantly associated with intention in this step of the sequential regression analysis.

In the second step of the regression analysis knowledge and fear beliefs were added to the model. The factors explained 17.3% of the variation intention ($F= 5.808$, $p<.001$). Sickle cell trait screening knowledge was significantly and negatively associated with intention ($\beta= -.331$, $p<.001$). Fear beliefs, response efficacy and perceived threat, were both significantly and positively associated with intention ($\beta= .131$, $p<.05$ and $\beta= .224$, $p<.001$, respectively). In addition, demographic factors, age and sex were found to be associated with intention. Results indicated that participants in the

age groups 26-30 and 31-35 were more likely to intend on going to their doctor to ask for sickle cell trait screening compared to participants aged 18 to 20 (β= .465, p<.01 and β=.713, p<.01, respectively). Women were more likely to intend on going to their doctor to ask for sickle cell trait screening compared to men (β= .317, p<.05).

Finally, in the last step of the analyses, the three RAA global factors were added to the model. All three global constructs of the RAA influenced intention over and above the four significant demographic factors and knowledge and fear beliefs variables employment, education, response efficacy, and sickle cell trait screening knowledge, with perceived behavioral control having the largest weight. The RAA constructs explained 63.9% of the variation in intention (F= 34.136, p<.001). Results of the OLS regression indicated that attitude (β = .348, p<.001) perceived norm (β = .177, p<.001), and perceived behavioral control (β = .581, p<.001) all had statistically significant relative regression weights. For fear beliefs, response efficacy was significantly and negatively associated with intention (β= -.073, p<.05). Sickle cell trait screening knowledge was significantly and negatively associated with intention (β= -.175, p<.01). In addition, education was significantly associated with intention in this step. Participants with a high school diploma/GED or some college were less likely to intend on going to their doctor to ask for sickle cell trait screening compared to participants with less than a high school education (β= -1.009 and β= -1.115, p<.05 respectively). Participants with an undergraduate or graduate degree were also less likely to intend on going to their doctor to ask for sickle cell trait screening compared to participants with less than a high school education (β= -1.376 and β= -1.461, p<.001, respectively).

[Insert Table 6]

Study Limitations

Despite the strengths of the study, the limitations of this study have been considered. First, the RAA suggests that a salient belief elicitation specific to the study and with the target population should be conducted prior to measuring intention. The present study did not employ a randomized sample and therefore causation cannot be inferred. In addition, the data contain self-reported information which may be inaccurate due to respondent bias. The data employed a convenience sample; therefore, the results may not be generalizable to the population outside of the study.

Despite the limitations of the study this study addressed gaps that were identified in the literature regarding factor influencing sickle cell trait. To our knowledge, this is the first study that used the RAA to understand factors influencing intention of to go to the doctor to ask sickle cell trait among this high risk population. We believe the limitations do not outweigh the relative contribution of this study.

Discussion

The purpose of this study was to twofold: 1) to determine if the RAA is an appropriate theoretical framework when applied within the context of sickle cell trait screening; and 2) to examine the association among the RAA global constructs in determining intention to go to your doctor to ask sickle cell trait screening within the next 12 months among African American men and women within middle reproductive ages 18-35. The primary finding indicates that the RAA is an appropriate theoretical framework for identifying factors underlying intention to go to the doctor to ask for sickle cell trait screening among this specific population. Not only is this finding consistent with the principles of the RAA, but it also supported by the 46.2% increase in the

variation in predicting intention being explained by the addition of the three RAA constructs to the regression model (Fishbein, 2008; Fishbein & Ajzen, 2010).

In previous studies predicting intention, attitude, perceived norm, and perceived behavioral control, explained 40-49% of the variation in intention (McEachan, Connor, Taylor, Lawton, 2011). Moreover, Godin and Kok (1996) indicated that the model has been shown to be a poor predictor of intention to perform screening behaviors with only 15.9% of the variation explained. Through demonstrating that intention could be predicted with the RAA's three global components over and above all demographic and belief factors, this study proves that the RAA is not only an appropriate theoretical method for predicting intention within the context of sickle cell trait screening; but also provides evidence that the framework is capable of explaining a greater variation within the context of screening behaviors.

This study was the first to apply the Reasoned Action Approach (RAA) to understanding determinants of intention to go to your doctor to ask sickle cell trait screening within the next 12 months. This study found that there were several determinants that influence intention (age, education, attitude, perceived norm, and perceived behavioral control. Of significant importance, perceived behavioral control had the largest weight influencing intention. This is consistent with previous studies on predicting intention within the context of detection behaviors such as participation in colorectal cancer screening among high risk groups. In these studies all three global constructs significantly predicted screening intentions with perceived behavioral control prediction intention over and above attitude and perceived norm (DeVellis, B.M.,

Blalock, S.J., and Sandler, R.S., 1990). It is also consistent with other studies predicting intention using a sample of students and adults.

Finally, this study was the first to assess intention to go to the doctor to ask for sickle cell trait screening. Results indicated that intention is slightly positive, one on a scale ranging from 3 to 3. This information is beneficial for sickle cell agencies who are interested in developing programs and interventions geared toward increasing sickle cell trait screening. In addition, since the intention is positive, but not at the maximum level, there is an opportunity for community agencies to increase intention among African Americans aged 18 to 35.

Practical Implications

Determining factors associated with intention to go your doctor to ask for sickle cell trait screening will assist health educators and health care professionals in developing interventions aimed at increasing the number of African Americans who ask screening for sickle cell trait. The results of this study indicate a starting point for developing such interventions. Health educators and genetic counselors seeking to improve genetic screening rates, such as screening for sickle cell trait should focus on increasing positive attitude towards sickle cell trait screening, improving social support/norm, and encouraging perceived behavioral control. However, special emphasis should be placed on placed on increasing perceived behavioral control (self-efficacy) over going to your doctor to ask for sickle cell trait screening. Furthermore, steps should also be taken to determine differences between previous participants and nonparticipants within the context of going to your doctor to ask for sickle cell trait screening. Determining these differences could improve participation and adherence to sickle cell trait screening.

Research Recommendations

This study found that perceived behavioral control was the strongest predictor of intention to ask screening for sickle cell trait. Within this context, perceived behavioral control is an individual's perception of the degree to which they are capable of, or have control over going to your doctor to ask for sickle cell trait screening. Future studies should work to identify which control beliefs, barriers or facilitators completing the behavior, should be the focus of interventions. Identifying these beliefs would require further research. This research should begin with determining salient beliefs associated with the behavior. The RAA suggests that effective targeting of the most predictive global constructs in behavior change intervention design requires identifying salient beliefs held by the specific population (Fishbein & Ajzen, 2010). Therefore, we recommend further examination of the underlying belief structure to determine the individual salient beliefs underlying attitude toward the behavior, perceived norm, and perceived behavioral control. These future analyses would help in specifying focal areas for interventions with a goal to increase the number of African Americans who go to their doctor to ask for sickle cell trait screening.

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Conceptual Framework for Manuscript 1

Sample: African Americans within Reproductive Age Range 18-35yrs, who do know their sickle cell trait status, to go to their doctor ask for screening for sickle cell trait

Definitions: Sickle cell **disease** is a group of blood disorders that cause the blood cells to be become sickle shaped. Sickle cell **trait** is the gene that causes sickle cell **disease**.

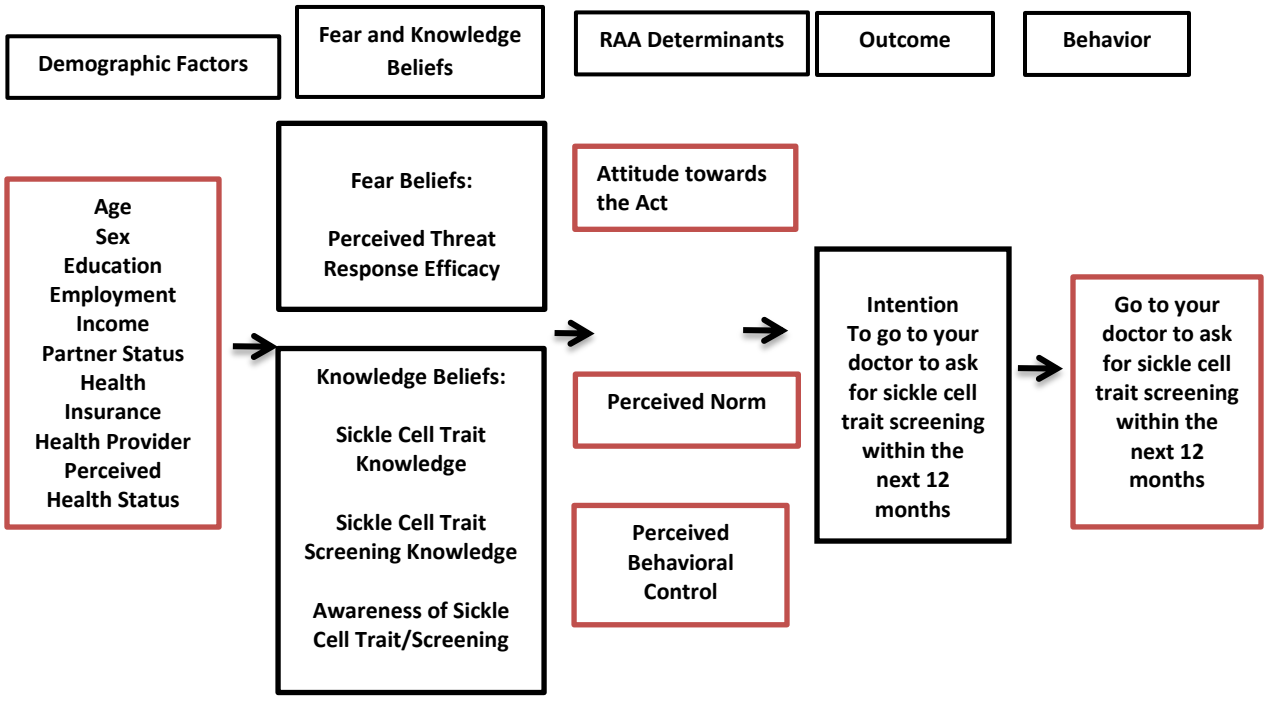

Table 1: Descriptive Characteristics of Study Sample

Variable	%
Demographic Factors	
Sex: Female	63.3
Health Insurance Status: Yes	86.3
Partner Status: In a Relationship	43.0
Perceived Health Status	
Excellent	18.7
Very Good	28.3
Good	38.3
Fair	13.7
Poor	1.0
Age	
18-20	11.3
21-25	22.3
25-30	31.3
31-35	35.0
Education	
Less Than High School	1.0
Some HS	6.0
High School Diploma or GED	28.0
Some College	32.7
College Degree or Higher	20.3
Graduate Work or Degree	12.0
Employment Status	
Do not work/Student	32.7
Employed for wages (PT)	19.3
Employed for wages (FT)	48.0
Income Level	
<10,000	36.3
10,000-19,999	14.3
20,000-39,999	17.3
40,00-49,999	11.0
≥50,000	13.3
N= 300	

Table 2: Reliability Analysis of Reasoned Action Approach Variables

Construct	# of items	Mean	Variance	SD	Cronbach's α
Intention	3	3.00	15.60	3.95	0.76
Attitude Toward the Act	4	4.67	11.92	3.45	0.71
Perceived Norm	4	2.66	25.83	5.08	0.70
Perceived Behavioral Control	3	4.97	11.96	3.46	0.51

Table 3: Pearson Correlation Analysis of the Reasoned Action Approach Global Components

Predictor Variable	Intention	Attitude Toward the Act	Perceived Norm	Perceived Behavioral Control
Mean Intention	-	.619**	.547**	.705**
Mean Attitude Toward the Act	.619**	-	.496**	.618**
Mean Perceived Norm	.547**	.496**	-	.474**
Mean Perceived Behavioral Control	.705**	.618**	.474**	-

Significance Level: * *P*< .05, ***P*<.01

Table 5: Bivariate Correlation with Dependent Variable to determine which variables to use in the Linear Regression

Demographic Variable	Pearson's Correlation	P Value
Sex	.080	.169
Age	.158**	.006
Marital Status	.009	.433
Education	-.122*	.035
Employment Status	-.149**	.010
Income Level	-.090	.119
Health Care Provider	.001	.992
General Health Status	.023	.693
Health Insurance Status	.045	.871
Sickle Cell Awareness	.096	.096
Sickle Cell Trait Knowledge	-.032	.582
Sickle Cell Screening Knowledge	-.209	.000
Perceived Threat	.259**	.000
Response Efficacy	.173**	.003

Table 6: 3-Step Sequential Regression Predicting Intention

	Model 1: R^2=.106 F(4.209, p<.001)		**Model 2:** R^2=.181 F(6.467, p<.001)		**Model 3:** R^2=.650 F(35.771, p<.001)	
Variable	**β Coefficient**	**(SE)**	**β Coefficient**	**(SE)**	**β Coefficient**	**(SE)**
Constant	.285	.497	-.174	.486	-.719*	.322
Demographic Factors						
Age	.038*	.016	.037***	.015	.017	.010
Employment Status						
Unemployed	.095	.192	.118	.184	-.001	.123
Employed Part-Time	.168	.206	.168	.197	.202	.130
Employed Full-Time	Ref	Ref	Ref	Ref	Ref	Ref
Student	-.889**	.330	-.907**	.314	-.505*	.209
Education						
Less than HS	-1.051	.740	-.615	.710	.998*	.480
Some HS	.524	.345	.499	.329	.181	.223
HS Diploma/GED	-.024	.192	.136	.186	.093	.122
Some College	Ref	Ref	Ref	Ref	Ref	Ref
Undergraduate Degree	-.453*	.207	-.390	.197	-.298*	.131
Graduate Degree	-.250	.259	-.249	.244	-.244	.161
Sickle Cell Trait Screening Knowledge (Incorrect)	Ref	Ref	Ref	Ref	Ref	Ref
Sickle Cell Trait Screening Knowledge (Partially Correct)	-.603**	.177	-.615***	.169	-.251*	.113
Sickle Cell Trait Screening Knowledge (Correct)	-.293	.210	-.481*	.202	-.283*	.133
EPPM Constructs						
Response Efficacy	-	-	.155**	.052	- .069	.036
Perceived Threat	-	-	.067***	.019	.026*	.013
RAA Constructs						
Attitude	-	-	-	-	.349***	.075
Perceived Norm	-	-	-	-	.174***	.044
Perceived Behavioral Control	-	-	-	-	.570***	.055

CHAPTER 5: CONCLUSIONS

Main Study

The purpose of the main study was to determine if the Reasoned Action Approach (RAA) is an appropriate theoretical framework to apply to sickle cell trait screening; and to identify determinants of going to your doctor to ask for sickle cell trait screening within the next 12 months. The main finding indicates that the RAA is an appropriate theoretical framework for identifying determinants of intention to go to your doctor to ask for sickle cell trait screening among this specific population. This finding was reflected in the additional 46.2% of the variation in predicting intention being explained by the three RAA global constructs.

The main study also found that there are several determinants that influence intention (age, perceived threat, attitude, perceived norm, and perceived behavioral control). Of these determinants, perceived behavioral control had the largest weight influencing intention. Therefore, interventions with a goal to increase the number of African Americans ages 18-35 who go to their to ask for screening for sickle cell trait should focus on increasing perceived behavioral control. Perceived behavioral control is defined as people's perceptions of the degree to which they are capable of, or have control over, performing a given behavior. Additional research is needed to determine the individual salient beliefs underlying attitude toward the behavior, perceived norm, and perceived behavioral control.

Finally, this study was the first to assess intention to go to the doctor to ask for sickle cell trait screening. Results indicated that intention is slightly positive, one on a scale ranging from 3 to 3. This information is beneficial for sickle cell agencies who are

interested in developing programs and interventions geared toward increasing sickle cell trait screening. In addition, since the intention is positive, but not at the maximum level, there is an opportunity for community agencies to increase intention among African Americans aged 18 to 35.

Secondary Study Part I

The purpose of secondary study part I was to determine if including an explicit recommended response (in the form of a verbal statement) in a brochure influenced mean attitude, perceived norm, and perceived behavioral control, and intention. This study found that adding an explicit recommended response to a communication in the form of a brochure did not have a significant multivariate effect on the outcome variables. There could be several reasons for not finding an effect. For example, I may not have used the right recommended response; this was the study to explore the use of communicating an explicit recommended response within this context and as a result, an explicit recommended response may not necessarily be appropriate for this behavior. In addition, the brochures used to communicate the explicit recommended response contained standard information from brochures about sickle cell trait and sickle cell trait screening. As a result, the information within the brochures were not culturally tailored to my target population nor the behavior of interest. Therefore additional research is needed to explore other recommended responses and to design the brochure with content that is specific to behavior of interest.

Secondary Study Part II

There was a significant increase in sickle cell trait knowledge after exposure to a communication in the form of a brochure. Descriptively, exposure to a communication

in the form of a brochure increased the number of different specific beliefs about sickle cell trait and sickle cell trait screening. There was a significant difference from pre to post in the number of respondents who stated they did not know what sickle cell trait and sickle cell trait screening were. There was a significant difference from pre to post in the number of respondents who stated sickle cell trait and sickle cell trait screening were important. Beliefs were identified in this study; however, there is still a need to determine if these beliefs influence intention. Although beliefs were identified in this study, there is still a need to conduct a full elicitation to determine behavioral beliefs, normative beliefs, and control beliefs influencing intention.

Overall Conclusion

Future studies should consider developing a brochure that is specific to the behavior, "Go to your doctor to ask for sickle cell trait screening." There is a need to identify underlying beliefs of going to the doctor to ask for sickle cell trait screening. There is a need for more research on the steps after participants adopt the behavior of going to the doctor to ask for sickle cell trait screening (What happens at the doctor's office?; What the role of physicians and doctors' offices?; Do we know from a public health perspective what the implications are to getting screened?). As it relates to a reproductive health decision, there is evidence to support social justice implications. However, additional research is needed to better articulate the implications of sickle cell trait from a public health perspective.

Limitations

Overall Limitations

1) Self-reported data: The survey instrument required participants to self-report data pertaining to factors influencing their intention to go to the doctor to ask for sickle cell trait screening. Such data may be inaccurate due to respondent bias.
2) In the main study, for the regression analysis, correlations among the variables do not imply or prove causal relationships among the variables.
3) The study sample was a convenience sample, and therefore the findings are not generalizable outside of the study participants.
4) During data collection the researcher did not note the site which data was being collected.
5) The RAA suggests that a salient belief elicitation specific to the study and with the target population should be conducted prior to measuring intention. In addition, the data contain self-reported information which may be inaccurate due to respondent bias. The data included Indiana residents; therefore, the results may not be generalizable to other states.

Main Study Limitations

1) Perceived behavioral control had low reliability which was reflected in a low Cronbach's alpha.
2) One item for perceived behavorial control was measured incorrectly. The item stated, "How SURE are you that you will go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?" This item should have been stated as, "How SURE are you that you can go to your doctor to ask for Sickle Cell Trait screening in the next 12 months?

3) This study did not use a randomized sample. Therefore, the random sample assumption for linear regression is violated.
4) Although this study illustrates an association while controlling for other variables, correlations among the variables do not imply or prove causal relationships among the variables.

Secondary Study Limitations

1) The brochure contained information from the standard brochures on sickle cell trait and sickle cell trait screening as opposed to having information that was specific to the behavior.
2) Few participants recognized the intended main point of the brochure.
3) In the pre-post design, study participants were not randomized.

