Using the Theory of Reasoned Action to Analyze African American College Students Intentions to Participate in Bio banking Research

Bethrand O. Ugwu

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The proliferation of biobanks has created new opportunities for researchers to conduct cutting-edge research that was not possible a decade ago. The results of early studies using biospecimens in cancer research have been encouraging. However, researchers are concerned about the applicability of the new knowledge that is being produced to racially diverse subgroups because African American (AA) participation in biobanking research is low. The current study assessed how AA college students’ attitudes and social norms influenced their intentions to participate in biobanking research. This research was guided by Ajzen and Fishbein’s Theory of Reasoned Action as the analytic lens. **Methods:** An exploratory sequential, mixed-method study design was employed to collect cross-sectional open-ended questionnaire and survey data over a six-month study period. A total of 27 participants participated in the initial qualitative phase (open-ended questionnaires) to develop theory-based quantitative measures. In phase II, 105 participants responded to the newly-developed quantitative measures that were analyzed to evaluate four theory-driven hypotheses. **Results:** In the study phase I, a total of twelve most frequently mentioned behavioral beliefs about donating biospecimens along with personal health information (PHI) to biobanks were identified. Similarly, a total of ten most frequently mentioned normative referents who could approve and/or disapprove donating
biospecimens along with PHI to biobank were identified.

In the study phase II, the behavioral beliefs and normative referents identified in phase I were used to draw up a cross-sectional survey. Regression analysis revealed that attitude had a statistically significant association with intention to participate in biobanking ($P$-value <.0001, Parameter estimate = 0.68). Two beliefs, “making medical treatment better” and “helping to find cures to diseases,” showed statistically significant association with attitude. All the twelve behavioral beliefs significantly correlated with attitude except “unpleasant findings of which researchers would notify me.”

There was no significant association between subjective norms and behavioral intention in regression analysis. Correlations between each of the normative referents with subjective norms were not significant. Results from this research will be used to inform theory-based interventions to increase AA participation in biobanking research.

INDEX WORDS: Biobanking, Theory of Reasoned Action (TRA), College students, African Americans.
USING THE THEORY OF REASONED ACTION TO ANALYZE AFRICAN AMERICAN COLLEGE STUDENTS’ INTENTIONS TO PARTICIPATE IN BIOBANKING RESEARCH

by

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DOCTOR OF PUBLIC HEALTH

STATESBORO, GEORGIA
USING THE THEORY OF REASONED ACTION TO ANALYZE AFRICAN AMERICAN COLLEGE STUDENTS’ INTENTIONS TO PARTICIPATE IN BIOBANKING RESEARCH

by

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Haresh Rochani
Levi Ross (Non-voting member)

Electronic Version Approved:
May 2019
DEDICATION

I will primarily dedicate this dissertation to my mother who died in 2009, in Nigeria, while I was in the United States pursuing my academic studies in public health. First, because it took long before I closed the sense of hurt that, I was not in the medical team that attended to her during her final days on earth. I still remember vividly the jubilation she had when I brought home the good news of admission into the University of Calabar Medical School. The pain of not being in her medical team was quite deep but I took consolation in the fact that I was in constant communication with her throughout the period and she kept reassuring me that she would be okay, oblivious to both of us that her death was very near. I also took comfort in the fact that her wonderful virtues of humility and hard-work which she imbued in me at the early stage of my life saw me through the turbulent periods of my immigration to the United States. A mother and wife, who sometimes would work for twelve straight hours and still made sure her husband and the kids had a well-prepared meal to eat. It was that virtue of hard work and humility that made possible this doctoral degree a success story. May her Soul continue to rest in peace. Amen.
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My deep appreciation goes out to my immediate family who had been very supportive throughout this process. I will particularly thank my father, a seasoned teacher, for inculcating that learning zeal in me and urging me to always aspire higher. Special thanks to my elder brother, Rodrick Ugwu, wonderful family friends, Charles Ugwu, uncle Bertrand Ugwu, Martins Onyirimba, and Micheal Ezigbo for making sure that my immigration to the USA was smooth.

Special thanks to Prof. David Matson who had never met me before but believed so much in my abilities from far away the United States. Thank you so much, Sir, for providing me with an opportunity to come to the United States to study.
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<th>Full Form</th>
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<td>AA</td>
<td>African American</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic Acid</td>
</tr>
<tr>
<td>GWAS</td>
<td>Genome-Wide Association Studies</td>
</tr>
<tr>
<td>NCI</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>PHI</td>
<td>Personal Health Information</td>
</tr>
<tr>
<td>PI</td>
<td>Principal Investigator</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribonucleic Acid</td>
</tr>
<tr>
<td>TRA</td>
<td>Theory of Reasoned Action</td>
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<tr>
<td>US</td>
<td>United States</td>
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CHAPTER 1

BACKGROUND AND SIGNIFICANCE

Introduction

Biobanks, or biorepositories, are collections of human, animal and/or plant samples such as urine, saliva, blood, tissue, cells, DNA, RNA, and protein and the accompanying background information systematically stored “for a population or a large subset of a population” (Mora et al., 2015, p.1116). Donated biospecimens can be collected for immediate use in a particular research project or they can be stored for many years for use in future research studies with purposes not yet identified (Oxford University, 2016). Biobanking is the process by which samples of bodily fluid or tissue are collected for research use to improve scientific understanding of chronic health conditions and diseases, many of which disproportionately affect minority populations (Oxford University, 2016). Biospecimens are most useful when they are accompanied by survey data to allow researchers to develop comprehensive profiles that allow complex gene-environment interaction models of diseases to be explored. Biobanking surveys can be quite lengthy as they collect detailed information about donors’ socio-demographic characteristics, family medical history, health risk, and health promotion behaviors.

Results generated from biomedical studies using biospecimens from biobanking have been useful for developing new therapeutic and disease prevention strategies. These biomedical studies usually target all age groups and seek to detect disease risks and progression at the molecular levels or the earliest stages. However, given that disease prevention is usually most effective when interventions are implemented either early in the disease cycle or early in human
development, targeting young adults for biobanking health education and disease prevention is important.

Nationally, there is also increased interest in personalized medicine as shown by the launch of the precision medicine initiative in 2015 by the United States (US) government (Halbert, McDonald, Vadaparampil, Rice, & Jefferson, 2016). The goal of the precision medicine initiative is to develop and implement personalized approaches for disease prevention and treatment based on genetic, molecular, environmental, and lifestyle factors. To achieve the goal of precision medicine initiatives, a national research cohort is currently being created. Many hospitals have started linking genetic sequences of individuals to electronic medical records and lifestyle behaviors (Gainer et al., 2016). Requests for volunteers to donate biospecimens to biobanks will consequently increase. Therefore, it is quite conceivable that present-day college students will be increasingly approached throughout their lifetime for possible enrollment in biobanking. Many current college students will also likely, in the future, engage in health promotion activities that advocate for enrollment in biobanking, therefore, assessing their attitudes and social perceptions about participation in biobanking is very important and fundamental.

Conducting research on biobanking with a focus at the molecular level will help to provide better understanding of individual’s genetic interactions with lifestyle behaviors and environmental factors, development of vaccines for certain diseases, understanding personalized medicine such as finding a good fit between an individual’s genetic sequence and treatment modality as is done in cancer treatment today, and cures for many diseases. However, more racially representative samples are needed to ensure that biospecimen analyses are sufficiently powered to produce generalizable results that can apply to diverse subpopulations. Studies on
racial composition in the database of a cross-section of biobanks currently operating in the United States show that members of racial minority groups represent a very small percentage (10% - 12%) of collected samples (Erwin et al., 2013 and Simon et al., 2014).

Biobanking is a relatively new phenomenon in the US with more than half (59%) of the biobanks currently operating in the US being formed after 2001 (Henderson et al., 2013). However, the number of biobanks has increased dramatically over the past two decades following the completion of human genomic sequencing in 2001. Previous research performed on biospecimens has focused on improving understanding of chronic diseases that disproportionately impact African Americans, such as cancer (Clay et al., 2015, Dang et al., 2014, Erwin et al., 2013, & Lee et al., 2012). Despite the potential health benefits that are possible with new knowledge produced by biobanking, research suggests that African American (AA) participation in biobanking is relatively low. Given that AAs have a higher lifetime risk for developing and dying prematurely from many types of cancer, increasing AA participation in biobanking is an important national public health goal. The current dissertation research study utilized The Theory of Reasoned Action to assess how AA college students’ attitudes and social norms influence their intentions to participate in biobanking research in the United States.