Lessons Learned

Communicating through a brochure is difficult. You can get the brochure into a person's hands how do you get them to read it? If they do read it, the content needs to reflect the goal of the brochure (i.e., adopting a behavior). Even if you have the right content, your audience still needs to recognize your main point. Communicating research results to community organizations is difficult. They have questions that researchers may be able assist them in answering. If you are able to find answers to the researcher questions, translating the information in language they can understand can prove to be challenging. Although you start out seeking answers to specific questions, the further you go into the research, the more these questions will evolve. I believe the true test of the dissertation was not find the right answer to the question but to learn to

navigate the different paths of finding answers to the research question and then making decisions about which path to take.

Dissertation Reflection

The current research has helped me to better understand the factors influencing intention go to the doctor to ask for sickle cell trait screening within a priority population. This study was the first to apply the Reasoned Action Approach (RAA) to understanding this behavior. As result, it contributes to the gap in knowledge and literature regarding sickle cell trait screening. Through demonstrating that intention could be predicted with the RAA's three global components over and above all other demographic factors, this study proves that the RAA is an appropriate theoretical method for understanding factors association with going to the doctor to ask for sickle cell trait screening.

Furthermore, the results of this study indicate a starting point for developing interventions geared toward increasing the number of African Americans who ask for screening for sickle cell trait. Perceived behavioral control was identified as being the strongest predictor of intention. Future studies should work to clarify which area of perceived behavioral control, capacity to complete the behavior or autonomy in completing the behavior, should be the focus of interventions. Such clarification would require further research of the barriers and circumstances in which African Americans are faced as it relates to going to the doctor to ask for sickle cell trait screening. One approach that would be beneficial to understanding these circumstances is to identify salient beliefs associated with the behavior. While it was not reported in either manuscript for this study, during data collection, participants were asked about their beliefs regarding going to the doctor to ask for sickle cell trait screening. Analysis of

these data will be conducted in the future. Results of these future analyses would help in specifying focal areas for interventions with a goal to increase the number of African Americans who go to their doctor to ask for sickle cell trait screening.

By working with the Martin Center Sickle Cell Initiative and the Indiana Hemophilia Center located in Indianapolis, Indiana, I was able to identify areas of need related to sickle cell trait within the state. One of these areas was a better understanding of existing knowledge among African Americans. This study has contributed to lessening this gap by exploring beliefs about sickle cell trait and sickle cell trait screening. Results indicated that a low level of sickle cell trait and sickle cell trait knowledge exists among African Americans within the ages of 18-35. However, it was found that this knowledge can be increased if this population reads and has a clear understanding of the information presented in a brochure. Furthermore, this study highlights that beliefs about sickle cell trait and sickle cell trait screening can be significantly modified after reading and understanding information found in brochures. Most importantly, as it relates to sickle trait, the brochure used in this study containing information on severity and susceptibility, was able to decrease the number of individuals who did not know what this concept was as well as increase the number of individuals felt it was important. As it relates to sickle cell trait screening, the brochure used in the study containing information of the steps to screening, was able to decrease the number of individuals who did not know what this concept was as well as increase the number of individuals who recognized the positive implications of getting screened.

Now that the data has been collected and analyzed my next step is to report the findings to the community. As both a research and a health educator, I recognize the

importance of helping the community to understand the implications of my research. As a member of the African American population I also appreciate the value of understanding information that may affect my health and the health of my family. I believe the results of this study will go a long way in understanding how to effectively communicate to at-risk populations concerning complicated health topics, as well as how to effectively communicate with a specific goal to change health behavior.

Future and Professional Direction

The work I have completed as a requirement of my doctoral program does not end with my dissertation. My acceptance into the Meharry-Community Engagement Research Core Postdoctoral Fellowship in Community-Based Participatory Research will provide me with several opportunities to work and educate marginalized communities. It is a rarity in life to work hard and have those efforts rewarded by being extended an offer to be put into a position where your work could make a difference. Although this is fellowship is not the position I initially sought to accept, this is the one reflects the growth that has taken place over the past few years. Through accepting a training position, I am also acknowledging that despite my accomplishments thus far, there is still much more to learn. I will also be able to continue my behavioral research in a manner that allows me to elucidate factors that influence screening. To this extent, my dissertation research will continue to evolve as my career transitions. I have always viewed myself as a health educator within a research/academic setting. I now have the opportunity to improve the health of minority communities by engaging in research with members of the community. This sentiment will be used as a foundation to my future professional journey.

Personal Reflection

My interest in sickle cell disease and sickle cell trait developed from a personal connection to the topic. I was once told that as a researcher you should avoid topics in which you are personally vested, rather you select a topic based on popularity and funding. In my case, learning about a topic through personal experience has led me to become an advocate in an area in which I am truly passionate. When people first meet me, they perceive me to be a quiet person. I would not describe myself as being quiet, but rather waiting for the moment when there is a need to use my voice to speak for those who suffer in silence. Through my sickle cell research I hope that my voice is loud and clear.

I recognize that in order to advocate for others through my research, I had to have a team advocating on my behalf. There are no words to express my appreciation for the countless hours in which I was supported by my research team. As I look back on my doctoral career and my dissertation research I have come to realize that the time, effort, and drive instilled in me by research committee could only be the result of potential they see in me and my ability to be a quality researcher. For this, I show my gratitude through producing meaningful research.

Throughout my time working on this degree I have had many people to tell me to pause and appreciate my successes along the way. This has not been an easy task for. My successes along this journey have not been without strife and sacrifice. However, as I continue to move forward on this journey called life, recognizing that there will more obstacles for me to overcome, I am taking this time to pause and tell myself, "Job well done!"

Outline of Potential Articles

Below is an outline of potential manuscripts that I plan to draft and publish:

Manuscript 1: Beliefs about going to the doctor to ask for screening for sickle cell trait: An Application of the Reasoned Action Approach

- This manuscript will provide a deeper understanding of the underlying salient beliefs (salient consequences, salient referents, and salient circumstances) that are associated with intention to go to your doctor to ask for sickle cell trait screening within the next 12 months among African American ages 18-35.
- Journal of Interest:

Manuscript 2: Knowledge Regarding Sickle Cell Trait and Sickle Cell Trait Screening among African Americans aged 18-35

- This manuscript will highlight findings from qualitative data collected on knowledge of sickle cell trait and sickle cell trait screening among African Americans aged 18-35. The manuscript will discuss factors (sickle cell awareness, age, education, etc.) associated with knowledge.
- Journal of Interest:

Manuscript 3: The Meaning of Sickle Cell Trait and Sickle Cell Trait Screening in the African American Community: A Content Analysis

- This manuscript will address how sickle cell trait and sickle cell trait screening are defined by African Americans aged 18-35.
- Journal of interest:

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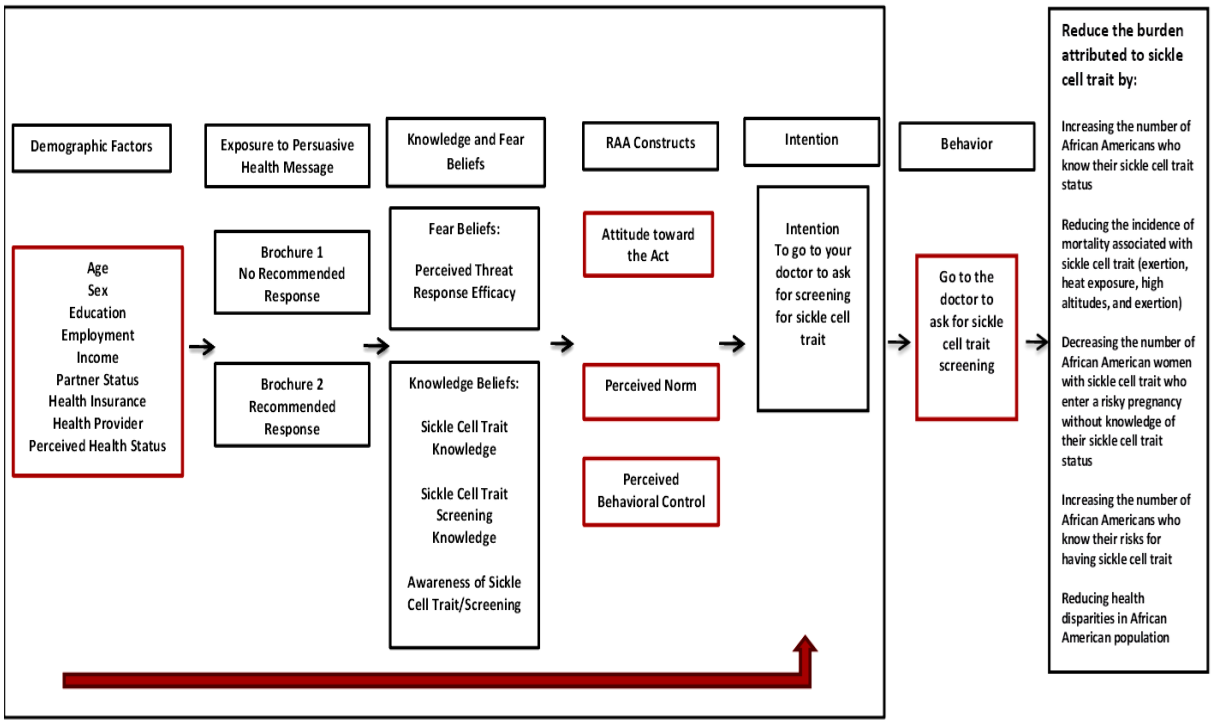
Appendix A: Expanded Conceptual Framework

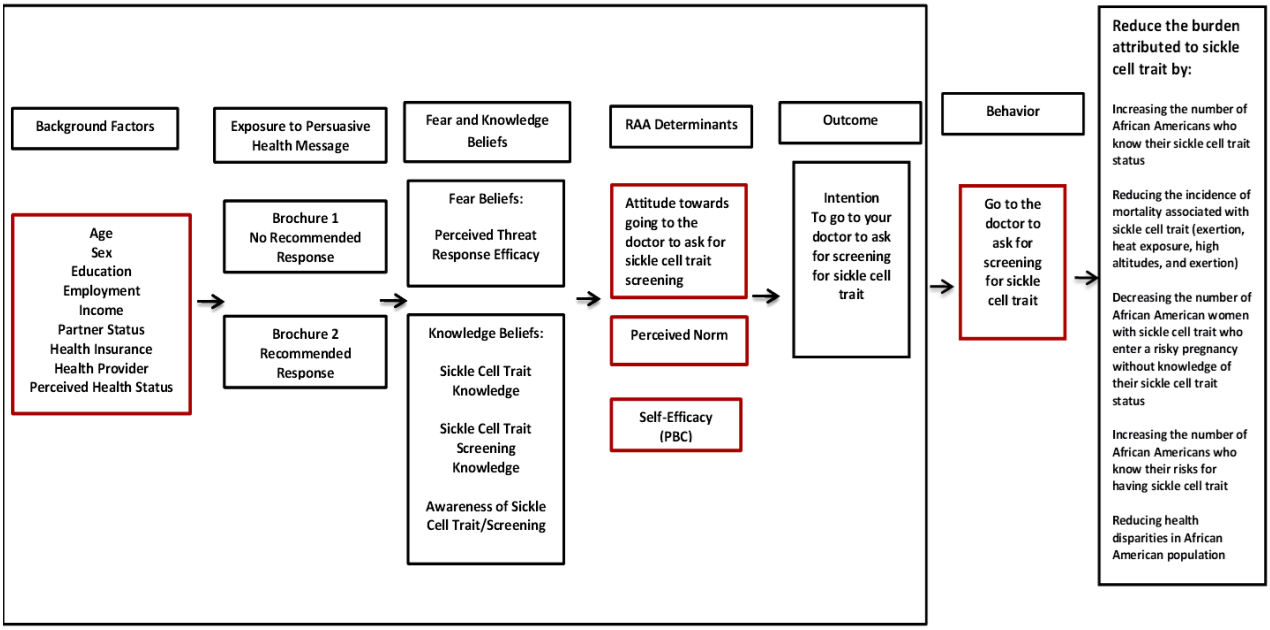
Sample: African Americans within Reproductive Age Range 18-35yrs, who do know their sickle cell trait status, to go to their doctor ask for screening for sickle cell trait
Definitions: Sickle cell **disease** is a group of blood disorders that cause the blood cells to be become sickle shaped. Sickle cell **trait** is the gene that causes sickle cell **disease**.



Appendix B: Conceptual Framework for Dissertation Study

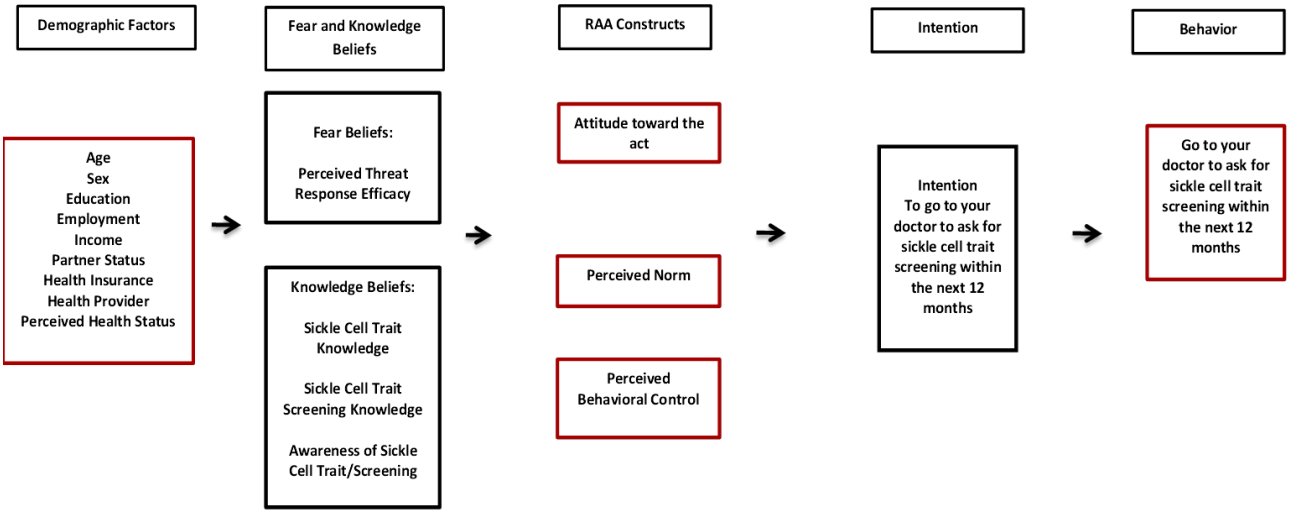
Sample: African Americans within Reproductive Age Range 18-35yrs, who do know their sickle cell trait status, to go to their doctor ask for screening for sickle cell trait

Definitions: Sickle cell **disease** is a group of blood disorders that cause the blood cells to be become sickle shaped. Sickle cell **trait** is the gene that causes sickle cell **disease**.



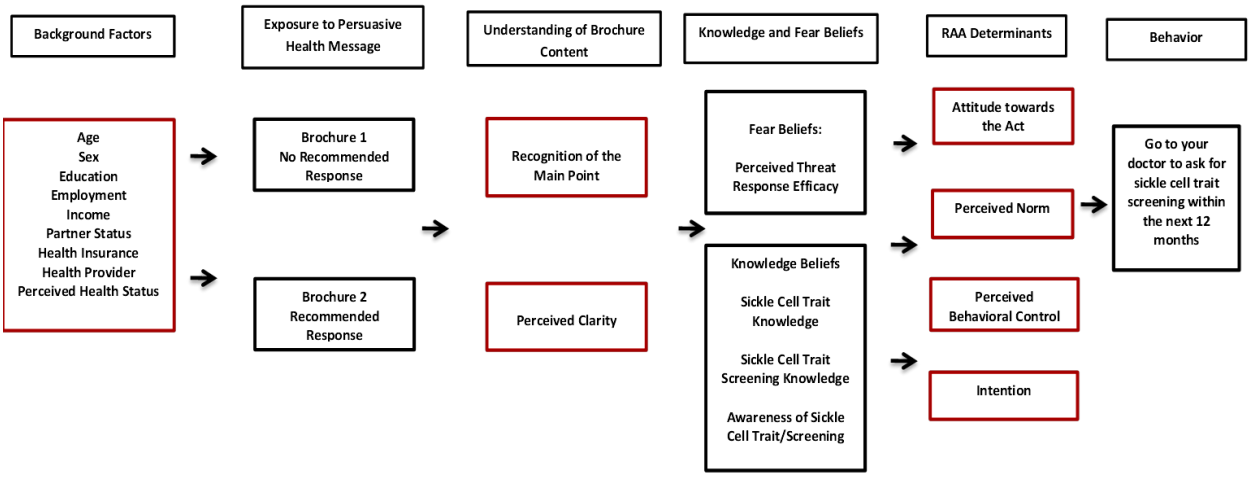
Appendix C: Conceptual Framework for Main Study

Sample: African Americans within Reproductive Age Range 18-35yrs, who do not know their sickle cell trait status



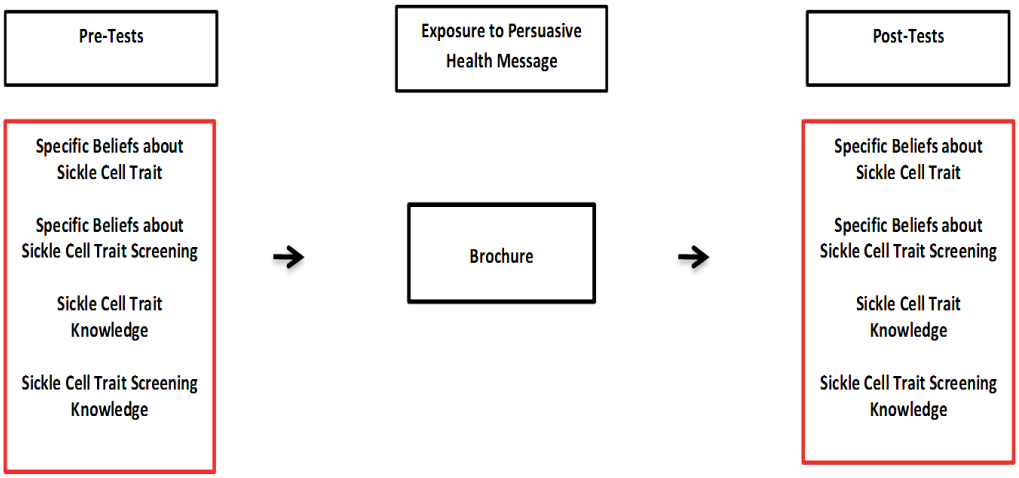
Appendix D: Conceptual Framework for Secondary Study Part I
Experimental Design

Sample: African Americans within Reproductive Age Range 18-35yrs, who do not know their sickle cell trait status



Conceptual Framework for Secondary Study Part II
Pre-Post Design

Sample: African Americans within Reproductive Age Range 18-35yrs, who do not know their sickle cell trait status



Protocol Summary

Protocol Number: 1402761981

Status: Submitted to IRB **Expiration Date:**

Last Approval Date:

Investigator: Middlestadt, Susan Elizabeth

Protocol Details

Type: Exempt

Description:

Application Date: 02/26/2014

Reference Num 1:

Reference Num 2:

FDA Application No:

Title: Sickle Cell Screening Behavior

Organizations

Type	Organization
Performing Organization	Indiana University

Personnel

Person Name	Units		Role	Affiliate	Training
Middlestadt, Susan Elizabeth	BL-APHS	APPLIED HEAL	PI	IU	Y
Mayo, Tilicia L	BA-IUHC	IU HEALTH CENTER	CO-PI	IU	Y

Attachments

Description	Attachment Type	Last Updated	Updated By
Questionnaire	Data Collection Instrument	02/23/2014 19:31:50	tmayo
Exempt Checklist	Exempt Research Checklist	02/23/2014 19:55:57	tmayo
Study Information Sheet	Study Information Sheet	02/25/2014 15:28:08	tmayo
Email Invitations	Recruitment Materials	02/25/2014 15:27:26	tmayo

Roles

Protocol Aggregator

User Id	User Name	Unit Name
	Mayo, Tilicia L	

IRB APPROVAL

This research project, including all noted attachments, has been reviewed and approved by the Indiana University IRB.