Researchers face a myriad of barriers at multiple socio-ecological levels when attempting to recruit AAs into biobanking studies. Challenges identified at the individual levels include: lack of awareness of available studies; lack of scientific literacy among potential participants; negative attitudes towards participating in research; negative perceptions of institutions sponsoring the research; mistrust; inaccurate beliefs regarding community norms for participating in research; and lack of motivation for participation in research studies (Buseh et al., 2013, Brown et al., 2016, Dang et al., 2014, Erwin et al., 2013, Gabriel et al., 2014, Scott
Challenges identified at the protocol level include: inconvenient scheduling of appointments; lack of or inappropriate participants’ incentives; lack of culturally sensitive enrollment materials; lack of time to explain complex study protocols; complex consent forms; poor timing of innovations to participate; and lack of or insufficient reach of communications about study outcomes (Braun et al., 2014, Brown et al., 2016, Gabriel et al., 2014 & Wendler, 2012). Overcoming these barriers requires great effort and ingenuity from investigators. Health educators can help to develop solutions to overcome many of the aforementioned barriers to participation at the individual and interpersonal levels after the salient determinants that exist within AA sub-population have been identified. Currently, there are few published studies that can explain biobanking participation among AAs (Buseh et al., 2013, Erwin et al., 2013 & Scott et al., 2010). Given that behavioral intention is the greatest determinant of the likelihood of performing a behavior when measuring TRA constructs, factors that facilitate or inhibit the intention to participate in biobanking will similarly impact the performance of the behavior. Therefore, the present dissertation sought to identify factors that may influence the intention to participate in biobanking.

Several factors have hampered AA participation in biobanking studies. A majority of the studies undertaken to investigate these factors utilized a community-based participatory research model (CBPR) (Buseh et al., 2013, Erwin et al., 2013; Gabriel et al., 2014; Hagiwara et al., 2014; Scott et al., 2010). None of the studies applied an individual level health behavior theory. However, there is a need to present a different perspective on the issue by using individual-level theory to more comprehensively understand AAs’ individual perceptions about participation in biobanking. One theory that may be used to gain insights into the ways that individual and interpersonal level factors influence participation in biobanking is the Theory of Reasoned
Action (TRA) (Ajzen & Fishbein., 1980). The Theory of Reasoned Action is very useful when the behavior being investigated is under voluntary control. Considering that participation in biobanking is a voluntary behavior, the TRA is therefore deemed appropriate for this study.

The Theory of Reasoned Action asserts that health behaviors are influenced by a combination of internal factors and perceived social influences. The eight constructs that comprise the model are listed below in Figure 1.1. The TRA has two outcome variables (i.e., behavior and behavioral intentions) and six explanatory or predictor variables (i.e., behavioral beliefs, evaluation of behavioral outcomes, normative beliefs, motivation to comply, attitude and subjective norm). Direct and indirect measurements of attitude and subjective norms were useful in predicting intention and establishing the level of correlation between direct and indirect measures of intention.
Figure 1.1 The Theory of Reasoned Action (Adapted from Ajzen & Fishbein, 1980)

Statement of the problem

Biobanking has offered the public health community with opportunities to collect donated human samples such as blood, tissues, organs, etc. for genomic analysis to advance scientific knowledge and cure diseases. However, data from the existing literature indicates that AAs are underrepresented in biobanking and subsequent genetic analysis in biomedical research. While many determinants of intention to participate in biobanking have been identified at multiple socio-ecological levels, there is currently a lack of consensus for why AAs are underrepresented in biobanking and biomedical research. Public health practitioners in
conjunction with other health professionals support increasing AAs’ donations into biobank databases. However, there is a paucity of research to explain the reasons for the underrepresentation of AA in biobanking so that appropriate interventions can be developed.