☒ Exempt

Category(ies), if applicable:

(2) Expedited Category(ies),

if applicable

Authorized IRB Signature: Digitally signed by Casey Mumaw, CIP DN: cn=Casey Mumaw, CIP, o, ou, email=kmumaw@iu.edu, c=US Date: 2014.02.26 12:00:55 -05'00' Casey Mumaw, CIP IRB Approval Date: 2/26/2014

Printed Name of IRB Member:

Appendix F: Evidence Tables

Table 1: Definitions

1a How is sickle cell **disease** defined?		
Citation	Method	Definitions
Centers for Disease Control and Prevention	National Center on Birth Defects and Developmental Disorders The National Center on Birth Defects and Developmental Disabilities (NCBDDD) has prioritized its work with an immediate focus on blood disorders that affect those most in need of information, resources, and access to care. Sickle Cell Disease is one of several blood disorders that are considered priorities.	Sickle cell disease is a group of inherited blood disorders that cause the body to make sickle-shaped red blood cells Sickle cell disease (SCD) is a common inherited blood disorder in the United States
Sickle Cell Disease Association of America	SCDAA is a national non-profit organization whose main purpose is to advocate for sickle cell related issues.	Sickle cell disease is an inherited blood disorder that affects red blood cells.
National Heart, Lung, and Blood Institute	Sickle cell disease advisory committee	Sickle cell disease is a serious disorder in which the body makes sickle-shaped red blood cells.
Indiana Hemophilia and Thrombosis Center	Sickle Cell Disease and Sickle Cell **Trait** brochure	Sickle cell is an inherited (genetic) disorder that results in abnormal red blood cells, the cells that carry oxygen throughout the body.
Martin Center Sickle Cell Initiative	Programs and Services brochure	Sickle Cell Disease is a genetic blood disorder where the body produces abnormal red blood cells that cannot carry normal levels of oxygen.
1b How is sickle cell **trait** defined?		
Oheng-Frempong, J. (2008). Lessons learned from carrier screening sickle cell disease consumer perspectives. National Institutes of Health.	Health Communication from the National Coordinating and Evaluation Center-Sickle Cell Disease Association of America The Sickle Cell Disease Association of America serves as the National Coordinating and Evaluation Center for the projects of the Newborn Screening Sickle Cell Disease initiative of Health Resources and Services Administration's Maternal Child Health Bureau	Medical terminology issues: What to call sickle cell **trait**?: **trait**, carrier, AS, How to explain what sickle cell **trait** actually is? What is most important for people to know and in what order?
Sickle Cell Disease Association of America	SCDAA is a national non-profit organization whose main purpose is to advocate for sickle cell related issues.	People who inherit one sickle cell gene and one normal gene have *sickle cell **trait*** (SCT).
National Heart, Lung, and Blood Institute	Sickle cell disease advisory committee	People who inherit a sickle hemoglobin gene from one parent and a

		normal gene from the other parent have *sickle cell **trait***.
Centers for Disease Control and Prevention	National Center on Birth Defects and Developmental Disorders	The carrier state for sickle cell.
Health Resources and Services Administration	Secretary's Advisory Committee on Newborn Heritable Disorders in Newborns and Children	Inheritance of a normal beta hemoglobin gene from one parent and a sickle cell gene from the other
Martin Center Sickle Cell Initiative, 2012 MCSI is a not for profit agency funded by the United Way of Central Indiana and the Indiana State Department of Health	Programs and Services brochure	Sickle Cell **Trait** is a genetic blood disorder in which a person has one Sickle Cell gene and one normal gene.

Table 2: Scope and Significance

2a. What is significance of sickle cell **disease** defined as [a serious blood disorder that causes the body to make sickle-shaped red blood cells]?		
Citation	Method	Findings
Centers for Disease Control and Prevention; National Heart, Lung, and Blood Institute. (2009). Disease and conditions index. Sickle cell anemia: who is at risk? Bethesda, MD: US Department of Health and Human Services, National Institutes of Health	Registry and Surveillance System for Hemoglobinopathies; Hemoglobinopathies monitoring *Note*: Prevalence statistics for sickle cell **disease** are only estimates. RuSH (Registry and Surveillance System for Hemoglobinopathies) only began in 2010, is still in its pilot stage and only includes 7 states. Each US state is responsible for tracking the number of individuals with sickle cell **disease**. This method of tracking varies with each state.	Sickle cell disease occurs in about 1 out of every 500 African American births and 1 out of every 36,000 Hispanic-American births. 90,000-100,000 Americans are estimated to have sickle cell disease.
National Heart, Lung, and Blood Institute. (2009). Disease and conditions index. Sickle cell anemia: who is at risk? Bethesda, MD: US Department of Health and Human Services, National Institutes of Health	Registry and Surveillance System for Hemoglobinopathies	The exact number of people living with SCD in the U.S. is unknown. Currently, there are no data systems in the United States to determine the number of people who have SCD and other hemoglobinopathies
Davis, H., Moore, R.M., Gergen, P.J. (1997). Costs of Hospitalizations associated with sickle cell disease in the United States. *Public Health Reports, 112*, 40-43.	Secondary data analysis using national hospital discharge survey data (1989-1993) from the National Center for Health Statistics The National Hospital Discharge Survey (NHDS), which was conducted annually from 1965-2010, was a national probability survey designed to meet the need for information on characteristics of inpatients discharged from non-Federal short-stay hospitals in the United States.	From 1989 through 1993, an average of 75,000 hospitalizations due to SCD occurred in the United States in children and adults, costing approximately $475 million per year. In 66% of hospital discharge records, government programs were listed as the expected principal source of payment.
Steiner, C.A. & Miller, J.L. (2006). Sickle Cell Disease Patients in U.S. Hospitals, 2004. Agency for Healthcare Research and Quality, 1-9.	(Statistical Brief) presents data on Healthcare Cost and Utilization Project on nationwide hospitalizations for sickle cell disease from 1994 through 2004. The Healthcare Cost and Utilization Project is a family of databases and related software tools and products developed through a Federal-State-Industry partnership and sponsored by AHRQ. HCUP databases are derived from administrative data and contain encounter-level, clinical and nonclinical information including all-listed diagnoses and procedures, discharge status, patient demographics, and charges for all patients, regardless of payer (e.g., Medicare, Medicaid, private insurance, uninsured), beginning in 1988.	The total hospital costs in 2004 for hospitalizations principally for SCD were approximately $488 million. Among those hospital stays principally for SCD, 66 percent were paid by Medicaid and 13 percent were paid by Medicare, both public payers of health care.
2b. What is the significance of sickle cell **trait** defined as [the carrier state for sickle cell **disease**]?		
Oheng-Frempong, J. (2008). Lessons learned from carrier screening sickle cell disease consumer perspectives. National Institutes of Health.	Health Communication from the National Coordinating and Evaluation Center-Sickle Cell Disease Association of America The Sickle Cell Disease Association of America serves as the National Coordinating	Medical Terminology Issues: What to call "sickle cell **trait**?" How to explain what sickle cell **trait** actually is? How do we adequately simplify

	and Evaluation Center for the projects of the Newborn Screening Sickle Cell Disease initiative of Health Resources and Services Administration's Maternal Child Health Bureau	complicated information? (How 2 parents have a child with sickle cell disease? Why to get tested? How to get tested?) The term "**trait**" is not very descriptive, and the term "carrier" implies contagion or burden, so the use of "AS" to describe carrier status might be more obvious, and highlights the importance of the "S" gene
Health People 2020 Objective Healthy People 2020 Objectives were selected by the Federal Intragency Workgroup, Objectives for the Blood Disorders were coordinated by the Maternal and Child Health Bureau (HRSA) and NHLBI (NIH)	RuSH, NIH	Increase the proportion of hemoglobinopathy carriers who know their own carrier status
Motulsky AG. (1973). Frequency of sickling disorders in U.S. blacks. New Engl J Med, 288, 31-33.	Hardy Weinberg statistics (min, max, and most likely predictions) Epidemiologic data from the Department of Medicine and Genetics, University of Washington	2 million Americans have sickle cell **trait**. Parents who are both carriers have a 25% probability with each pregnancy of having a child with sickle cell disease.
Centers for Disease Control and Prevention	Registry and Surveillance System for Hemoglobinopathies *Note*: Prevalence statistics for sickle cell **trait** are only estimates. RuSH (Registry and Surveillance System for Hemoglobinopathies) only began in 2010, is still in its pilot stage and only includes 7 states. Each US state is responsible for tracking the number of individuals with sickle cell **trait**. This method of tracking varies with each state	Sickle cell **trait** occurs among about 1 in 12 Blacks or African Americans., 8.3% of African Americans
Kark, J.A., Posey, D.M., Schumacher, H.R., Ruehle, C.J. (1987). Sickle-cell **trait** as a risk factor for sudden death in physical training. *New England Journal of Medicine, 317*, 781-787.	Case Study, 1977-1981; N= 2million recruit records; recruits in basic training aged 17 to 34 To test the association between sickle cell **trait** and exercise related death.	Recruits in basic training with sickle-cell **trait** have a substantially increased, age-dependent risk of exercise-related sudden death unexplained by any known preexisting cause.
National Athletic Trainers Association: Consensus Statement: Sickle Cell **Trait** and the Athlete	Statement from the committee task for force	Red blood cells can sickle during intense exertion, blocking blood vessels and posing a grave risk for athletes with sickle cell **trait**.
Larrabee, K.D., Monga, M. (1997). Women with sickle cell **trait** are at increased risk for preeclampsia. *American Journal of Obstetrics and Gynecology, 177*(2), 425-428.	Case Control Study, N=1584	Sickle cell **trait**–positive women are at significantly higher risk for development of perinatal complications.

Austin H, Key NS, Benson JM, Lally C, Dowling NF, Whitsett C, Hooper WC. (2007). Sickle cell **trait** and the risk of venous thromboembolism among blacks. *Blood, 110*, 908-912.	Case control study, 515 patients, 555 controls	Individuals with sickle cell **trait** are at an increased risk of venous thromboembolism.
Centers for Disease Control and Prevention ; National Athletic Trainers Association: Consensus Statement: Sickle Cell **Trait** and the Athlete	National Center on Birth Defects and Developmental Disorders ; Statement from the committee task for force	The following conditions could be harmful for people with sickle cell **trait**: — Increased pressure in the atmosphere (which can be experienced, for example, while scuba diving). — Low oxygen levels in the air (which can be experienced, for example, when mountain climbing, exercising extremely hard in military boot camp, or training for an athletic competition). — Dehydration (for example, when one has too little water in the body). — High altitudes (which can be experienced, for example, when flying, mountain climbing, or visiting a city at a high altitude).

Table 3: Priority Group

3a. Who is at risk of sickle cell **disease** defined as [a serious blood disorder that causes the body to make sickle-shaped red blood cells]?		
Citation	Method	Findings
Centers for Disease Control and Prevention	Registry and Surveillance System for Hemoglobinopathies; Hemoglobinopathies monitoring *Note*: Prevalence statistics for sickle cell **trait** are only estimates. RuSH (Registry and Surveillance System for Hemoglobinopathies) only began in 2010, is still in its pilot stage and only includes 7 states. Each US state is responsible for tracking the number of individuals with sickle cell **trait**. This method of tracking varies with each state.	SCD affects 90,000 to 100,000 Americans and occurs among about 1 out of every 500 Black or African-American births.
3b. Which group is priority when addressing sickle cell **trait** defined as [the carrier state for sickle cell **disease**]?		
Motulsky AG. (1973). Frequency of sickling disorders in U.S. blacks. New Engl J Med, 288, 31-33.	Hardy Weinberg statistics (min, max, and most likely predictions) Epidemiologic data from the Department of Medicine and Genetics, University of Washington	One in every 150 African American couples in the U.S. is at risk of giving birth to a child with sickle cell disease (about 3,000 pregnancies per year)
Centers for Disease Control and Prevention	Registry and Surveillance System for Hemoglobinopathies; Hemoglobinopathies monitoring *Note*: Prevalence statistics for sickle cell **trait** are only estimates. RuSH (Registry and Surveillance System for Hemoglobinopathies) only began in 2010, is still in its pilot stage and only includes 7 states. Each US state is responsible for tracking the number of individuals with sickle cell **trait**. This method of tracking varies with each state.	SCT occurs among about 1 in 12 (8.3%) Blacks or African Americans.
Sickle Cell Disease Association of America	SCDAA is a national non-profit organization whose main purpose is to advocate for sickle cell related issues. Research & Screening Executive Summary (Statement by the organization, no references provided)	Knowledge of carrier status is important for reproductive planning since carriers can have children with sickle cell disease. People who are considering children should know about the probabilities of significant genetic disorders in those children. This information requires knowledge about the genotype of both patient and partner.
Centers for Disease Control and Prevention	National Center on Birth Defects and Developmental Disorders	Women with SCD or SCT might want to see a genetic counselor for information about the disease and the chances that SCD or SCT was passed to their baby.
Indiana Hemophilia and Thrombosis Center	Sickle cell disease and Sickle cell **trait** brochure	It is important to know if you have sickle cell **trait** (are a sickle cell carrier) before you decide to have children.

Table 4: Genetic Screening

4a. What racial/ethnic disparities exist in genetic screening?			
Qualitative Studies			
Citation	Method	Findings	Comments
There were no qualitative studies found answering the question.			
Quantitative Studies			
Citation	Method	Findings	Comments
Suther, S., Kuros, G-E. (2009.) Barriers to the use of genetic testing: A study of racial and ethnic disparities. *Genetics in Medicine, 11*(9), 655-662.	Secondary data analysis, N= 1724 (National representative sample data) collected in 2000 by the University of Maryland College Park Survey Research Center Objective: To examine racial and ethnic differences in the following barriers to genetic testing: (a) knowledge about genetic testing; (b) type of health insurance coverage; (c) concerns about the potential misuse of genetic testing; and (d) lack of trust in a medical doctor to keep their medical information private. Socio-ecological Model	Ordered logistic regression was used with the 4 outcome variables (Knowledge score was created and used in regression analysis) Blacks and Latinos are less likely to use genetic testing than non-Hispanic whites. The odds of having adequate knowledge among blacks and Latinos compared with non-Hispanic whites was lower by 28% and 52%, respectively	Knowledge index used (Survey not included) 7 questions about genetic testing
Armstrong, K., Micco, E., Carney, A., Stopfer, J., Putt, M. (2005). Racial Differences in the Use of BRCA ½ Testing Among Women with a Family History of Breast or Ovarian Cancer. *JAMA, 293*(14), 1729-1736.	Case Control Study, Women 18-80, N=603 Objectives: To investigate the relationship between race and the use of BRCA1/2 counseling among women with a family history of breast or ovarian cancer. To determine the contribution of socioeconomic characteristics, cancer risk perception and worry, attitude about genetic testing, and interactions with doctors to racial differences in utilization. (Age, educ, income, race, and religion, attitude)	Adjustment for racial differences in *BRCA1/2* mutation probability, sociodemographic factors, and risk perception led to slight increases in the point estimate of the odds ratio (OR) for the association between race and *BRCA1/2* counseling (OR, 0.22-0.40) The racial disparity in use of *BRCA1/2* counseling in this population was not explained by differences in the probability of carrying a *BRCA1/2* mutation, socioeconomic status, cancer risk perception and worry, attitude about the risks and benefits of *BRCA1/2* testing, or doctor discussions of *BRCA1/2* testing. African American women with a family history of breast or ovarian cancer were less likely to undergo genetic counseling for *BRCA1/2* testing than are white women with a family history of breast or ovarian cancer.	Discusses how attitude were measured
4b. What are the determinants that influence genetic screening?			
Qualitative Studies			
Citation	Method	Findings	Comments

Halbert, C.H., Kessler, L.J., Mitchell, E. (2005). Genetic testing for inherited breast cancer risk in African Americans. Cancer Investigation, 23:285–295.	Literature review Qualitative; Literature review The purpose of this review was to synthesize literature on knowledge and attitude about genetic counseling and testing for inherited breast cancer risk in African Americans. PubMed database to identify studies related to BRCA1/2 testing in African Americans that were published between 1995 and 2003.	Concerns about the familial implications of genetic test results were associated significantly with participation in genetic counseling and testing. Women who are not informed about the availability of genetic counseling and testing or are less aware about how cancer risk can be transmitted in families may be less likely to initiate discussions with their physician about whether risk counseling or genetic testing would be informative. Overall, studies have shown that knowledge about breast cancer genetics and exposure to information about genetic testing is limited among African American women. African American women reported significantly lower levels of knowledge about breast cancer genetics than Caucasian women, even though educational levels were comparable. Compared with Caucasian women, African American women reported significantly lower levels of knowledge about inherited disease and exposure to information about genetic testing.	Lists specific studies related to determinants (knowledge and attitude).
Singer, E., Antonucci, T., Van Hoewyk, J. (2004). Racial and Ethnic Variations in Knowledge and Attitude about Genetic Testing. *Genetic Testing*, *8*(1), 31-43.	Cognitive interviews with 15 African-American and Latino respondents This study explores the values, attitude, and beliefs of African-Americans, Latinos, and non-Hispanic Whites with respect to genetic testing by means of a telephone survey of representative samples of these three groups.	For all three race/ethnic groups, doctors were the most important source— 37.9% of White respondents, 50% of African-American respondents, and 32.3% of Latino respondents Latino and African-American respondents had more reservations about the future of genetic testing than White respondents did. African-American respondents indicated significantly less efficacy and trust than White respondents. African-Americans were more likely to report being covered by Medicaid, making cost a barrier to genetic testing.	Addresses beliefs and attitude toward testing

Quantitative Studies			
Citation	Method	Findings	Comments
Zimmerman, R.K., Tabbarah, M., Nowalk, M.P., Raymund, M., Jewell, I.K., Wilson, S.A., Ricci, E.M. (2006). Racial Differences in Beliefs about Genetic Screening among Patients at Inner-City Neighborhood Health Centers. *Journal of the National Medical Association, 98*(3), 370-377.	Telephone Survey, N=314 Objective: To identify racial differences in beliefs about the causes of diseases whose etiology is environmental (e.g., exposure to influenza virus), genetic (e.g., sickle cell disease) or a combination (obesity), and to explore racial differences in beliefs about genetic testing, ethical and religious values and concerns about discrimination. Logistic regression using race as the outcome variable Theory of Reasoned Action used to guide questionnaire- beliefs and attitude about genetic screening (intention was not measured)	African Americans were more likely than Caucasians to agree that genetic testing led to racial discrimination. African Americans were likely than Caucasians to agree that genetic research was unethical but believed all pregnant women should have genetic tests.	Questionnaire items for attitude construct
Peters, N., Rose, A., Armstrong, K. (2004). The Association between Race and Attitude about predictive genetic testing. *Cancer Epidemiology, Biomarkers, and Prevention. 13*, 361-365.	Cross sectional survey, N=430 Objective: To investigate differences in attitude about predictive genetic testing for cancer risk between African-American and Caucasian residents of the city of Philadelphia. No theory discussed, attitude construct (focus groups, lit review, and expert opinion guided instrument development)	African-Americans were more likely to report that the government would use genetic tests to label groups as inferior, and less likely to endorse the potential health benefits of testing.	Instrument Development Questionnaire items for attitude construct
Suther, S., Kuros, G-E. (2009.) Barriers to the use of genetic testing: A study of racial and ethnic disparities. *Genetics in Medicine, 11*(9), 655-662.	Secondary data analysis, N= 1724 (National representative sample data) collected in 2000 by the University of Maryland College Park Survey Research Center Objective: To examine racial and ethnic differences in the following barriers to genetic testing: (a) knowledge about genetic testing; (b) type of health insurance coverage; (c) concerns about the potential misuse of genetic testing; and (d) lack of trust in a medical doctor to keep their medical information private. Socio-ecological Model	Evidence of 23 determinants: knowledge or lack of adequate information provided by their physicians about genetic testing. ; health insurance coverage Both blacks and Latinos had significantly lower knowledge of genetic testing compared with non-Hispanic whites.	
Pagán, J.A., Dejun S., Lifeng L., Armstrong, K., David A.A. (2009). Racial and Ethnic Disparities in Awareness of Genetic Testing for	N=25,364 National Health Interview Survey This study assesses the relative importance of contributing factors to gaps in awareness of genetic	48% of white respondents in the 2005 NHIS reported that they had heard about genetic testing, followed by 30.8% of blacks, 27.7% of Asians, and 19% of Hispanics.	