**Statement of the purpose**

The purpose of this research was two-fold. The first was to identify factors that influence the intention to participate in biobanking among AA college students. This purpose was achieved by using the Theory of Reasoned Action (TRA) as the theoretical lens through which the influence of these factors on intention could be understood (Ajzen & Fishbein, 1980). In addition, this research also examined the applicability of the TRA as a model to explain intentions to participate in biobanking. The specific aims and hypotheses of the study were as listed below.

**AIMS**

**AIM 1:** To conduct elicitation research to identify how the constructs of the TRA manifest among AA college students’ experiences with participating in biobanking.

**AIM 1a:** To identify the salient behavioral beliefs and outcome evaluations related to AA college students’ participation in biobanking.

**AIM 1b:** To identify the salient normative references related to AA college students’ participation in biobanking.

**AIM 2:** To examine the applicability of the TRA as a model to explain intentions to participate in biobanking.

**AIM 2a:** To identify the constructs of TRA that are most significantly associated with
intention to participate in biobanking among AA college students.

AIM 2b: To determine specific behavioral beliefs and normative referents that significantly influence the constructs of TRA among AA college students with respect to participation in biobanking.

The four theory-driven research hypotheses to be tested under these aims are:

1. There will be a positive relationship between measures of attitudes toward participation in biobanking and behavioral intention.

2. There will be a positive relationship between measures of subjective norm regarding participation in biobanking, and behavioral intention.

3. Indirect measures of attitudes (behavioral beliefs x outcome evaluations) toward participation in biobanking will be positively related to direct measures of attitudes toward the behavior.

4. Indirect measures of the subjective norm (normative beliefs x motivation to comply) for participation in biobanking, will be positively related to direct measures of subjective norm regarding the behavior.
Research Design

The study gathered qualitative and quantitative data from AA college students using an exploratory sequential mixed method research design (See Figure 1.2 above). An initial phase of qualitative research using open-ended questionnaires was followed by a quantitative phase using an online anonymous self-administered survey. Two types of biobanking behaviors that together
constitute participation in biobanking were studied jointly as a single dependent variable—1) donating a biological specimen; 2) completion of a personal health history questionnaire. Therefore, the single behavior investigated is the "completion of personal history questionnaire along with the donation of biological specimen" to a biobank. Survey instruments were developed based on the Theory of Reasoned Action (TRA). Table 1.1 below provides the logic model of the quantitative phase of the study (phase II). An elicitation survey and an online anonymous self-administered cross-sectional survey were utilized to understand attitudes and subjective norms toward biobanking among AA college students. Primary data from the elicitation survey were analyzed to identify salient beliefs and referents for the construction of the final online self-administered cross-sectional survey for the second phase. Responses from the online cross-sectional survey in the second phase were analyzed to identify which theoretical constructs most significantly influenced intention to participate in biobanking.
Table 1.1. Conceptual Model for the Study Phase II (Quantitative Phase)

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<th>Construct Definitions</th>
<th>Aims Answered</th>
<th>Hypotheses Answered</th>
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<tr>
<td>Behavior Intention</td>
<td>Perceived likelihood of performing the behavior</td>
<td>AIM2:</td>
<td>1, 2, 3, and 4</td>
</tr>
<tr>
<td>Attitude</td>
<td>Overall evaluation of the behavior</td>
<td>AIM2:</td>
<td>1</td>
</tr>
<tr>
<td>Instrumental and Experiential Attitude (Direct Measure)</td>
<td>Belief that behavioral performance is associated with certain outcomes</td>
<td>AIM2:</td>
<td>1 and 3</td>
</tr>
<tr>
<td>Behavioral belief (Indirect Measure)</td>
<td>Value attached to a behavioral outcome</td>
<td>AIM2:</td>
<td>2</td>
</tr>
<tr>
<td>Subjective Norm (Direct Measure)</td>
<td>Belief about whether most people approve or disapprove of the behavior</td>
<td>AIM2</td>
<td>2 and 4</td>
</tr>
<tr>
<td>Normative belief (Indirect Measure)</td>
<td>Belief about whether each referent approves or disapproves of the behavior</td>
<td>AIM2:</td>
<td>2 and 4</td>
</tr>
<tr>
<td>Motivation to comply (Indirect)</td>
<td>Motivation to do what each referent thinks</td>
<td>AIM2:</td>
<td>2 and 4</td>
</tr>
</tbody>
</table>

Source: Adapted from Glanz et al, 2008
Significance of the study

A review of the literature suggests that very few studies have utilized individual-level health behavior theory to study factors that influence the intention to participate in biobanking. Many previous studies have used community-based participatory research (CBPR) approaches to study participation in biobanking. In other to provide a fresh angle in an attempt to understand why AA participation in biobanking is low, the current dissertation study used individual-level theory to investigate biobanking. It also presented an opportunity to explore and discover yet unidentified modifiable factors in biobanking through the elicitation study.

When investigating the intention to perform behaviors that are under volitional control, researchers recommend using TRA (Montano & Kasprzyk, 2008). Participation in biobanking is under volitional control since patients and healthy individuals have the absolute choice of either to donate or not to donate their biological specimens for biobanking. Donating a biological specimen is also completely free and at no financial cost. This explains the choice of the Theory of Reasoned Action as the theoretical framework for the study. Indirect measurement of intention offered the researcher the opportunity to identify those factors that influence the intention to participate in biobanking. These identified factors are amenable to intervention and constitute the focus for future health promotion programs. Direct measurement of intention helped to validate indirect measures of intention.

Delimitations of the study

The study’s target population was AA college students at Georgia Southern University, Statesboro campus. The reason for the choice of college students is that disease prevention is usually most effective when interventions are implemented either early in the disease cycle or
early in human development, hence the need to target young adults for biobanking education efforts. In addition, there is currently a renewed interest in precision medicine in the US with the 2015 launch of the precision medicine initiative. Therefore, present-day college students will be constantly approached throughout their lifetime to donate biospecimen as well as serve as advocates for biobanking health promotion.

An AA is defined by the study as an individual who was born in the United States and self-identifies as AA. The study target population was limited to college students, born in the United States and identify as AA. The target population was limited to those born in the US to ensure that the study will have a pool of participants with similar cultural experience about biobanking and participation in biobanking. The study also defines “AA college student” as any AA enrolled for a graduate or undergraduate course at Georgia Southern University, Statesboro campus. The study setting was limited to Georgia Southern University Statesboro Campus because of the convenience it presents in recruiting young adult AA college students. Open-ended questionnaires were utilized in phase one of the study. Open-ended questionnaires were used because the participants are college students and the researchers believed they would be able to clearly explain themselves in written understandable responses to the questionnaires. Face to face interviews or focus groups is often used where researchers are worried about getting clear and understandable responses. In addition, an open-ended questionnaire is simple, easy to use and many researchers have used it in similar studies in the past with credible results (Kelleher et al., 2016; Lederer et al., 2014; Pastor et al., 2015 & Stenius et al. 2016).

The research also did not consider the construct of perceived behavioral control to be relevant in this study because the actual behavior of donating biospecimens along with PHI to biobanks was not measured. The study only measured behavioral intention. According to
Montaño and Kasprzyk (2008), the TRA asserts that behavioral intention is the most important determinant of a behavior. In addition, the actual behavior was not measured because biobanking is a relatively new phenomenon in the US of which many members of the population have little to no knowledge about. This was confirmed in our current study where an overwhelming majority of participants admitted that they knew “nothing at all” of biobanking (82.69%) and had never donated before to biobanks (97.12%). Previously, Henderson et al., 2013, reported that over 58% of biobanks operating currently in the US were formed after the completion of the human genomic project in 2001. In addition, the 2015-US national precision medicine initiative on biobanking is yet to kick off as the modalities are still being worked out. Hence, biobanking institutions in the US are currently few, thereby making availability of donation sites to be scarce. The implication is that members of the society may not have had enough reasonable experiences to share about the ease or difficulty of performing the behavior. This makes constructs of perceived behavioral control not very relevant in this study.