Cancer Risk. American Journal of Preventive Medicine, 37(6), 524-530.	testing for cancer risk across racial and ethnic groups. Variables: demographic factors, SES, health status, nativity/length of residency in the U.S., personal/family history of cancer, and perceived cancer risk	Factors associated with a higher probability of being aware of genetic testing include being white, older, female, employed, married, in better health, born in the U.S. or residing longer in the U.S. (for immigrants), not residing in the South, being more highly educated, having private health insurance coverage, and having a personal/parental history of cancer. Lower educational attainment among African Americans, and regional differences, contributed substantially to the white– black gap in awareness of genetic testing for cancer risk.	

Table 5- Determinants

What are the determinants of genetic sickle cell trait screening in African Americans?			
Qualitative Studies			
Citation	Research Method	Findings	Comments
Long, K. A., Thomas, S. B., Grubs, R. E., Gettig, E. A. & Krishnamurti, L. (2010). Attitude and Beliefs of African-Americans Toward Genetics, Genetic Testing, and Sickle Cell Disease Education and Awareness. *J Genet Counsel*. 1-21: DOI 10.1007/s10897-011-9388-3.	Qualitative; Afr. Amer. men and women aged 18 and older, qualitative surveys and focus groups (4). Attitude and beliefs regarding genetics and genetic testing including prenatal testing and newborn screening	Limited understanding of the inheritance and probable risk of giving birth to a child with the disease. Awareness helps mother prepare. Awareness of a genetic condition allows the mother to be knowledgeable about possible recurrence of genetic conditions and in select cases, make changes to lower the chance of recurrence of the genetic condition.	Discusses knowledge of sickle cell trait status Information used as foundation to more assess attitude and beliefs regarding SCD and perceived barriers to SCD education and awareness.
Quantitative Studies			
Gustafson, S.L., Gettig, E.A., Watt-Morse, M., Krishnamurti, L. (2007). Health beliefs among African American women regarding genetic testing and counseling for sickle cell disease. Genetics in Medicine. 9(5), 303-310.	Quantitative; Anonymous questionnaire using a 12-question measure with a 5-point Likert scale response	Perceive low levels of personal susceptibility Established family/cultural scripts	African American women have a relatively high belief of the severity of sickle cell disease and benefits of genetic counseling but frequently do not appear to believe that they are at risk of having a child with the disease.

Table 6: Awareness of Sickle Cell **Trait**

What evidence exists on awareness of sickle cell **trait** amongst African Americans?			
Citation	Method	Findings	Comments
Grant, A.M. RuSH: Sickle Cell Surveillance System. Division of Blood Disorders, Centers for Disease Control and Prevention.	Registry and Surveillance System for Hemoglobinopathies; Hemoglobinopathies monitoring *Note*: Prevalence statistics for sickle cell **disease** are only estimates. RuSH (Registry and Surveillance System for Hemoglobinopathies) only began in 2010, is still in its pilot stage and only includes 7 states. Each US state is responsible for tracking the number of individuals with sickle cell **disease**. This method of tracking varies with each state.	Sickle cell challenges: Unknown Prevalence, Lack of access to specialty care/quality care especially for adults, Lack of understanding of risk factors and complications over the lifespan, Lack of understanding the overall impact and barriers to diffusion of effective interventions, No national coordination of services, Lack of community awareness	
Treadwell MJ, McClough L, & Vichinsky E (2006). Using qualitative and quantitative strategies to evaluate knowledge and perceptions about sickle cell disease and sickle cell **trait**. *Journal of the National Medical Association*, 98, 04-10.	Focus Groups Surveys, N = 282 To evaluate knowledge, perceptions and the effectiveness of different sources of information about sickle cell **trait** (SCT) and sickle cell disease (SCD); to determine individual knowledge of SCT status.	Only 16% of survey respondents knew SCT status. 86.2% of survey respondents had correct general knowledge about the genetic basis and severity of SCD. 16.7% or respondents knew their own **trait** status.	

Table 7

What theory or conceptual framework or construct(s) might be useful to understand why people would or would not be screened for sickle cell **trait**?				
Citation	Research Method	Theory/Construct	Findings	Comments
Ajzen, I. (2002). Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior. *Journal of Applied Social Psychology, 32*, 665-683.	Open ended questionnaire Review	Perceived behavioral control, internal locus of control, self-efficacy	Perceived control over performance of a behavior can account for considerable variance in intentions and actions. Self-efficacy and controllability may both reflect beliefs about the presence of internal as well as external factors.	1) Discusses the conceptual and operational issues underlying the measurement of perceived behavioral control
Sheats, J.L. & Middlestadt, S.E. (2013). Salient beliefs about eating and buying dark green vegetables as told by Mid-western African-American women. *Appetite, 65*, 205-209.	Qualitative survey (N=30) Semi-structure interviews Salient belief elicitation Objective: To assess salient, top-of-the-mind, beliefs (consequences, circumstances and referents) about eating and buying more dark green leafy vegetables each week over the next 3 months	Reasoned Action Approach Perceived disadvantages and advantages Perceived consequences and circumstances Referents, approve, disapprove	Frequently mentioned categories of perceived advantages of buying more that differed from the eating elicitation included “will eat more dark green leafy vegetables” (33.3%), “help me eat healthier meals” (26.7%), “help my family eat more dark green leafy vegetables”(16.7%) and “improve the health of my family” (13%). The most frequently mentioned perceived salient circumstances that differed from the behavior eating was that “not being fresh or of good quality” (13.3%) made it difficult to buy more dark	Tables are included in the Appendix

			green leafy vegetables.	
Witte, K., & Allen, M. (2000). A meta-analysis of fear appeals: implications for effective public health campaigns. *Health Education & Behavior*, *27* (5), 591-615	Meta-Analysis, N=98 to examine how people reacted (both perceptually and persuasively) to fear appeal messages	Fear Appeal Theory	The stronger the fear appeal, the greater the fear aroused, the greater the severity of the threat perceived, and the greater the susceptibility to the threat perceived. Fear, severity, susceptibility, self-efficacy, and response efficacy—result in greater positive levels of attitude, intentions, and behavior change. Strong fear appeals induce high perceived severity and susceptibility Strong fear appeals and high self-efficacy messages prompt greatest change Strong fear appeals and low self-efficacy produce most defensive responses	Table of Effects of Message Feature on Attitude, Intentions, and Behaviors
Gore, T.D. (2005). Testing the theoretical design of a health risk message: Reexamining the major tenets of the extended parallel Process model. *Health Education & Behavior*, *32*(1), 27-41.	2 x 2 experimental design (N=145), college students at a mid-western university Examined how two health risk messages regarding meningitis.	Extended Parallel Process Model Two health risk messages: a high-fear and a high efficacy message	Participants who initially had low-efficacy perceptions moved toward danger control processes, $p < .001$ Participants who initially held fear control responses would move further into fear	Pre/Post design but still a good model for my dissertation

			control processes, p <.001	

Table 8: Use of Persuasive Health Messages

How have persuasive health messages been used to increase behavior change?			
Citation	Research method	Construct	findings
Cecelia Gatson Grindel, C.G., Brown, L., Lee, C., and Blumenthal, D. (2004). The Effect of Breast Cancer Screening Messages on knowledge, attitude, perceived risk, and mammography screening of African American women in the rural south. *Oncology Nursing forum –31*(4), 801-808.	Repeated measures experimental design, N=450 Examined the effect of three types of breast cancer screening messages on knowledge, attitude, perceived risk for breast cancer, and mammography screening of African American women.	Knowledge, awareness, attitude, perceived risk	No significant difference between messages for knowledge, attitude, and perceived risk. Education, income, and health insurance were all positively associated with getting a mammogram.
Gore, T.D. (2005). Testing the theoretical design of a health risk message: Reexamining the major tenets of the extended parallel Process model. *Health Education & Behavior, 32*(1), 27-41.	2 x 2 experimental design (N=145), college students at a mid-western university Examined how two health risk messages regarding meningitis.	Extended Parallel Process Model Two health risk messages: a high-fear and a high efficacy message	Participants who initially had low-efficacy perceptions moved toward danger control processes, p <.001 Participants who initially held fear control responses would move further into fear control processes, p <.001

Appendix G: Population Table

Table 9: Cities with Highest African American Percentage (Population 5,000+)

Rank		African American Percentage
1.	Gary	84%
2.	East Chicago	36%
3.	Indianapolis	26%
4.	Michigan City	26%
5.	South Bend	25%
6.	Merrillville	23%
7.	Ft. Wayne	17%
8.	Lawrence	16%
9.	Marion	16%
10.	Anderson	15%

http://www.idcide.com/lists/in/on-population-african-american-percentage.html

Appendix H: Sickle Cell Trait Prevalence
Fourteen Indiana Counties with Highest Frequencies Of Sickle Cell Trait or Disease (All Ages)

County/Major City	Estimated Number of Newborns with Sickle Cell Trait *++ (Annually)	Estimated Number of Newborns with Sickle Cell Disease *+ (Annually)	Estimated Number of Blacks with Sickle Cell Trait *++ (All Ages)	Estimated Number of Blacks with Sickle Cell Disease *+ (All Ages)
Marion (Indianapolis)	392	10	17,023	426
Lake (Gary)	236	6	11,753	294
Allen (Fort Wayne)	80	2	3,057	76
St. Joseph (South Bend)	63	2	2,433	61
Vanderburgh (Evansville)	26	1	1,244	31
Madison (Anderson)	18	0	991	25
Laporte (Michigan City)	20	1	961	24
Delaware (Muncie)	14	0	721	18
Elkhart (Elkhart)	20	1	712	18
Vigo (Terre Haute)	9	0	595	15
Grant (Marion)	12	0	510	13
Clark (Jefferson)	10	0	473	12
Howard (Kokomo)	7	0	441	11
Wayne (Richmond)	7	0	381	10

*Based on 1990 U.S. Census Public Health Statistics figures for total black live births
**Based on 1990 U.S. Census Public Health Statistics figures for total black population
+Calculated as 1 in 400, per national incidence in black population.
++Calculated as 1 in 10, per national incidence in black population Prepared by Office of Minority Health, Sickle Cell Newborn Screening Program, Indiana State Department of Health

Appendix I: Recruitment Locations

Recruitment Location	Method of Recruitment	# of Times
Indianapolis Central Library	In-Person Active Recruitment/Posted Flyer	1
Indianapolis East Branch Library	Left Flyers/Posted Flyer	1
Dubois Branch Library (Gary)	In-Person Active Recruitment/Posted Flyer	2
Kennedy Branch Library (Gary)	Posted Flyer	1
Clark Road MB Church	Posted Flyer	1
Mount Pleasant MB Church	Posted Flyer/Listed information in church bulletin	1
Eastern Star Church	Posted Flyer	1
Mount Zion Church Health Fair-Indianapolis	In-Person Active Recruitment/Left Flyers	1
Marion County Health Dept.	In-person Active Recruitment/Left Flyers	2
Indiana University (Indianapolis)	Posted Flyer	1
Indiana University (Bloomington)	Emailed flyer through GROUPS listserv	1
Indiana University (Bloomington)	Emailed flyer through Athletic listserv	1
Bethel Church	Passed out flyers, spoke to congregation	1
Sickle Cell Conference	In-Person Active Recruitment	1
Martin Center Sickle Cell Initiative	In-Person Active Recruitment (Support Meeting)/Left Flyers	1
Hudson Campbell Athletic Center-Gary	Left flyers	1
Ten Facebook pages (2 in Bloomington, 7 in Indianapolis, 1 in Gary)	All posted study information once (Verified by investigator)	1

Appendix J: Construct Table

Table 11: Construct, Item Description, Response Scale, Scoring

Construct	Items	Response Scale	Scoring	Analysis
Brochure 1	What is the main point of the brochure? What aspect of the brochure helped you to determine the main point?	Open Ended	As a condition: Dummy 0/1	
Brochure 2 Explicit Textual Response	What is the main point of the brochure? Q4 What aspect of the brochure helped you to determine the main point?	Open Ended	As a condition: Dummy 0/1	
Knowledge				
Pre/Post Sickle Cell Trait Knowledge	What does sickle cell trait mean to you?	Open Ended		
Pre/Post Sickle Cell Trait Screening Knowledge	What sickle cell trait screening mean to you?			
Intention	**3 items**			
	Q12 How LIKELY or UNLIKELY are you to go to your doctor to ask for sickle cell trait screening? Q21 What statement best describes your intention when it comes going to your doctor to ask for screening for Sickle Cell ***Trait***? Q22 How likely are you to ask for sickle cell trait screening from your doctor?	7 point bipolar scale: extremely unlikely/extremely likely	-3 to 3	Calculate Mean
Attitude	**4 items**			
Behavioral Belief	Q6 What are the advantages or good things that might happen if you go to your doctor to ask for sickle cell trait screening? Q7 What are the disadvantages or bad things that might happen if you go to your doctor to ask for sickle cell trait screening?	Open-ended with option up to 3 suggestions	N/A	
	Q13 Would it be GOOD or	7 point semantic	-3 to 3	Calculate

	BAD for you to ask for sickle cell trait screening from your doctor? Q14 Would it be WISE or FOOLISH for you to ask for sickle cell trait screening from your doctor?	evaluative differential scale: Good/bad Wise/Foolish		Mean
Perceived Norm	**4 items**			
Normative Beliefs	Q10 Who (individuals or groups) do you think would approve of or support you going to your doctor to ask for sickle cell trait screening? Q11 Who (individuals or groups) do you think would disapprove of or support you going to your doctor to ask for sickle cell trait screening?	Open-ended with option up to 3 suggestions	N/A	
	Q15 How LIKELY or UNLIKELY is it that African Americans age 18-35, WHO ARE LIKE YOU would ask for sickle cell trait screening from your doctor? Q16 How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU think you should ask for sickle cell trait screening from your doctor?	7 point Likert type scale: extremely unlikely/extremely likely	-3 to 3	Calculate Mean
Perceived Behavioral Control	**4 items**			
Control Beliefs	Q8 What might make it EASIER for you to go to your doctor to ask for sickle cell trait screening? Q9 What might make it HARDER for you to go to your doctor to ask for sickle cell trait screening?	Open-ended with option up to 3 suggestions	N/A	
	Q19 How SURE are you that you will ask for sickle cell trait screening from your doctor? Q20 How much is it UP TO YOU ask for sickle cell trait screening from your doctor?	5 point semantic evaluative differential scale: Not at all sure/completely sure	-2 to 2	Calculate Mean

Response Efficacy	**3 items**			
	Q23 Going to the doctor to get screened for sickle cell trait is an effective method for learning your sickle cell trait status. Q24 Going to the doctor to get screened for sickle cell will decrease my chances of becoming ill due to complications from sickle cell trait. Q25 If I go to the doctor to get screened for sickle cell trait, I do not have to worry as much about the complications associated with sickle cell trait.	5 point agreement scale	-2 to 2	Calculate Mean
Perceived Threat	**4 items**		-4 to 4	Calculate Mean
Perceived Severity	Q26 I believe that sickle cell trait is severe. Q27 I believe that sickle cell trait has serious negative consequences.	5 point agreement scale	-2 to 2	
Perceived Susceptibility	Q28 I am at risk for having sickle cell trait. Q29 It is possible that I could have sickle cell trait.	5 point agreement scale	-2 to 2	
Demographic Factors				
Awareness of Sickle Cell Trait/Screening 3 items	Q43 Have you personally known or know anyone who has Sickle Cell ***Disease***? Q44 Prior to today, had you ever heard of *Sickle Cell **Trait***? Q45 Have you personally known or know anyone who has *Sickle Cell **Trait***?	Nominal No/Unsure/Yes	0 to 6	Calculate Mean
Age in years	Q30 What is your age? _____ Years 98 Refused to Answer	Interval	# years	
Sex	Q31 What is your sex?	Nominal	Dummy 0/1	
Education	Q32 What is the highest level of education you have	Nominal	Dummy 1/4	

	completed?			
Employment	Q33 How would you describe your employment status?	Nominal	Dummy 0/2	
Income	Q34 What is your household income?	Interval	# dyads	
Insurance	Q35 What type of health insurance do you have?	Nominal	Dummy 0/3	
Marital Status	Q36 What is your marital status?	Nominal	Dummy 0/4	
Health Care Provider	Q40 Do you have one person, or one medical practitioner, who you think of as your personal doctor, doctor, or health care provider?	Nominal	Dummy 0/1	
Perceived Health Status	Q37 Would you say that in general your health is...?	Nominal	Dummy 0/4	
Additional Questions (Was asked but not analyzed for dissertation)				
Reproductive 1	Q38 Do you have any biological children?	Nominal	Dummy 0/1	
Reproductive 2	Q39 Do you plan to have biological children in the future?	Nominal	Dummy 0/2	
Athlete	Q41 Do you currently participate in an organized sport for an academic institution? (i.e., college, high school)	Nominal	Dummy 0/1	
Military	Q42 Do you plan to go into the military?	Nominal	Dummy 0/1	

Appendix K: Codebook

Construct	Items	Coding
Eligibility		
Race	Do you self-identify as being Black/African American or mixed with African ancestry?	1= No 2= Yes
Status	Do you know your Sickle Cell ***Trait*** status?	0=No 1=Yes
Location	What is your zip code?	Open Ended
Brochure Group		
Brochure 1	Randomly Assigned	0=No 1=Yes
Brochure 2 Explicit Response	Randomly Assigned	0=No 1=Yes
Recognition of the Main Point of the Brochure-Actual understanding of the main point of the brochure	**3 items**	
Brochure 1	What is the main point of the brochure	Open Ended
	What helped you to determine the main point of the brochure?	Open Ended
	The information in brochure was clear and easy to understand	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
Brochure 2 Explicit Response	What is the main point of the brochure?	Open Ended
	What helped you to determine the main point?	Open Ended
	The information in brochure was clear and easy to understand	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Strongly Agree 3 Extremely Agree
Perceived Clarity (Binary)- Perceived understanding of the information presented within the brochure		
	The information in brochure was clear and easy to understand	0= Did not understand 1= Understand "Understand" was based on a clarity score of 3 or extremely agree
Recognition of Main Point (Binary)		
	What is the main point of the brochure?	0= Did not get main point 1= Got main point Main point was to go to the doctor to ask for

		screening for sickle cell trait.
Knowledge (Pre/post) Open-Ended	**4 items**	
	Q4 In your own words, what does sickle cell trait mean to you? Q5 In your own words, what does getting screened for Sickle Cell Trait mean to you?	Open Ended Open Ended
Knowledge (Pre/post) Coded	**2 items**	
	Q4 In your own words, what does sickle cell trait mean to you?	0= Incorrect 1= Partially Correct 2= Completely Correct Responses coded as personal relevance did not provided a definition but rather responded with personal significance to sickle cell trait. Partially Correct responses indicated that sickle cell trait is an inherited gene or indicated the manifestation of sickle cell trait (Ex. "an inherited gene" "Having a sickle shaped cell.") Completely correct responses indicated that sickle cell trait means you are a carrier for sickle cell disease, or made reference to the hereditary nature of the trait (Ex. "It means you are a carrier for sickle cell")
	Q5 In your own words, what does getting screened for Sickle Cell Trait mean to you?	0= Incorrect 1= Partially Correct 2= Completely Correct Responses coded as personal relevance did not provided a definition but rather responded with personal significance to sickle cell trait screening. Partially correct responses indicated finding out or being told if you have sickle cell trait (Ex. "To be notified if I have the trait.")

		Completely correct responses indicated testing or screening (genetic or blood) to determine if you have sickle trait (Ex. "It means that you will take a test to see if you have the sickle cell trait. A blood test.")
Intention- Indications of a person's readiness to perform a behavior	**4 items**	
	Q6 How LIKELY or UNLIKELY are you to go to your doctor to ask for sickle cell trait screening in the next 12 months?	-3 Extremely Unlikely -2 Quite Unlikely -1 Slightly Unlikely 0 Neutral 1 Slightly Likely 2 Quite Likely 3 Extremely Likely
	Q19 I intend to go to my doctor to ask for Sickle Cell ***Trait*** screening within the next 12 months.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
	Q20 What statement best describes your intention when it comes going to your doctor to ask for screening for Sickle Cell ***Trait***?	-1 I do not intend on going to my doctor to ask for screening for Sickle Cell Trait now or in the future. 0 I intend to go to my doctor to ask for Sickle Cell Trait screening within the next the next 5 years. 1 I intend to go to my doctor to ask for Sickle Cell Trait screening within the next 4 to 12 months 2 I intend to go to my doctor to ask for Sickle Cell Trait screening within the next 1 to 3 months. 3 I intend to go to my doctor to ask for Sickle Cell Trait screening within the next 30 days.
Attitude Toward the Behavior (Attitude)- Tendency to respond with some degree of favorableness or unfavorableness to a psychological object	**4 items**	

Behavioral Belief	What are the advantages or good things that might happen if you go to your doctor to ask for sickle cell trait screening? What are the disadvantages or bad things that might happen if you go to your doctor to ask for sickle cell trait screening?	Open-ended with option up to 3 suggestions
Instrumental	Q7 Would it be GOOD or BAD for you to go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Extremely Bad -2 Quite Bad -1 Slightly Bad 0 Neither Bad or Good 1 Slightly Good 2 Quite Good 3 Extremely Good
	Q8 Would it be WISE or FOOLISH for you to go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Extremely Foolish -2 Quite Foolish -1 Slightly Foolish 0 Neutral 1 Slightly Wise 2 Quite Wise 3 Extremely Wise
Experiential	Q16 My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is boring/fun.	-3 Extremely Boring -2 Quite Boring -1 Slightly Boring 0 Neutral 1 Slightly Fun 2 Quite Fun 3 Extremely Fun
	Q17 My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is unenjoyable/enjoyable	-3 Extremely Unenjoyable -2 Quite Unenjoyable -1 Slightly Unenjoyable 0 Neutral 1 Slightly Enjoyable 2 Quite Enjoyable 3 Extremely Enjoyable
Perceived Norm- The more one believes that important others think one should (or should not) perform the behavior and/or that important others or "others like me" are themselves performing the behavior	**4 items**	
Normative Beliefs	Who (individuals or groups) do you think would approve of or support you to go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months? Who (individuals or groups) do you think would disapprove of or support you to go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	Open-ended with option up to 3 suggestions
Descriptive	Q9 How LIKELY or UNLIKELY is it that African Americans age 18-35, WHO ARE LIKE YOU would you to go to their doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Extremely Unlikely -2 Quite Unlikely -1 Slightly Unlikely 0 Neutral 1 Slightly Likely 2 Quite Likely

		3 Extremely Likely
	Q12 How many of the people whose opinion you value have asked sickle cell trait screening from their doctor in the next 12 months?	-3 Virtually None -2 -1 0 Some 1 2 3 Virtually All
Injunctive	Q10 How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU think you should you to go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Extremely Unlikely -2 Quite Unlikely -1 Slightly Unlikely 0 Neutral 1 Slightly Likely 2 Quite Likely 3 Extremely Likely
	Q11 How LIKELY or UNLIKELY is that MOST PEOPLE WHO ARE IMPORTANT TO YOU would approve you going to the doctor to ask for sickle cell trait screening in the next 12 months?	-3 Extremely Unlikely -2 Quite Unlikely -1 Slightly Unlikely 0 Neutral 1 Slightly Likely 2 Quite Likely 3 Extremely Likely
Perceived Behavioral Control- People's perceptions of the degree to which they are capable of, or have control over, performing a given behavior	**4 items**	
Control Beliefs	Q8 What might make it EASY for you to go to your doctor to ask for sickle cell trait screening in the next 12 months? Q9 What might make it DIFFICULT for you to go to your doctor to ask for sickle cell trait screening in the next 12 months?	Open-ended with option up to 3 suggestions
Capacity	Q13 How SURE are you that you will go to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Not at all sure -2 -1 0 Somewhat sure 1 2 3 Completely sure
	Q18 I am CONFIDENT that I can go to the doctor to ask for Sickle Cell Trait screening in the next 12 months.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
Autonomy	Q14 How much UNDER YOUR CONTROL is going to your doctor to ask for Sickle Cell ***Trait*** screening in the next 12 months?	-3 Not at all under my control -2 -1 0 Somewhat under my control 1 2 3 Completely under my

		control
	Q15 My going to the doctor to ask for Sickle Cell Trait screening in the next 12 months is UP TO ME.	-3 Not at all up me -2 -1 0 Somewhat up to me 1 2 3 Completely up to me
Response Efficacy- Beliefs about the effectiveness of the recommended response to avert the threat	**1 item**	
	Q25 Going to the doctor to get screened for sickle cell trait is an effective method for learning your sickle cell trait status.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
Perceived Threat- A threat is the negative consequences that occur if you don't do what is advocated	**4 items**	
Perceived Severity	Q21 I believe that sickle cell trait is severe.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
	Q22 Sickle cell trait has serious negative consequences.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
Perceived Susceptibility	Q23 I am at risk for having sickle cell trait.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
	Q24 It is possible that I could have sickle cell trait.	-3 Extremely Disagree -2 Quite Disagree -1 Slightly Disagree 0 Neutral 1 Slightly Agree 2 Quite Agree 3 Extremely Agree
Demographic Factors		
Awareness of Sickle Cell Trait/Screening 3 items	Q38 Have you personally known or know anyone who has Sickle Cell ***Disease***?	0=No 1=Unsure 2=Yes
	Q39 Prior to today, had you ever heard of *Sickle Cell* ***Trait***?	0=No 1=Unsure 2=Yes

	Q40 Have you personally known or know anyone who has *Sickle Cell* ***Trait***?	0=No 1=Unsure 2=Yes
Age in years	Q26 What is your age? _____ Years 98 Refused to Answer	Open Ended
Sex	Q27 What is your sex?	1= Male 2= Female
Education	Q28 What is the highest level of education you have completed?	1= Less than HS 2= Some HS 3= HS Diploma/GED 4= Some College 5= Undergraduate Degree 6= Graduate Work or Degree
Employment	Q29 How would you describe your employment status?	1= Unemployed 2= Employed Part-Time 3= Employed Full-Time 4= Student Recoded 1= Unemployed/Student 2= Employed Part-Time 3= Employed Full-Time
Income	Q30 What is your household income?	1= Less than 10,000 2= 10,000 to 19,999 3= 20,000 to 29,999 4= 30,000 to 39,999 5= 40,000 to 49,999 6= 50,000 or greater
Insurance	Q31 What type of health insurance do you have?	1= Uninsured 2= Self-pay 3=Employer Paid 4= Medicaid/Medicare
Partner Status	Q32 What is your marital status?	1= Single/Not in a relationship 2= Single/In a relationship 3= Cohabitating 4= Married 5= Separated/Divorced 6= Widowed Recoded 1= Not in a relationship 2= In a relationship
Health Care Provider	Q36 Do you have one person, or one medical practitioner, who you think of as your personal doctor, doctor, or health care provider?	0=No 1=Yes
Perceived Health Status	Q33 Would you say that in general your health is...?	1= Excellent 2= Very Good 3= Good 4= Fair 5= Poor

Appendix L: Survey Instrument

Directions: You will be shown a brochure containing information about sickle cell trait. Upon completion of viewing the brochure a questionnaire will follow that asks about your thoughts and feelings related to sickle cell trait screening health information. The questionnaire is voluntary and anonymous.

Please keep in mind:

- We want to know what you think, feel, and do.
- Your answers will remain completely anonymous.
- You may omit any question or section that makes you uncomfortable.
- The survey will take about 20 minutes.

Thank you in advance for your time!

Eligibility Questions

1) Do you self-identify as being Black or African American?
___ Yes
___ No
___ Refuse to Answer

2) Do you know your Sickle Cell ***Trait*** status?
___ Yes
___ No
___ Not Sure

Part I: Please tell us the things that come to your mind for each of the following questions. List 1-3 top-of-the-mind responses. There are no right or wrong answers; just write what comes to your mind first.

3) What is the main point of the brochure?

4) What aspect of the brochure helped you to determine the main point?

5) What does sickle cell trait mean to you?

Meaning 1:

Meaning 2:

Meaning 3:

6) What are the advantages or good things that might happen if you go to your doctor to ask for sickle cell trait screening?

Advantage 1:

Advantage 2:

Advantage 3:

7) What are the disadvantages or bad things that might happen if you go to your doctor to ask for sickle cell trait screening?

Disadvantage 1:

Disadvantage 2:

Disadvantage 3:

8) What might make it easier for you to go to your doctor to ask for sickle cell trait screening?

Easier 1:

Easier 2:

Easier 3:

9) What might make it harder for you to go to your doctor to ask for sickle cell trait screening?

Harder 1:

Harder 2:

Harder 3:

10) Who (individuals or groups) do you think would approve of or support you going to your doctor to ask for sickle cell trait screening?

Approving People/Group 1:

Approving People/Group 2:

Approving People/Group 3:

11) Who (individuals or groups) do you think would disapprove of or support you going to your doctor to ask for sickle cell trait screening?

Disapproving People/Group 1:

Disapproving People/Group 2:

Disapproving People/Group 3:

12) How LIKELY or UNLIKELY are you to go to your doctor to ask for sickle cell trait screening?
1 Extremely unlikely
2 Quite unlikely
3 Somewhat unlikely
4 Neither
5 Somewhat likely
6 Quite likely
7 Extremely likely
98 Refuse to Answer

13) Would it be GOOD or BAD for you to ask for sickle cell trait screening from your doctor?
1 Extremely bad
2 Quite bad
3 Somewhat bad
4 Neither
5 Somewhat good
6 Quite good
7 Extremely good
98 Refuse to Answer

14) Would it be WISE or FOOLISH for you to ask for sickle cell trait screening from your doctor?
1 Extremely unwise
2 Quite unwise
3 Somewhat unwise
4 Neither
5 Somewhat wise
6 Quite wise
7 Extremely wise
98 Refuse to Answer

15) How LIKELY or UNLIKELY is it that African Americans age 18-35, WHO ARE LIKE YOU would ask for sickle cell trait screening from your doctor?
1 Extremely unlikely
2 Quite unlikely
3 Somewhat unlikely
4 Neither
5 Somewhat likely
6 Quite likely
7 Extremely likely
98 Refuse to Answer

16) How LIKELY or UNLIKELY is it that MOST PEOPLE WHO ARE IMPORTANT TO YOU think you should ask for sickle cell trait screening from your doctor?
1 Extremely unlikely
2 Quite unlikely
3 Somewhat unlikely
4 Neither
5 Somewhat likely
6 Quite likely
7 Extremely likely
98 Refuse to Answer

17) How many of the people whom you respect and admire have asked sickle cell trait screening from their doctor?
1 Very Few
2 Quite a Few
3 Only a Little
4 None
5 Some
6 A lot
7 Virtually All
98 Refuse to Answer

18) Would it be EASY or HARD for you to ask for sickle cell trait screening from your doctor?
1 Extremely hard
2 Quite hard
3 Somewhat hard
4 Neither
5 Somewhat easy
6 Quite easy
7 Extremely easy
98 Refuse to Answer

19) How SURE are you that you will ask for sickle cell trait screening from your doctor?
1 Not at all sure
2 A little sure
3 Somewhat sure
4 Quite sure
5 Completely sure
8 Refuse to Answer

20) How much is it UP TO YOU to ask for sickle cell trait screening from your doctor?

1 Not at all up to me
2 A little up to me
3 Somewhat up to me
4 Quite up to me
5 Completely up to me
8 Refuse to Answer

21) What statement best describes your intention when it comes going to your doctor to ask for screening for Sickle Cell ***Trait***?

___ I intend to go to my doctor to ask for Sickle Cell ***Trait*** screening within the next 30 days.
___ I intend to go to my doctor to ask for Sickle Cell ***Trait*** screening within the next 3 months.
___ I do not intend to go to my doctor to ask for Sickle Cell ***Trait*** screening within the next 30 days but will consider it in the future.
___ I do not intend on going to my doctor to ask for sickle cell trait screening now or in the future.

22) How likely are you to ask for sickle cell trait screening from your doctor?

1 Extremely unlikely
2 Quite unlikely
3 Somewhat unlikely
4 Neither
5 Somewhat likely
6 Quite likely
7 Extremely likely
98 Refuse to Answer

23) Going to the doctor to get screened for sickle cell trait is an effective method for learning your sickle cell trait status.

1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

24) Going to the doctor to get screened for sickle cell will decrease my chances of becoming ill due to complications from sickle cell trait.

1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

25) If I go to the doctor to get screened for sickle cell trait, I do not have to worry as much about the complications associated with sickle cell trait.

1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

26) I believe that sickle cell trait is severe.
1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

27) I believe that sickle cell trait has serious negative consequences.
1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

28) I am at risk for having sickle cell trait.
1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

29) It is possible that I could have sickle cell trait.
1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

Check the response that you believe is the best fit for you. Check only 1 response for each question.

30) What is your age? _____ Years
98 Refused to Answer

31) What is your sex?
___ Male
___ Female
___ Other

32) What is the highest level of education you have completed?
___ Some high school education
___ High School Diploma or GED
___ Some College
___ Undergraduate Degree
___ Post Graduate Work or Degree

33) How would you describe your employment status?

___ Unemployed
___ Employed Part-time
___ Employed Full-time

34) What is your household income?
___ < $20,000
___ $20,000–<$45,000
___ $45,000-$60,000
___ >$60,000

35) What type of health insurance do you have?
___ Uninsured
___ Self-Pay
___ Employer paid
___ Medicaid

36) What is your marital status?
___ Single/Not in a relationship
___ Single/In a relationship
___ Cohabitating
___ Married
___ Separated/Divorced

37) Would you say that in general your health is...?
___ Excellent
___ Very Good
___ Good
___ Fair
___ Poor

38) Do you have any biological children?
___ No
___ Yes

39) Do you plan to have biological children in the future?
___ No
___ Not Sure
___ Not Yes

40) Do you have one person, or one medical practitioner, who you think of as your personal doctor, doctor, or health care provider?
___ No
___ Yes

41) Do you currently participate in an organized sport for an academic institution? (i.e., college, high school)
___ No
___ Yes

42) Do you plan to go into the military?
___No
___Not Sure
___Yes

43) Have you personally known or know anyone who has Sickle Cell ***Disease***?
___No
___Not Sure
___Yes

44) Prior to today, had you ever heard of *Sickle Cell* ***Trait***?
___ No
___ Not Sure
___ Yes

45) Have you personally known or know anyone who has *Sickle Cell* ***Trait***?
___No
___Not Sure
___Yes

THANK YOU

Appendix M: Coding of Sickle Cell Trait and Sickle Cell Trait Screening Beliefs

Responses to the questions, "In your own words, what does getting screened for Sickle Cell Trait mean to you?" and "In your own words, what does getting screened for Sickle Cell Trait mean to you?" were also analyzed for content and recoded as sickle cell trait beliefs and sickle cell trait screening beliefs, respectively. Coding of responses occurred in two phases. In the first phase, in vivo (direct words or phrases from the responses) coding was conducted to identify ideas related to sickle cell trait and sickle cell trait screening (Saldana, 2009). In the second phase, focused coding was used to categorize in vivo codes based on similarities and differences in beliefs (Saldana, 2009). Researchers then met to share results from the two phases of coding. Frequencies were calculated for both sets of beliefs. Twelve categories represented sickle cell trait beliefs while eleven categories represented sickle cell trait screening beliefs. Sickle cell trait beliefs included: it's a disease; it affects the blood; it's important to find out if you have sickle cell trait; I don't know what sickle cell trait is; it's a gene that is inherited; having health problems; more knowledge and awareness of the disease; it's important; it's the gene for sickle cell disease; nothing to me; living a healthier life; and other. Sickle cell trait screening beliefs included: I don't know what sickle cell trait screening is; there is a need to be screened for sickle cell trait; it's important to me; it runs in the family; finding out if you have sickle cell trait; nothing to me; having a positive impact on health; you have an illness; not everyone needs to be screened for sickle cell trait; there may be barrier to getting screened; and other.