The researchers also believed that, although there are physical and logistic barriers such as lack of sites for donation and transport difficulties to donation sites, such barriers can only inhibit volunteers from performing the actual behavior. The barriers would not prevent someone from having an intention to donate biospecimens to biobanks. Intention is a voluntary and free-will act that exists only in the mind and would not be hampered by physical barriers. Hence, the barriers would only be relevant to volunteers when they want to transition from intention to actual performance of the behavior. The current study, therefore, chose attitude and subjective norms as the relevant constructs in predicting behavioral intention in this behavior under investigation. Perceived behavioral control was therefore not used since the actual behavior was
not measured. According to Montano & Kasprzyk, (2008), the construct of perceived behavioral control is best suited for situation or behavior that is not under voluntary control.

**Limitations**

The research design was mixed methods—a qualitative phase followed by a quantitative phase. The qualitative phase design utilized open-ended questionnaires while quantitative phase research design employed a cross-sectional online survey among United States-born AA college students at Georgia Southern University. However, these designs excluded the rest of the members of the AA community in Statesboro. In addition, the use of a convenient sample of college students limited the generalizability of results from the study. The use of open-ended questionnaires in the first phase of the study was a limitation in comprehensive data gathering, as it will not provide an opportunity to more deeply explore the thoughts of participants. Therefore, a mixed method approach using focus groups and cross-sectional surveys that includes other members of the Statesboro AA community would have been more informative but financial and time constraints have limited the research to college students.

**Assumptions**

Operationalizing the constructs of TRA is based on the expectancy-value conceptualization. This implies “that an attitude (toward an object or an action) is determined by expectations or beliefs concerning attributes of the object or action and evaluations of those attributes” (Fishbein and Ajzen, 1980). Similarly, the subjective norm toward an object or action is determined by normative referents concerning attributes of the object or action and motivation to comply with those referents. Attitude and subjective norm toward an object or action determine intention toward the object or action. However, when attitude and subjective norms
are measured indirectly, intention can only be indirectly predicted accurately if behavioral beliefs and normative referents elicited are pertinent. The assumption in phase one of the study is that people have different aims, perspectives, assumptions, and attitude; interact and can change, within a context which structures and constrains their activities (Hathaway, 1995). Therefore, conducting open-ended questionnaires among the target population and interpreting the themes identified should accurately help researchers understand and identify these aims, assumptions, attitudes, and perspectives which constitute the pertinent behavioral beliefs and normative referents of the target population interacting within their context.

When pertinent behavioral beliefs, pertinent normative referents, attitudes, and subjective norms are measured accurately to predict intention to participate in biobanking, the resulting measures of attitude and subjective norms should each positively correlated with measures of behavioral intention to participate in biobanking. The assumption in phase two of the study is that there is “a cause and effect relationship” between subjective norms and attitude on one hand and behavioral intention on the other hand and that the elicited pertinent behavioral beliefs, normative referents, attitude and subjective norms will be accurately measured to predict intention to participate in biobanking among the target population (Hathaway, 1995). In addition, for measures of the constructs of TRA to be consistent and reliable, there has to be a high degree of correspondence among measures of attitude, subjective norms, intention and behavior in terms of action, target, context and time of the measurements (Fishbein & Ajzen., 1980).

Definition of Terms

In the course of completing this dissertation, the following terms were frequently used.
**Biobanks/Biorepositories.** These are institutions that store biological samples, which is usually human, for research (Mora et al., 2014)

**Biomarkers.** These are characteristics that are objectively measured as indicators of biological, pathologic and pharmacological processes (Strimbu & Travel, 2010).

**Biomedical research.** This is the investigation of biological processes of life, disease prevention and treatment, and how genetic and environmental factors interact to impact health through careful experimentation, observation, laboratory work, analysis, and testing (New Jersey Association for Biomedical Research, 2016).

**Biospecimens/biological samples.** These are the samples stored in biobanks. It can be urine, blood, tissue, cells, DNA, RNA, and protein from humans, animals, or plants (National Cancer Institute (NCI), 2015).

**Phenotype.** An individual's observable traits such as height, eye color, blood type, etc which arises from the interaction of genes and environment.

**Plasma.** Pale yellow liquid part of blood and lymphatic which provides suspension medium for cells. Plasma is devoid of cells.