Appendix N: Main Study Tables

Table 1: Descriptive Characteristics of Study Sample

Variable	%
Demographic Factors	
Sex: Female	63.3
Health Insurance Status: Yes	86.3
Partner Status: In a Relationship	43.0
Perceived Health Status	
Excellent	18.7
Very Good	28.3
Good	38.3
Fair	13.7
Poor	1.0
Age	
18-20	11.3
21-25	22.3
25-30	31.3
31-35	35.0
Education	
Less Than High School	1.0
Some HS	6.0
High School Diploma or GED	28.0
Some College	32.7
College Degree or Higher	20.3
Graduate Work or Degree	12.0
Employment Status	
Do not work/Student	32.7
Employed for wages (PT)	19.3
Employed for wages (FT)	48.0
Income Level	
<10,000	36.3
10,000-19,999	14.3
20,000-39,999	17.3
40,00-49,999	11.0
≥50,000	13.3
N= 300	

Table 2: Pearson Correlation of RAA Determinants with Intention as the Outcome Variable

Predictor Variable	Intention	Attitude Toward the Act	Perceived Norm	Perceived Behavioral Control
Mean Intention	-	.619**	.547**	.705**
Mean Attitude Toward the Act	.619**	-	.496**	.618**
Mean Perceived Norm	.547**	.496**	-	.474**
Mean Perceived Behavioral Control	.705**	.618**	.474**	-

Significance Level: *P< .05, **P<.01, ***P<.001

Table 3: Reliability Analysis of Fear and Knowledge Belief Factors, RAA Factors, and Outcome Variable (Intention)

Construct	# of items	Mean	Variance	SD	Cronbach's α
Fear and Knowledge Belief Factors					
Awareness of Sickle Cell Trait/Screening	3	4.11	3.95	1.99	0.73
Sickle Cell Trait Knowledge	1	0.72	0.75	0.87	-
Sickle Cell Screening Knowledge	1	0.61	0.61	0.78	-
Response Efficacy	1	1.93	2.24	1.50	-
Perceived Threat	2	1.99	15.46	3.93	0.63
RAA Factors					
Attitude Toward the Act	4	1.17	0.75	0.86	0.71
Perceived Norm	4	0.66	1.61	1.27	0.70
Perceived Behavioral Control	3	1.66	1.32	1.15	0.51
Outcome Variable					
Intention	3	1.00	1.73	1.32	0.76

Table 4: Pearson Correlation with Intention as Dependent Variable to determine which variables to use in the Linear Regression

Demographic Factor	Pearson's Correlation	P Value
Sex	.080	.169
Age	.158	.006
In a Relationship	.105	.069
Education	-.122	.035
Employment Status	.014	.807
Income Level	-.090	.119
Health Care Provider	.001	.992
General Health Status	.023	.693
Health Insurance Status	.045	.871
Awareness of Sickle Cell Trait/Screening	.096	.096
Sickle Cell Trait Knowledge	-.032	.582
Sickle Cell Screening Knowledge	-.209	.000
Perceived Threat	.259	.000
Response Efficacy	.173	.003

Table 5: RAA Factors Associated with Intention to go to your Doctor to Ask for Sickle Cell Trait Screening based on the Linear Regression Model

R^2= .589, F(143.823, p<.001)			
Predictor Variable	β Coefficient	P Value	SE
Mean Attitude Toward the Act	.336**	<.001	.075
Mean Perceived Norm	.220**	<.001	.046
Mean Perceived Behavioral Control	.546**	<.001	.055

Table 6: 3-Step Sequential Regression Predicting Intention with Demographic Factors, Knowledge and fear beliefs and RAA Determinants as Independent Variables

	Model 1: R^2=.069 df=10, 289 F=3.210, p<.001		Model 2: R^2=.173 df=13, 286 F=5.808, p<.001		Model 3: R^2=.639 df=16, 283 F=34.136, p<.001	
Variable	β Coefficient	(SE)	β Coefficient	(SE)	β Coefficient	(SE)
Demographic Factors						
Age						
18-20	Ref	Ref	Ref	Ref	Ref	Ref
21-25	.563	.285	.317	.154	.113	.180
26-30	.868**	.276	.465**	.270	.308	.176
31-35	.987**	.276	.713**	.264	.319	.178
Education						
Less than HS	Ref	Ref	Ref	Ref	Ref	Ref
Some HS	1.207	.818	.822	.775	-.966	.533
HS Diploma or GED	.679	.755	.496	.714	-1.009*	.484
Some College	.524	.760	.246	.723	-1.115*	.488
Undergraduate Degree	.002	.769	-.132	.733	-1.376**	.496
Graduate Work or Degree	-.075	.781	-.207	.746	-1.461**	.505
Sex (Female)	.297	.162	.317*	.154	-.017	.103
Partner Status (In a Relationship)	.251	.151	.230	.144	.090	.096
Knowledge and fear beliefs						
Sickle Cell Trait Screening Knowledge	-	-	-.331**	.097	-.175**	.065
Response Efficacy	-	-	.131*	.053	- .073*	.037
Perceived Threat	-	-	.224***	.058	.076	.039
RAA Determinants						
Attitude Toward the Act	-	-	-	-	.348***	.076
Perceived Norm	-	-	-	-	.177***	.044
Perceived Behavioral Control	-	-	-	-	.581***	.056
Constant	-.714	.788	-.554	.744	.520	.499

Significance Level: *P< .05, **P<.01, ***P<.001

Appendix O: Secondary Study Part I Tables

Table 1: Descriptive Characteristics of Study Sample

Variable	% or Mean (std dev)
Demographic Factors	
Sex: Female	63.3
Health Insurance Status: Yes	86.3
Partner Status: In a Relationship	43.0
Perceived Health Status	
Excellent	18.7
Very Good	28.3
Good	38.3
Fair	13.7
Poor	1.0
Age	
18-20	11.3
21-25	22.3
25-30	31.3
31-35	35.0
Education	
Less Than High School	1.0
Some HS	6.0
High School Diploma or GED	28.0
Some College	32.7
College Degree or Higher	20.3
Graduate Work or Degree	12.0
Employment Status	
Do not work	26.7
Employed for wages (PT)	19.3
Employed for wages (FT)	48.0
Student	6.0
Income Level	
<10,000	36.3
10,000-19,999	14.3
20,000-39,999	17.3
40,00-49,999	11.0
≥50,000	13.3
Pre Brochure Sickle Cell Trait Knowledge	0.59
Pre Brochure Sickle Cell Trait Screening Knowledge	0.56
N= 300	

Table 2: Descriptive Statistics on Outcome Variables

Outcome Variables	Mean (Std Dev)
Understanding of Brochure	
Recognition of the Main Point of the Brochure (Yes)	0.14(0.35)
Perceived Brochure Clarity	2.19(1.43)
Knowledge and fear beliefs	
Awareness of Sickle Cell Trait/Screening	4.11(1.99)
Post Brochure Sickle Cell Trait Knowledge	0.72(0.87)
Post Brochure Sickle Cell Trait Screening Knowledge	0.61(0.78)
Response Efficacy	1.93(2.24)
Perceived Threat	1.99(3.93)
RAA Factors	
Attitude Toward the Act	1.99(0.86)
Perceived Norm	0.66(1.27)
Perceived Behavioral Control	1.66(1.15)
Intention	1.00(1.32)

Table 3: Descriptives Comparing Brochures on Demographic Variables

Study Characteristics	Brochure 1 No Explicit Recommended Response (n=143)		Brochure 2 Explicit Recommended Response (n=157)	
	N	% or Mean (Std dev)	N	% or Mean (Std dev)
Demographic Variable				
Sex: Male	52	36.4	58	36.9
Partner Status: In a Relationship	69	48.3	60	38.2
Health Insurance Status: Yes	122	85.3	137	87.3
Health Care Provider: Yes	104	72.7	105	66.9
Age	143	27.5(5.4)	157	28.2(5.0)
Education*				
Less Than High School Diploma	0	0.0	3	1.9
Some High School	8	5.6	10	6.42
High School Diploma/GED	41	28.7	43	27.4
Some College	52	36.4	46	29.3
Undergraduate Degree	34	23.8	27	17.2
Graduate Work or Degree	8	5.6	28	17.8
Employment Status				
Do not work	38	26.6	42	26.8
Employed for wages (PT)	41	21.7	27	17.2
Employed for wages (FT)	64	44.8	80	51.0
Student	10	7.0	8	5.1
Income Level				
<10,000	47	32.9	62	39.5
10,000-19,999	25	17.5	18	11.5
20,000-29,999	22	15.4	30	19.1
30,000-39,999	18	12.6	15	9.6
40,00-49,999	13	9.1	10	6.4
≥50,000	18	12.6	22	14.0
Perceived Health Status				
Excellent	29	20.3	27	17.2
Very Good	35	24.5	50	31.8
Good	57	39.9	58	36.9
Fair	19	13.3	22	14.0
Poor	3	2.1	0	0.0
Pre Brochure Sickle Cell Trait Knowledge	143	0.57(0.7)	157	0.62(0.8)
Pre Brochure Sickle Cell Trait Screening Knowledge	143	0.57(0.7)	157	0.54(0.7)

N= 300
*= p<.05 based on Chi Square Analysis

Table 4: Descriptives Comparing Brochures on Outcome Variables

	N	% or Mean (Std dev)	N	% or Mean (Std dev)
Outcome Variable				
Brochure Understanding				
Recognition of the Main Point of the Brochure *	143	0.10(0.30)	157	0.18(0.38)
Perceived Brochure Clarity	143	2.10(1.53)	157	2.28(1.33)
Knowledge and fear beliefs				
Awareness of Sickle Cell Trait/Screening	143	3.86(2.00)	157	4.34(1.96)
Post Brochure Sickle Cell Trait Knowledge	143	0.76(0.88)	157	0.68(0.86)
Post Brochure Sickle Cell Trait Screening Knowledge	143	0.67(0.81)	157	0.55(0.75)
Response Efficacy	143	2.00(1.55)	157	1.87(1.54)
Perceived Threat	143	2.17(4.08)	157	1.82(3.79)
RAA Factors				
Attitude Toward the Act	143	1.13(0.81)	157	1.20(0.91)
Perceived Norm	143	0.51(1.31)	157	0.80(1.22)
Perceived Behavioral Control	143	1.65(1.14)	157	1.67(1.17)
Intention	143	0.95(1.32)	157	1.04(1.32)

Table 5: MANOVA on Outcome Variables Using Brochure Group as the Independent Variable

Variable	F	p-value	Df	Error of df
Recognition of the Main Point of the Brochure	4.050	0.045	1	288
Perceived Brochure Clarity	1.215	0.271	1	288
Awareness of Sickle Cell Trait/Screening	4.482	0.035	1	288
Post Brochure Sickle Cell Trait Knowledge	0.502	0.479	1	288
Post Brochure Sickle Cell Trait Screening Knowledge	3.116	0.079	1	288
Response Efficacy	0.542	0.462	1	288
Perceived Threat	0.603	0.438	1	288
Attitude Toward the Act	0.376	0.540	1	288
Perceived Norm	3.854	0.051	1	288
Perceived Behavioral Control	0.025	0.875	1	288
Intention	0.358	0.550	1	288
Pillai's Trace: F=1.514, df = 11, 288, p=.126				

Table 6: MANOVA on Outcome Variables Using Brochure Group as the Independent Variable and "Main Point of the Brochure" as a Covariate

Variable	F	p-value	df	Error of df
Main Point of the Brochure				
Perceived Brochure Clarity	0.457	0.499	1	287
Awareness of Sickle Cell Trait/Screening	0.765	0.382	1	287
Post Brochure Sickle Cell Trait Knowledge	1.178	0.279	1	287
Post Brochure Sickle Cell Trait Screening Knowledge	0.001	0.977	1	287
Response Efficacy	0.717	0.398	1	287
Perceived Threat	4.502	0.035	1	287
Attitude Toward the Act	0.210	0.647	1	287
Perceived Norm	0.657	0.418	1	287
Perceived Behavioral Control	0.008	0.928	1	287
Intention	0.018	0.892	1	287
Brochure Group				
Perceived Brochure Clarity	1.031	0.311	1	287
Awareness of Sickle Cell Trait/Screening	4.003	0.046	1	287
Post Brochure Sickle Cell Trait Knowledge	0.646	0.422	1	287
Post Brochure Sickle Cell Trait Screening Knowledge	1.741	0.188	1	287
Response Efficacy	0.687	0.408	1	287
Perceived Threat	1.043	0.308	1	287
Attitude Toward the Act	0.437	0.509	1	287
Perceived Norm	4.172	0.042	1	287
Perceived Behavioral Control	0.021	0.885	1	287
Intention	0.334	0.564	1	287
Pillai's Trace: F=0.904, df= 10, 288 p=.530				

Secondary Study Part II Tables

Table 1: Paired Sample T-Test Pre/Post Sickle Cell Trait Knowledge and Sickle Cell Trait Screening Knowledge (Based on Correct Definition Coding)

Variable	Mean	Std Dev	SE	95% Confidence Intervals		t	df	p-value
				Lower	Upper			
Pre Brochure Sickle Cell Trait Knowledge	0.59	0.737	0.043	-0.238	-0.009	-2.117	299	0.035
Post Brochure Sickle Cell Trait Knowledge	0.72	0.867	0.050					
Pre Brochure Sickle Cell Trait Screening Knowledge	0.56	0.718	0.041	-0.136	0.030	-1.266	299	0.206
Post Brochure Sickle Cell Trait Screening Knowledge	0.61	0.779	0.045					

Table 2: McNemar Test Comparing Frequency of Pre/Post Brochure Sickle Cell Trait Beliefs (Generalized Categories)

	Pre- Sickle Cell Trait	Post-Sickle Cell Trait	Total
Sickle cell Trait means having health problems.*	41(13.7)	23(7.7)	64(10.7)
Sickle cell Trait means death. **	9(3.0)	0(0.0)	9(1.5)
Sickle cell Trait means nothing to me.	4(1.3)	3(5.1)	7(1.2)
Sickle cell Trait is means a lot to me because my family member has it.	4(1.3)	1(0.3)	5(0.8)
Sickle cell Trait is important. **	3(1.0)	15(5.0)	18(3.0)
Sickle Cell Trait means that it's important to get tested. ***	0(0.0)	24(30.5)	24(4.0)
Sickle Cell Trait means it's important to know my status. **	0(0.0)	10(3.0)	10(1.7)
Sickle Cell Trait means a better understanding of the disease.*	0(0.0)	3(1.0)	3(0.5)
Sickle Cell Trait means more people could have it than I thought.*	0(0.0)	5(1.7)	5(0.8)
Sickle Cell Trait is important because I could pass the gene on to my children. ***	0(0.0)	22(7.3)	22(3.7)
Sickle Cell Trait means better means living a healthier life.	0(0.0)	3(1.0)	3(0.5)
Sickle Cell Trait means you are a carrier for sickle cell.	14(4.7)	17(5.7)	31(5.2)
Sickle Cell Trait means having the gene for sickle cell. **	27(9.0)	11(3.7)	38(6.3)
Sickle Cell Trait means you have a blood disorder.	40(13.3)	46(15.3)	86(14.3)
Sickle Cell Trait means you inherit the trait from a parent.	36(12.0)	38(12.7)	74(12.3)
Sickle Cell Trait means you don't have the disease but you carry the trait. ***	0(0.0)	24(8.0)	24(4.0)
Sickle Cell Trait is a gene mutation that causes sickle cell.	1(0.3)	4(1.3)	5(0.8)
I don't know what Sickle Cell Trait means. ***	43(14.3)	4(1.3)	47(7.8)
Sickle Cell Trait has something to do with the blood. ***	15(5.0)	0(0.0)	15(2.5)
Sickle Cell Trait means having a low blood count. ***	13(4.3)	0(0.0)	13(2.2)
Sickle Cell Trait means lower blood oxygen.	3(1.0)	0(0.0)	3(0.5)
Sickle Cell Trait means sickled blood cells. ***	12(4.0)	0(0.0)	12(2.0)
Sickle Cell Trait is an autoimmune disorder. **	8(2.7)	0(0.0)	8(1.3)
Sickle Cell Trait is a disease that primarily affects Blacks/African Americans. ***	1(0.3)	24(8.0)	25(4.2)
Sickle Cell Trait is a disease. **	0(0.0)	10(3.3)	11(1.8)
Means more people have it than I thought	0(0.0)	5(1.7)	5(0.8)
Other	26(8.7)	13(4.3)	39(6.5)
Total	300(100)	300(100)	600(100)
Significance Level: *P< .05, **P<.01, ***P<.001 Note: Based on McNemar Test			

Table 3: McNemar Test Comparing Frequency of Pre/Post Brochure Comparison of Sickle Cell Trait Screening Beliefs (Generalized Categories)

	Pre-Sickle Cell Trait Screening	Post-Sickle Cell Trait Screening	Total
Sickle Cell Trait screening is important to me**	12(4.0)	31(10.3)	43(7.2)
Sickle Cell Trait screening means more health knowledge and awareness	16(5.3)	19(6.3)	35(5.8)
Sickle Cell Trait screening means nothing to me*	13(4.3)	3(1.0)	16(2.7)
Sickle Cell Trait screening means preventing complications from the disease**	17(5.7)	5(1.7)	22(3.7)
Sickle Cell Trait screening means saving your life	9(3.0)	9(3.0)	18(3.0)
Sickle Cell Trait screening means knowing the likelihood of my child having trait or disease***	10(3.3)	33(11.0)	43(7.2)
Sickle Cell Trait screening is important because a family member has it	4(1.3)	0(0.0)	4(0.7)
Sickle Cell Trait screening is scary	1(0.3)	0(0.0)	1(0.2)
Sickle Cell Trait screening will cost me money	1(0.3)	0(0.0)	1(0.2)
Sickle Cell Trait screening means I need to go get screened**	0(0.0)	10(3.3)	10(1.7)
Sickle Cell Trait screening means everyone should know their status**	0(0.0)	9(3.0)	9(1.5)
Sickle Cell Trait screening means it's important for African Americans to get tested	1(0.3)	6(2.0)	7(1.2)
Sickle Cell Trait Screening is a test to determine if you have the trait. ***	131(13.7)	53(17.7)	184(30.7)
Sickle Cell Trait Screening means checking your blood***	0(0.0)	28(9.3)	28(4.7)
Sickle Cell Trait Screening means it's important to check my status.	18(6.0)	23(7.7)	41(6.8)
I don't need to be screened for sickle cell trait.	2(0.7)	3(1.0)	5(0.8)
I don't know what Sickle Cell Trait Screening means***	32(10.7)	3(1.0)	35(5.8)
Sickle Cell Trait Screening means learning my status**	9(3.0)	24(8.0)	33(5.5)
Sickle Cell Trait Screening is a blood disorder	0(0.0)	5(1.7)	5(0.8)
Sickle Cell Trait Screening means you are sick	5(1.7)	4(1.3)	9(1.5)
Sickle Cell Trait Screening means you have sickle cell trait	1(0.3)	0(0.0)	1(0.2)
Sickle Cell Trait Screening is something you inherit	2(0.7)	0(0.0)	2(0.3)
Sickle Cell Trait Screening means getting help	0(0.0)	4(1.3)	4(0.7)
Sickle Cell Trait Screening means you only need to get screened if it runs in your family	0(0.0)	5(1.7)	5(0.8)
Sickle Cell Trait Screening means going to the doctor to get tested**	0(0.0)	11(3.7)	11(1.8)
Sickle Cell Trait Screening means better health	0(0.0)	2(0.7)	2(0.3)
Other	16(5.3)	9(0.0)	25(4.2)
Total	300(100)	300(100)	600(100)
Significance Level: *P< .05, **P<.01, ***P<.001			

Table 4: McNemar Test Comparing Frequency of Pre/Post Brochure of Sickle Cell Trait Beliefs (Generalized Categories with Sub-Themes)

	Pre- Sickle Cell Trait Count (%)	Post-Sickle Cell Trait Count (%)	Total Count (%)
Sickle Cell Trait means having health problems. **	50(16.7)	23(7.7)	73(12.2)
Sickle Cell Trait means having health problems.			
Sickle Cell Trait means death			
Sickle Cell Trait means it's a disease. ***	9(3.0)	35(11.7)	44(7.3)
Sickle Cell Trait is a disease			
Sickle Cell Trait is a disease that primarily effects Blacks/African Americans			
Sickle Cell Trait is an autoimmune disorder			
Sickle Cell Trait means it affects the blood. ***	83(27.7)	46(15.3)	129(21.5)
Sickle Cell Trait means you have a blood disorder.			
Sickle Cell Trait has something to do with the blood.			
Sickle Cell Trait means having a low blood count.			
Sickle Cell Trait means lower blood oxygen.			
Sickle Cell Trait means sickled blood cells			
Sickle Cell Trait means it's the gene for sickle cell disease.	42(14.0)	56(18.7)	98(16.3)
Sickle Cell Trait means you don't have the disease but you carry the trait			
Sickle Cell Trait is a gene mutation that causes sickle cell.			
It means you are a carrier for sickle cell			
Sickle Cell Trait means having the gene for sickle cell**			
*Sickle Cell Trait means it's important to find out if you have sickle cell trait****	0(0.0)	34(11.3)	34(5.7)
Sickle Cell Trait means that it's important to get tested			
Sickle Cell Trait means it's important to know my status			
*Sickle Cell Trait means I don't know what sickle cell trait is****	43(14.3)	4(1.3)	47(7.8)
I don't know what Sickle Cell Trait means			
*Sickle Cell Trait means it's a gene that is inherited****	40(13.3)	60(20.0)	100(16.7)
Sickle Cell Trait means you inherit the trait from a parent.			
Sickle Cell Trait is important because I could pass the gene on to my children			
Sickle cell Trait is means a lot to me because my family member has it			
*Sickle Cell Trait means more knowledge and awareness of the disease***	(0.0)	8(2.7)	8(1.3)
Sickle Cell Trait means a better understanding of the disease			
Sickle Cell Trait means more people could have it than I thought			
*Sickle Cell Trait means it's important***	3(1.0)	15(5.0)	18(3.0)
Sickle cell Trait is important			
Sickle Cell Trait means nothing to me	4(1.3)	3(1.0)	7(1.2)
Sickle Cell Trait means nothing tome			
Sickle Cell Trait means living a healthier life	(0.0)	3(1.0)	3(0.5)
Sickle Cell Trait means other	26(8.7)	13(4.3)	39(6.5)
Total	300(100)	300(100)	600(100)
Significance Level: *P< .05, **P<.01, ***P<.001			

Table 5: McNemar Test Comparing Frequency of Pre/Post Brochure of Sickle Cell Trait Screening Beliefs (Generalized Categories with Sub-Themes)

	Pre-Sickle Cell Trait Screening Count (%)	Post-Sickle Cell Trait Screening Count (%)	Total Count (%)
*Sickle Cell Trait Screening means it's important to me***	12(4.0)	31(10.3)	43(7.2)
Sickle Cell Trait screening is important to me			
*Sickle Cell Trait Screening means nothing to me**	13(4.3)	3(1.0)	16(2.7)
Sickle Cell Trait screening means nothing to me			
Sickle Cell Trait Screening means having a positive impact on health	42(14.0)	32(10.7)	74(12.3)
Sickle Cell Trait screening means more health knowledge and awareness			
Sickle Cell Trait screening means preventing complications from the disease			
Sickle Cell Trait screening means saving your life			
Sickle Cell Trait Screening means better health			
Sickle Cell Trait Screening means getting help.			
*Sickle Cell Trait Screening means it runs in the family **	16(5.3)	33(11.0)	49(8.2)
Knowing the likelihood of my child having trait or disease			
Sickle Cell Trait screening is important because a family member has it			
Sickle Cell Trait Screening is something you inherit			
Sickle Cell Trait Screening means there may be barriers to getting screened	2(0.7)	0(0.0)	(0.3)
Sickle Cell Trait screening is scary			
Sickle Cell Trait screening will cost me money			
*Sickle Cell Trait Screening means here is a need to be screened for sickle cell trait****	19(6.3)	49(16.3)	68(1.1)
Sickle Cell Trait screening means I need to go get screened			
Sickle Cell Trait screening means everyone should know their status			
Sickle Cell Trait screening means it's important for African Americans to get tested			
Sickle Cell Trait Screening means it's important to check my status			
*Sickle Cell Trait Screening means finding out if you have sickle cell trait**	140(46.7)	117(39.0)	257(42.8)
Sickle Cell Trait Screening is a test to determine if you have the trait			
Sickle Cell Trait Screening means checking your blood			
Sickle Cell Trait Screening means learning my status			
Sickle Cell Trait Screening means going to the doctor to get tested			
*Sickle Cell Trait Screening means I don't know what sickle cell trait screening is****	32(10.7)	3(1.0)	35(5.8)
I don't know what Sickle Cell Trait Screening means			
Sickle Cell Trait Screening means you have an illness	6(2.0)	8(2.7)	15(2.5)
Sickle Cell Trait Screening is a blood disorder			
Sickle Cell Trait Screening means you are sick			
Sickle Cell Trait Screening means you have sickle cell trait			
Sickle Cell Trait Screening means not everyone needs to be screened for sickle cell trait	2(0.7)	8(2.7)	10(1.7)
You only need to get screened if it runs in your family			
I don't need to be screened for sickle cell trait			
Sickle Cell Trait Screening means other	16(5.3)	9(3.0)	25(4.2)
Total	300(100)	300(100)	600(100)
Significance Level: **P*< .05, ***P*<.01, ****P*<.001			

Appendix P: Additional Tables

Main Study Tables

Table 1: Descriptive Statistics on RAA Constructs

	Intention	Attitude Toward the Act	Perceived Norm	Perceived Behavioral Control
N	300	300	300	300
Mean	1.00	1.17	0.66	1.66
Std. Error of Mean	0.08	0.05	0.07	0.07
Median	1.00	1.25	0.75	1.67
Mode	1.00	1.50	0.75	3.00
Std. Deviation	1.32	0.86	1.27	1.15
Variance	1.73	0.75	1.61	1.32
Skewness	-0.50	-0.06	-0.19	-0.67
Std. Error of Skewness	0.14	0.14	0.14	0.14
Kurtosis	-0.43	0.46	-0.27	-0.19
Std. Error of Kurtosis	0.28	0.28	0.28	0.28
Minimum	-2.33	-1.75	-3.00	-2.00
Maximum	3.00	3.00	3.00	3.00

Table 2: Regression Predicting Intention Step 1: Demographic Factors Associated with Intention based on the Linear Regression Model

R^2=.068, df=4, F=6.412, p<.001				
Variable	β Coefficient	(SE)	t	p-value
Demographic Factors				
Age	.050	.015	3.407	.001
Sex	.324	.159	2.042	.042
Education	-.261	.070	-3.724	.000
Partner Status	.288	.150	1.915	.056
Constant	-.289	.488	-.592	.554

Table 3: Regression Predicting Intention Step 2: Demographic Factors and Fear & Knowledge Beliefs

R^2=.179, df=6, F=11.396, p<.001				
Variable	β Coefficient	(SE)	t	p-value
Demographic Factors				
Age	.041	.014	2.892	.004
Sex	.323	.150	2.153	.032
Education	-.230	.070	-3.277	.001
Partner Status	.256	.142	1.801	.073
Knowledge and fear beliefs				
Sickle Cell Trait Screening Knowledge	-.340	.096	-3.534	.000
Response Efficacy	.155	.052	2.512	.013
Perceived Threat	.067	.019	4.103	.000
Constant	-.325	.464	-.701	.484

Table 4: 3-Step Sequential Regression Predicting Intention

R^2=.641, df=10, F=54.384, p<.001				
Variable	β Coefficient	(SE)	t	p-value
Demographic Factors				
Age	.023	.010	2.373	.018
Sex	-.027	.101	-.272	.786
Education	-.166	.047	-3.535	.000
In a Relationship	.096	.095	1.012	.312
Knowledge and fear beliefs				
Sickle Cell Trait Screening Knowledge	-.179	.064	-2.786	.006
Response Efficacy	- .074	.036	-2.044	.042
Perceived Threat	.027	.013	2.094	.037
RAA Factors				
Attitude Toward the Act	.328	.074	4.458	.000
Perceived Norm	.191	.043	4.448	.000
Perceived Behavioral Control	.569	.055	10.421	.000
Constant	-.314	.314	-1.000	.318

Secondary Study Tables
Part I

Table 1: Multiple Linear Regression Predicting Intention Using Brochure Group as an Interaction Term

R^2=.611, F=32.329, p<.001			
Predictor Variable	β Coefficient	p-value	SE
Main Point	0.575	0.258	0.508
Perceived Brochure Clarity	-0.060	0.205	0.048
Post Brochure Sickle Cell Trait Knowledge	-0.251	0.164	0.180
Post Brochure Sickle Cell Trait Screening Knowledge	-0.134	0.506	0.202
Attitude Toward the Act	0.479	0.052	0.246
Perceived Norm	0.182	0.190	0.139
Perceived Behavioral Control	0.691	<0.001	0.174
Brochure Group	0.041	0.863	0.236
Brochure Group*Main Point	-0.291	0.325	0.295
Brochure Group*Perceived Brochure Clarity	0.072	0.316	0.072
Brochure Group*Post Brochure Sickle Cell Trait Knowledge	0.155	0.170	0.113
Brochure Group* Post Brochure Sickle Cell Trait Screening Knowledge	-0.098	0.448	0.128
Brochure Group*Attitude Toward the Act	-0.087	0.561	0.150
Brochure Group*Perceived Norm	0.023	0.798	0.092
Brochure Group*Perceived Behavioral Control	-0.102	0.358	0.111

Variable	F	p-value	df	Error of df

Table 2: MANOVA of Post Brochure Sickle Cell Trait and Sickle Cell Trait Screening Beliefs with Brochure Group as the Independent Variable

Variable	F	p-value	df	Error of df
Sickle Cell Trait Beliefs				
Having health problems	0.725	0.395	1	278
It's a disease	0.436	0.509	1	278
It's important to find out if you have sickle cell trait	0.380	0.538	1	278
I don't know what sickle cell trait is	0.466	0.495	1	278
It's a gene that is inherited	0.006	0.940	1	278
It affects the blood	0.009	0.925	1	278
More knowledge and awareness of the disease	1.546	0.215	1	278
It's important	2.465	0.117	1	278
It's the gene for sickle cell disease	0.006	0.937	1	278
Nothing to me	0.436	0.509	1	278
Living a healthier life	0.248	0.619	1	278
Other	1.553	0.214	1	278
Sickle Cell Trait Screening Beliefs				
I don't know what sickle cell trait screening is	0.248	0.619	1	278
There is a need to be screened for sickle cell trait	2.371	0.125	1	278
It's important to me	0.215	0.644	1	278
Runs in the family	0.406	0.524	1	278
Finding out if you have sickle cell trait	1.245	0.265	1	278
Nothing to me	0.436	0.509	1	278
Having a positive impact on health	0.020	0.888	1	278
You have an illness	0.230	0.632	1	278
Not everyone needs to be screened for sickle cell trait	0.018	0.894	1	278
Other	2.411	0.122	1	278
There may be barriers to getting screened	-	-	-	-
Pillai's Trace: F=0.894, p=.600				

Main Point				
Sickle Cell Trait Beliefs				
Having health problems	0.056	0.813	1	277
It's a disease	1.105	0.294	1	277
It's important to find out if you have sickle cell trait	0.167	0.683	1	277
I don't know what sickle cell trait is	0.646	0.422	1	277
It's a gene that is inherited	0.017	0.896	1	277
It affects the blood	0.035	0.851	1	277
More knowledge and awareness of the disease	0.965	0.327	1	277
It's important	0.462	0.497	1	277
It's the gene for sickle cell disease	0.022	0.882	1	277
Nothing to me	1.105	0.294	1	277
Living a healthier life	0.582	0.446	1	277
Other	0.000	0.998	1	277
Sickle Cell Trait Screening Beliefs				
I don't know what sickle cell trait screening is	0.582	0.446	1	277
There is a need to be screened for sickle cell trait	3.566	0.060	1	277
It's important to me	0.173	0.678	1	277
Runs in the family	5.200	0.023	1	277
Finding out if you have sickle cell trait	0.002	0.962	1	277
Nothing to me	1.105	0.294	1	277
Having a positive impact on health	0.501	0.480	1	277
You have an illness	0.039	0.843	1	277
Not everyone needs to be screened for sickle cell trait	0.860	0.355	1	277
Other	0.190	0.663	1	277
There may be barriers to getting screened	-	-	1	277
Brochure Group				
Sickle Cell Trait Beliefs				
Having health problems	0.760	0.384	1	277
It's a disease	0.605	0.437	1	277
It's important to find out if you have sickle cell trait	0.015	0.903	1	277
I don't know what sickle cell trait is	0.466	0.495	1	277
It's a gene that is inherited	0.006	0.940	1	277
It affects the blood	0.348	0.556	1	277
More knowledge and awareness of the disease	2.090	0.149	1	277
It's important	0.000	1.000	1	277
It's the gene for sickle cell disease	1.483	0.224	1	277
Nothing to me	0.605	0.437	1	277
Living a healthier life	0.340	0.561	1	277
Other	1.526	0.218	1	277
Sickle Cell Trait Screening Beliefs				
I don't know what sickle cell trait screening is	0.340	0.561	1	277
There is a need to be screened for sickle cell trait	3.078	0.080	1	277
It's important to me	0.258	0.612	1	277
Runs in the family	0.140	0.709	1	277
Finding out if you have sickle cell trait	1.236	0.267	1	277
Nothing to me	0.605	0.437	1	277
Having a positive impact on health	0.003	0.954	1	277
You have an illness	0.205	0.651	1	277
Not everyone needs to be screened for sickle cell trait	0.058	0.811	1	277
Other	2.531	0.113	1	277
There may be barriers to getting screened	-	-	-	-
Pillai's Trace: F=0.645, p=.883				

Table 3: MANOVA of Post Brochure Sickle Cell Trait and Sickle Cell Trait Screening Beliefs with Brochure Group as the Independent Variable and Main Point as a Covariate

Table 4: Kruskal Walls Nonparametric Test of Sickle Cell Trait and Sickle Cell Trait Screening Beliefs Using Brochure Group as the Independent Variable

Variable	$\chi 2$	p-value
Sickle Cell Trait Beliefs		
Having health problems	0.725	0.394
It's a disease	0.366	0.545
It's important to find out if you have sickle cell trait	0.006	0.940
I don't know what sickle cell trait is	0.009	0.925
It's a gene that is inherited	1.325	0.250
It affects the blood	0.381	0.537
More knowledge and awareness of the disease	2.453	0.117
It's important	0.006	0.937
It's the gene for sickle cell disease	0.467	0.494
Nothing to me	0.436	0.509
Living a healthier life	0.249	0.618
Other	1.550	0.213
Sickle Cell Trait Screening Beliefs		
I don't know what sickle cell trait screening is	0.249	0.618
There is a need to be screened for sickle cell trait	2.360	0.124
It's important to me	0.215	0.644
Runs in the family	0.407	0.523
Finding out if you have sickle cell trait	1.244	0.265
Nothing to me	0.436	0.509
Having a positive impact on health	0.020	0.888
You have an illness	0.231	0.631
Not everyone needs to be screened for sickle cell trait	0.018	0.894
Other	2.410	0.121
There may be barriers to getting screened	0.000	1.000

Secondary Study Additional Tables

Part II

Table 1: Paired Sample T-Test Pre/Post Sickle Cell Trait Knowledge (Correct Definition)

Variable	Mean	Std Dev	SE	95% Confidence Intervals		t	df	p-value
				Lower	Upper			
Pre Brochure Sickle Cell Trait Knowledge	0.59	0.737	0.043	-0.238	-0.009	-2.117	299	0.035
Post Brochure Sickle Cell Trait Knowledge	0.72	0.867	0.050					

Table 2: Paired Sample T-Test Pre/Post Sickle Cell Trait Screening Knowledge (Correct Definition)

Variable	Mean	Std Dev	SE	95% Confidence Intervals		t	df	p-value
				Lower	Upper			
Pre Brochure Sickle Cell Trait Screening Knowledge	0.56	0.718	0.041	-0.136	0.030	-1.266	299	0.206
Post Brochure Sickle Cell Trait Screening Knowledge	0.61	0.779	0.045					

Table 3: McNemar Test Comparing Frequency of Pre/Post Brochure Sickle Cell Trait Beliefs (Generalized Categories)

	Pre- Sickle Cell Trait Count (%)	Post-Sickle Cell Trait Count (%)	Total Count (%)
Sickle Cell Trait means...			
It's a disease. ***	9(3.0)	35(11.7)	44(7.3)
It affects the blood. ***	83(27.7)	46(15.3)	129(21.5)
It's important to find out if you have sickle cell trait. ***	0(0.0)	34(11.3)	34(5.7)
I don't know what sickle cell trait is. ***	43(14.3)	4(1.3)	47(7.8)
It's a gene that is inherited. ***	40(13.3)	60(20.0)	100(16.7)
Having health problems. **	50(16.7)	23(7.7)	73(12.2)
More knowledge and awareness of the disease. **	0(0.0)	8(2.7)	8(1.3)
It's important. **	3(1.0)	15(5.0)	18(3.0)
It's the gene for sickle cell disease.	42(14.0)	56(18.7)	98(16.3)
Nothing to me.	4(1.3)	3(1.0)	7(1.2)
Living a healthier life.	0(0.0)	3(1.0)	3(0.5)
Other	26(8.7)	13(4.3)	39(6.5)
Total	300(100)	300(100)	600(100)
Significance Level: *P< .05, **P<.01, ***P<.001			

Table 8: McNemar Test Comparing Frequency of Pre/Post Brochure Sickle Cell Trait Screening Beliefs (Generalized Categories)

	Pre-Sickle Cell Trait Screening	Post-Sickle Cell Trait Screening	Total
Sickle Cell Trait Screening means...			
I don't know what sickle cell trait screening is. ***	32(10.7)	3(1.0)	35(5.8)
There is a need to be screened for sickle cell trait***	19(6.3)	49(16.3)	68(1.1)
It's important to me**	12(4.0)	31(10.3)	43(7.2)
Runs in the family*	16(5.3)	33(11.0)	49(8.2)
Finding out if you have sickle cell trait*	140(46.7)	117(39.0)	257(42.8)
Nothing to me*	13(4.3)	3(1.0)	16(2.7)
Having a positive impact on health	42(14.0)	32(10.7)	74(12.3)
You have an illness	6(2.0)	9(3.0)	15(2.5)
Not everyone needs to be screened for sickle cell trait	2(0.7)	8(2.7)	10(1.7)
Other	16(5.3)	9(3.0)	25(4.2)
There may be barriers to getting screened	2(0.7)	0(0.0)	2(0.3)
Total	300(100)	300(100)	600(100)
Significance Level: *P< .05, **P<.01, ***P<.001.			

Appendix Q: Recruitment Material
Recruitment Flyer

PARTICIPANTS NEEDED FOR RESEARCH ON SICKLE CELL TRAIT SCREENINGAMONGST AFRICAN AMERICANS AGED 18-35

As a participant in this study, you are asked to complete an online survey, which will take approximately 15-25 minutes.
In appreciation for your time, you will receive
a $15 gift card.

For more information about participation in this study, please contact:

Tilicia Mayo-Gamble

Indiana University- Bloomington
School of Public Health
Department of Applied Health Science
IRB Study #

INDIANA UNIVERSITY

PARTICIPANTS NEEDED FOR RESEARCH ON SICKLE CELL TRAIT SCREENINGAMONGST AFRICAN AMERICANS AGED 18-35

As a participant in this study, you are asked to complete an online survey, which will take approximately 15-25 minutes.
In appreciation for your time, you will receive
a $15 gift card.