**Serum.** The protein-rich clear liquid that separates out when blood clots
CHAPTER TWO

LITERATURE REVIEW

The purpose of this dissertation research is to examine the applicability or usefulness of the TRA as a model to explain intentions to participate in biobanking. Relevant works of literature were reviewed with a focus on the evolution of biobanks in the US, participation prevalence in biobanking, the importance of biobanking, socio-ecological factors that influence participation in biobanking, and the Theory of Reasoned Action.

Evolution of Biobanks in the United States

A biobank or biorepository is a collection of human and animal samples such as urine, saliva, blood, tissue, cells, DNA, RNA, and protein and the accompanying background information systematically stored, “for a population or a large subset of a population” (Mora et al., 2015, p.1116). According to a study by Henderson and colleagues (2013), there has been a dramatic growth in biobanks in the United States in the past decade. Much of this growth is attributed to the completion of human genomic sequencing in 2001. Henderson et al., (2013) found that more than half (59%) of the biobanks in operation in the US were formed after the human genome sequencing milestone in 2001.

Biobanks are publicly and privately financed and are affiliated with different types of organizations (Lim, Dickherber, & Compton, 2011). The majority of biobanks currently in existence are affiliated with academic centers (67%), hospitals (23%), and research institutes (13%) (Henderson et al., 2013). Although biobanks can be configured to collect and maintain single or multiple types of samples, nearly 90% surveyed in 2013 indicated they retained
multiple types of samples (Henderson et al., 2013). The most common types of samples in biobank collections are found below in Table 2.1.

Table 2.1 Types of Biospecimens in Storage in a Survey of 456 Biobanks in the US

<table>
<thead>
<tr>
<th>Types of Biospecimens in Storage</th>
<th>Number of Biobanks</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum or plasma</td>
<td>349</td>
<td>77</td>
</tr>
<tr>
<td>Solid tissue specimens, including paraffin-embedded, frozen, or other</td>
<td>315</td>
<td>69</td>
</tr>
<tr>
<td>Whole blood</td>
<td>251</td>
<td>55</td>
</tr>
<tr>
<td>Peripheral blood cells or bone marrow</td>
<td>222</td>
<td>49</td>
</tr>
<tr>
<td>Cell lines</td>
<td>162</td>
<td>36</td>
</tr>
<tr>
<td>Saliva or buccal cells</td>
<td>155</td>
<td>34</td>
</tr>
<tr>
<td>Urine or stool</td>
<td>138</td>
<td>30</td>
</tr>
<tr>
<td>Cerebral spinal fluid</td>
<td>85</td>
<td>19</td>
</tr>
<tr>
<td>Cord blood or cord blood derivatives</td>
<td>51</td>
<td>11</td>
</tr>
<tr>
<td>Other biological specimens</td>
<td>40</td>
<td>9</td>
</tr>
<tr>
<td>Pathological body fluids (e.g., peritoneal fluid)</td>
<td>30</td>
<td>7</td>
</tr>
<tr>
<td>Hair/toenails</td>
<td>14</td>
<td>3</td>
</tr>
</tbody>
</table>

Source: Adapted from Henderson et al., 2013.

Results from research using biospecimens have been useful in developing promising preventive and therapeutic regimens for diseases affecting a variety of subpopulations. The enormous task of recruiting representative samples of healthy and unhealthy individuals from different racial and ethnic groups into biobanks has grown easier over time by greater
involvement from multiple agencies. Table 2.2 below shows the most common types of agencies that currently involved in biobanking collection and storage.

Table 2.2 Most Common Sources of Biospecimens Collection in the US

<table>
<thead>
<tr>
<th>Percentage of biobanks which get specimens from…</th>
<th>Number of Biobanks</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct from individuals donating them</td>
<td>343</td>
<td>75</td>
</tr>
<tr>
<td>Residual specimens acquired from clinical care in hospitals, clinical laboratories, or pathology</td>
<td>261</td>
<td>57</td>
</tr>
<tr>
<td>Research</td>
<td>60</td>
<td>13</td>
</tr>
<tr>
<td>Residual specimens from public health departments or programs</td>
<td>19</td>
<td>4</td>
</tr>
<tr>
<td>Vendors</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Organ/body donation organization</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Other repositories</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Orphaned collections</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

Source: Adapted from Henderson et al., 2013.