For more information about participation in this study, please contact:

Tilicia Mayo-Gamble

Indiana University- Bloomington
School of Public Health
Department of Applied Health Science
IRB Study #

INDIANA UNIVERSITY

Appendix R: Brochures

Sickle Cell Trait

What Is Sickle Cell Trait?

Sickle Cell Disease is a blood disorder that causes health problems.

Sickle Cell Trait is the carrier status for Sickle Cell Disease. It means that you inherited the Sickle Cell Disease gene from one of your parents.

Some people with Sickle Cell Trait have severe health problems. Some people with Sickle Cell Trait want to know their risk of passing the gene on to their children.

Who is affected by Sickle Cell Trait?

Sickle Cell Trait affects 1 in 12 Blacks or African Americans in the United States.

About 3 million people living in the United States have Sickle Cell Trait.

How Can You Find Out If You Have Sickle Cell Trait?

A simple blood test can be done to find out if you have Sickle Cell Trait.

A small sample of blood is taken from the finger (a "needle prick") and tested in a lab.

You can request a test at your doctor's offices, at hospitals or medical centers, at Sickle Cell agencies, and at local health departments.

Once you are tested you and your doctor can discuss the test results and what this means for you.

Sickle Cell Trait

What Is Sickle Cell Trait?

Sickle Cell Disease is a blood disorder that causes health problems.

Sickle Cell Trait is the carrier status for Sickle Cell Disease. It means that you inherited the Sickle Cell Disease gene from one of your parents.

Some people with Sickle Cell Trait have severe health problems. Some people with Sickle Cell Trait want to know their risk of passing the gene on to their children.

Who is affected by Sickle Cell Trait?

Sickle Cell Trait affects 1 in 12 Blacks or African Americans in the United States.

About 3 million people living in the United States have Sickle Cell Trait.

Go to your doctor to ask for Sickle Cell Trait screening

How Can You Find Out If You Have Sickle Cell Trait?

A simple blood test can be done to find out if you have Sickle Cell Trait.

A small sample of blood is taken from the finger (a "needle prick") and tested in a lab.

You can request a test at your doctor's offices, at hospitals or medical centers, at Sickle Cell agencies, and at local health departments.

Once you are tested you and your doctor can discuss the test results and what this means for you.

Curriculum Vitae

Tilicia L. Mayo-Gamble

Meharry-Vanderbilt Alliance, Community Engaged Research Core
Meharry Medical College, Dept of Family and Community Medicine
Dr. D.B. Todd Jr. Blvd, Nashville, TN 37208

Areas of Interest/Application

- Behavioral/Sociological factors associated with health care utilization
- Critical qualitative and quantitative approaches to determining factors associated with health care utilization
- Health communication used to modify behavior change/adoption
- Applied Research to reduce racial health disparities

Education

Doctor of Philosophy, Oct 2015
Indiana University, Bloomington, IN
Dept. of Applied Health Science
Major: Health Behavior
Minor Fields: Sociology
Advisor: Susan E. Middlestadt
Dissertation: Understanding factors that influence intention to go to the doctor ask for sickle cell trait screening among African Americans ages 18-35

Master of Public Health, May 2012
Indiana University, Indianapolis, IN
Major: Social & Behavioral Science

Master of Arts, Jan 2010
Indiana University, Indianapolis, IN
Major: Applied Communication
Minor: Health Communication

Bachelor of Arts, Aug 2006
Butler University, Indianapolis, IN
Major: Electronic Media
Minor: Communication Studies

Credentials

Certified Health Education Specialist (CHES), 2014
National Commission for Health Education Credentialing, Inc.

Collaborative Research Experience

Health Behavior Research

Indiana University Prenatal Smoking Study, 2014-2015
Cross Sectional Study
Principal Investigator: Dr. Jon T. Macy
Role: Research Assistant

Indiana University Smoking Survey, 2012-2015
Quantitative Longitudinal Study
Principal Investigators: Dr. Laurie Chassin, Dr. Clark Presson
Co-Investigator: Dr. Jon Macy
Role: Research Assistant

Eating Better Moving More, 2012-2015
Qualitative Research Study
Principal Investigator- Dr. Susan Middlestadt
Role: Research Assistant

Willingness towards Type 2 Diabetes Genetics Testing, 2012
Cross Sectional Study
Principal Investigator: Dr. Jennifer Wessel
Role: Recruitment, Survey Administer

Health Disparities Research

Center for Research on Race and Ethnicity, 2012-2015
Director: Dr. Pamela Braboy Jackson
Role: Research Collaboration

Health Partnerships Research

IU Health Bloomington/IUSPH-Bloomington Alliance , 2013-2015
Qualitative Study
Principal Investigator: Dr. Priscilla Barnes
Role: Research Assistant

Cultural Anthropology and Health Research

The Cultural Embeddedness of the Virtue of Forgiveness, 2011-2012
Qualitative Study
Principal Investigator- Dr. Kathryn Coe

Role: Research Assistant

Peer-Reviewed Publications

Mayo-Gamble, T.L. Lin, HC. (2014). Healthcare management and diabetes programs: Indiana 2006-2010. *American Journal of Managed Care*, 20(10), e461-468.

Mayo-Gamble, T.L. (In Press).Use of the health belief model: The case of sickle cell. *Health Education Monograph*.

Mayo-Gamble, T.L., Barnes, P. (Under Review). Strategically Connected: A Partnership Case Study Exploring Factors Influencing Mutuality."

Other Publications

Mayo, T.L. (2010). A Crisis within a Crisis: An Analysis of the Communication between Sickle Cell Patients and Healthcare Providers. *Science: Student Projects in the New Format.* Videoconferencing Materials and Student Round Table, Volgograd, Russia (Russian Publication).

Manuscripts under review or in progress

Munteanu, O., Barnes, P., **Mayo-Gamble, T.L**., Harris, D., Townsend, D., Dickinson, S., Ohmit, A. (2015). Sociological factors influencing utilization of depression screening among African Americans with chronic conditions. (In Progress)

Nyawade, S., **Mayo-Gamble, T.L.**, Middlestadt, S. (2014). Describing the perceived advantages and disadvantages of eating fruits and vegetables amongst youth and adults: A salient belief elicitation. (In Progress)

Grant Funding

Internal Funding Source: Indiana University Graduate School
Spring 2015
Role: Principal Investigator
Amount Funded: $1000

Internal Funding Source: Indiana University School of Public Health
Spring 2015
Purpose: Conduct Dissertation Research
Role: Principal Investigator
Amount Funded: $1000

Internal Funding Source: Indiana University School of Public Health
Spring 2015
Purpose: Travel Grant to Society of Public Health Education
Role: Grant Writer
Amount Funded: $100

Internal Funding Source: Indiana University School of Public Health
Spring 2015
Purpose: Travel Grant to Society of Public Health Education
Role: Grant Writer
Amount Funded: $200

External Funding Source: Indiana Collegiate Action Network
Fall 2014
Program: IU Drug and Alcohol Student Advisory Board
Role: Grant Writer
Amount Funded: $6000

Internal Funding Source: Indiana University School of Public Health
Fall 2014
Purpose: Conduct Pre-Dissertation Research
Role: Principal Investigator
Amount Funded: $5300

Internal Funding Source: Indiana University School of Public Health
Fall 2014
Purpose: Travel Grant to American Public Health Association
Role: Grant Writer
Amount Funded: $100

Internal Funding Source: Indiana University School of Public Health
Fall 2014
Purpose: Travel Grant to American Public Health Association
Role: Grant Writer
Amount Funded: $200

Internal Funding Source: Union Board/ Student Assembly
Spring 2014
Program: “Party Smart Bags” Alcohol Safety and Sexual Assault Prevention and Education Campaign
Role: OASIS Prevention Program Facilitator, Grant Co-Writer
Amount Funded: $1296

Internal Funding Source: Alcohol and Drug Workgroup
Spring 2014
Program: “Party Smart Bags” Alcohol Safety and Sexual Assault Prevention and Education Campaign
Role: OASIS Prevention Program Facilitator, Grant Writer
Amount Funded: $500

Internal Funding Source: Alcohol and Drug Workgroup
Fall 2013

Program: “Party Smart Bags” Alcohol Safety and Sexual Health Education Campaign
Role: OASIS Prevention Program Facilitator, Grant Writer
Amount Funded: $400

Fellowship

School of Public Health
2014-2015
Department of Applied Health Science
Doctoral Research Fellowship

Public Health Professional Experience

Office of Alternative Screening & Intervention Services (OASIS)
2013-2015
Indiana University-Division of Student Affairs
Graduate Assistant and Prevention Coordinator

- Manage a staff of Alcohol and Drug Peer Educators (8) including training, supervising and evaluating
- Coordinate alcohol and drug programs with Resident Assistants (RAs) and other RPS staff, Greek system, and faculty/staff
- Areas of training: programming, evaluation, drug content, conducting presentations, alcohol content
- Assist and coordinate large alcohol and drug programming on campus.
- Initiate and maintain large initiative projects
- Write and apply for internal and external grants to support programming in amounts of $500, $1000, and $6000
- Manage grants to accommodate programming activities
- In collaboration with peer educators and office counselors, conduct seminars/workshops pertinent to our mission
- Create and maintain partnership with various supportive departments on campus including RPS, the Health Center, Office of Student Ethics and Student Life and Learning

Indiana University Smoking Survey
2012-2015
Research Assistant

- Assist project director in all vital aspects of the particular project.
- Provide research support (Contacting participants, quantitative data collection, data input) for longitudinal smoking survey and clinical prenatal smoking cessation study
- Compile, process, and maintain data records
- Code data for input for electronic data processing
- Inputs and retrieve data using RedCap Clinical Software
- Manage small to medium projects
- Performs additional duties including typing, answering phones, preparing correspondence

IU Health Bloomington-IU School of Public Health-Bloomington Alliance
2013-2015
Project Coordinator

- Assist project leader in all vital aspects of the particular project.
- Assist teams in the design, execution and evaluation of research projects, including literature reviews, surveys, focus groups, data integration and analysis
- Communicate relevant information to all team members, such as change in schedule dates, changes in the project's requirements.
- Search and apply for external grant funding

Marion County Public Health Department -Indianapolis, IN
2006-2015
Environmental Health Specialist, Housing & Neighborhood Health

- Investigate housing complaints to determine if they meet minimum codes
- Conduct housing inspections and prepare paperwork once those inspections are completed.
- Responsible for organizing and keeping track of housing cases for court.
- Evaluate health status of neighborhoods and communicate that status to the community
- Identify abandoned properties to be developed through NSP funding
- Investigate foodborne illness complaints
- Inspect food establishments to determine if health standards are being maintained
- Enforce FDA codes for Marion County

Presentations and Posters

Nyawade, S., **Mayo-Gamble, T.L.**, Fly, A., Middlestadt. S.E. (2014). "How do we know when we should tailor an intervention? Using the Reasoned Action Approach to compare adults to youth on their beliefs about eating fruits and vegetables." American Public Health Association Conference. Poster Presenter.

Mayo-Gamble, T.L., Nyawade, S., Fly, A., Middlestadt. S.E. (2014). "Which benefit should we emphasize? Health or energy? An analysis of perceived advantages of eating fruit and vegetables." American Public Health Association Conference. Poster Presenter.

Mayo-Gamble, T.L. (2014). "Rethinking the Negative to Consider to the Positive: Experts' Advice on Sickle Cell Trait Screening." American School Health Association Conference. Poster Presenter.

Mayo-Gamble, T.L. (2014). "Rethinking the Negative to Consider to the Positive: Experts' Advice on Sickle Cell Trait Screening." Indiana Joint Nation Public Health Conference. Poster Presenter.

Mayo-Gamble, T.L. (2014). "To emphasize health or energy? An analysis of adult and youths in their perceptions of the advantages of eating fruit and vegetables." Indiana Joint Nation Public Health Conference. Poster Presenter.

Mayo-Gamble, T.L. (2012). "Is Forgiveness a Universal Value? Exploring the Possibility of a Universal Concept of Forgiveness." Society for Cross Cultural Research .Oral Presenter.

Mayo-Gamble, T.L. (2009). "The Impact of Media Technology on Black Males: An Intervention on the Health Literacy of Prostate Cancer." IUPUI Communication Week. Oral Presenter.

Mayo-Gamble, T.L. (2009). "A Crisis within a Crisis: An Analysis of the Communication between Sickle Cell Patients and Healthcare Providers." IUPUI/Volgograd, Russia International Video Conference. Oral Presenter.

Mayo-Gamble, T.L. (2008). "Technological Expressions and Uses in Politics: An Analysis of Various Co-Cultures' Expressions." Joseph Taylor Symposium. Invited Oral Presenter.

Mayo-Gamble, T.L. (2008). "Technological Expressions and Uses in Politics: An Analysis of Various Co-Cultures' Expressions." Central States Communication Association. Oral Presenter.

Teaching Experience

Associate Instructor (Instructor of Record)
2013-2014
School of Public Health-Bloomington, Indiana University
Developed teaching curriculum and syllabi, taught course, managed class, and assigned grades

Course: Stress Prevention & Management
Roster: 83 Students
This course is designed to help students learn about the body's reaction to perceived stress, mental and physical factors related to stress, and effective coping techniques to help mitigate causes of stress. Students may acquire several stress management techniques that include diaphragmatic breathing, visualization, meditation, and progressive muscular relaxation.

Course: Personal Health
Roster: 60 Students
This survey course provides a theoretical and practical treatment of the concepts of disease prevention and health promotion. Covers such topics as emotional health; aging and death; alcohol, tobacco, and drug abuse; physical fitness; nutrition and dieting; consumer health; chronic and communicable diseases; safety; and environmental health.

Teaching Assistant
Spring 2013
Course: Drug Use in American Society
Roster: 90 Students
An interdisciplinary approach to the study of drug use in American society. Examines the effects of alcohol, tobacco, and the "illicit" drugs on the physical, mental, and social health of the individuals.

Invited Lectures

School of Public Health-Bloomington
Spring 2014
Course: Stress Prevention and Management
Topic: Alcohol Safety and Sexual Assault Awareness
Roster: 80 Students

School of Public Health-Bloomington
Fall 2012

Course: Research and Evaluation Methods in Health & Safety
Topic: Qualitative Research Methods
Roster: 60 Students

School of Public Health-Bloomington, Indiana University
Fall 2012
Course: Nutrition Management
Topic: Food Safety
Roster: 60 Students

Academic Appointments

Associate Instructor
2012-2013
Indiana University, School of Public Health-Bloomington, Department of Applied Health Science

Graduate Assistant
2013-2015
Indiana University, OASIS/IU Health Center, Division of Student Affairs

Professional Service

Editorial Service
Reviewer
2014-Pres
American Public Health Association
Section: Alcohol, Tobacco and Other Drugs
Section: Community Health Workers

National Service

AmeriCorps Vista- Indianapolis, IN
Sum 2013
Indy Hunger Network: Summer Servings Associate

Community Service
Martin Center Sickle Cell Initiative- Volunteer/Advocate
2011-Pres

University Service
Committee on Diversity and Inclusion- Graduate Student Representative
2014-2015
School of Public Health-Bloomington
Council on Education for Public Health Accreditation Self-Study

Committee on Diversity and Inclusion
2014-2015
Research Subcommittee- Graduate Student Representative

School of Public Health-Bloomington
Council on Education for Public Health Accreditation Self-Study

Graduate Studies Grievance Committee-Graduate Student Representative
2013-2015
School of Public Health-Bloomington
Council on Education for Public Health Accreditation Self-Study

Inaugural School of Public Health Student Government- Board Member
2013-2014
School of Public Health-Bloomington
Council on Education for Public Health Accreditation Self-Study

Health Behavior Research Seminar-Coordinator
Fall 2013
School of Public Health-Bloomington
Department of Applied Health Science

Student Mentorship

Julius Lee-Community Health (Bachelor of Science) Indiana University
2013-2015
Kamille Brown- Human Biology (Bachelor of Science) Indiana University
Kenya Thomas-Biology (Bachelor of Science) Indiana University

Julius Lee- Community Health (Bachelor of Science) Indiana University
2011-2012
Kamille Brown-Human Biology (Bachelor of Science) Indiana University
Quanisha Morrow-Community Health (Bachelor of Science) Indiana University
Shanika Daniels-Community Health (Bachelor of Science) Indiana University

Specialized Trainings/Workshops

Topic: Motivational Interviewing
Fall 2013
Indiana University, Office of Alternative Screening and Intervention Services

Topic: Repeated Measure of Analysis Using SAS
Spr 2014
Statistical Computing Seminar, University of California

Professional Membership

American Public Health Association
2012-Pres
American Association for the Advancement of Science
2011-Pres

Indiana Public Health Association
2011-Pres
Center for Research on Race and Ethnicity in Society
2012-Pres

Honor Society Membership

Eta Sigma Gamma, National Health Education Honorary
2012-Pres

Awards

Office of Alternate Substance Abuse Intervention Services
2013-2014
Graduate Assistantship

AmeriCorps VISTA Volunteers in Service to America
Fall 2013
Educational Award

School of Public Health-Bloomington
2012-2013
Department of Applied Health Science
Graduate Assistantship

Employee Leadership Award
2011
Marion County Public Health Department-Indianapolis

Technical Skills

Quantitative and Quantitative Data Collection Methods and Techniques:

- Observational/cross-sectional research
- Community-based participatory research
- Semi-structured, structured, and ethnographic interviews
- Focus Groups
- Survey (paper and web-based)

Data analysis and Data visualizations:

- Quantitative -Statistical Analyses including parametric and non-parametric statistics, longitudinal data analysis, analysis of observational data (univariate and multivariate statistical modeling, etc.)
- Qualitative - Content analysis, coding, transcription
- Secondary data analysis

Software:

- SPSS (experienced)
- Stata (beginner)
- SAS(beginner)
- Nvivo qualitative data analysis (beginner)

- RStudio(beginner)
- Microsoft Suite

References for Tilicia L. Mayo-Gamble

Jackie Daniels, MSW
Director of OASIS
Indiana University Health Center
Eigenmann Hall, 7th Floor West
Email: danieljm@indiana.edu
Phone: (812) 856-3898

Priscilla Barnes, PhD
Assistant Professor
Department of Applied Health Science
Indiana University School of Public Health-Bloomington
1025 E. Seventh Street, Bloomington, IN 47405
Email: prbarnes@indiana.edu
Phone: (812) 855-4789

Hsien-Chang Lin
Assistant Professor of Health Policy and Management
Department of Applied Health Science
Indiana University School of Public Health-Bloomington
1025 E. Seventh Street, Bloomington, IN 47405
Email: linhsi@indiana.edu
Phone: (812) 855-6197

Rachel Dowty
Project Director
Department of Applied Health Science
Indiana University School of Public Health-Bloomington
1025 E. Seventh Street, Bloomington, IN 47405
Email: rmdowty@indiana.edu
Phone: (812) 855-2277

Maresa Murray, PhD
Clinical Associate Professor and Director of Undergraduate Education
Department of Applied Science
Indiana University School of Public Health-Bloomington
1025 E. Seventh Street, Bloomington, IN 47405
Email: marjmurr@indiana.edu
Phone: (812) 856-5213

Susan E. Middlestadt
Professor and Director of Graduate Education
Department of Applied Health Science
Indiana University School of Public Health-Bloomington

1025 E. Seventh Street, Bloomington, IN 47405
Email: semiddle@indiana.edu
Phone: (812) 856-2767