**Biobanking Enrollment Process**

Like other types of biomedical research, the biobanking research process involves an initial explanation of the research protocol to participants, signing of informed consent, completing surveys to provide PHI and final donation of the specimens. According to the 2016 National Cancer Institute Best Practices for Biospecimens Resources, biobank researchers have
two major options when enrolling participants into biobanking studies. One option involves having participants complete all aspects of the biobanking protocol in one sitting. The second option is to have participants complete different components of the protocol at separate times. The choice of which protocol to implement depends on multiple factors such as participant types (e.g. healthy vs unhealthy patients), types of specimen requested (e.g. saliva, blood, tissue or bone marrow), participants’ availability, and type of specimen collection site (e.g. a fully equipped hospital vs a mobile lab). However, in this dissertation, participation in biobanking is said to have occurred when a participant completes the three protocols of signing informed consent, completing a survey to provide PHI and donating biological specimens to a biobank, whether at one or multiple sittings.

**Biobanking Participation Prevalence**

Adequate representation of different sub-populations is needed to maximize the generalizability of research findings generated from biobanking studies. However, data from the existing literature indicate that individuals from racial/ethnic minority subpopulations are underrepresented in biobanking research. Evidence of this racial disparity in biobank participation is visible throughout the different regions of the country (Erwin et al., 2013 & Simon et al., 2014)

In a study conducted with biobank facilities in 15 Midwestern and Northeastern states, Simon & colleagues (2014) found that non-white patients represented only 11% of the total 130,386 specimens collected from seven facilities. AA patients constituted 8% of non-white patients. In another review of racial distributions of biobanking participants, Erwin et al. (2014) found that only 10% of the 8,000 samples in the Cancer Genome Atlas of the National Cancer Institute/National Human Genome Research Institute were non-white.
Racial disparities in biobanking participation are also found in studies of chronic diseases that disproportionately impact AAs. For example, in a sample of hospitalized cardiovascular patients, Sanner and colleagues (2007) found that minorities were less likely to participate in genetic biobanking than whites. Similarly, Haga (2010) found that, of the 344 publications from genome-wide association studies listed in the catalog of National Human Genome Research Institute, 67 were studies done in the United States. However, among the 67 studies conducted in the United States, 92% of the study participants were all white while AAs represented only 3%. Similarly, among the 67 studies, 79% of the initial study populations were white while 75% of the replication sample populations were also all white. The lack of racial heterogeneity in biobanking studies will negatively impact the generalizability of the results generated.

**Personalized Medicine (Precision medicine)**

The proliferation of biobanks is helping to create a paradigm shift in the ways that clinical and population-based research are conducted. Research accumulated over the past two decades supports the view that chronic diseases such as cancer, diabetes, and cardiovascular diseases are the result of lifestyle, genetic and environmental factors (Ma, Thabane, Beyene, & Raina, 2016; Olson et al., 2014 & Rappaport, S., 2016). Current scientific thinking acknowledges that these three determinants of health and illness operate in dynamic ways, and they are intertwined. Personalized medicine is a new field of healthcare that takes each individual’s unique clinical, genetic, and environmental profiles into account to develop individualized plans for the prevention and management of diseases and illnesses.

Technological advances are just allowing the longstanding concepts of personalized medicine to be put into practice. According to Cushing (1925), William Osler had long argued that “variability is the law of life, and as no two faces are the same, no two bodies are alike, and
no two individuals react alike, and behave alike under the abnormal conditions we know as disease” (p. 107). Improved understanding of the variability in genes, lifestyle factors, and social and physical environment among persons is the basis of personalized medicine.

The NIH’s precision medicine initiative of 2015 is the nation’s largest coordinated effort to date related to personalized medicine. The goal of this project is to compile a nationally representative cohort of at least one million volunteers. With enrollment for this project expected to begin in 2017, there will be increased calls for individuals around the country to participate in biobanking research.

**Biobanking research innovations**

Much of the value of biobanking lies in its ability to advance clinical and public health research through Genotype derived recruitment (GDR) (Olson et al., 2013). One of the end products of biobanking is the sequenced DNA and PHI of participants stored together. GDR is a process in which researchers select the DNA and PHI of each participant as a subject in a study instead of physically involving the participants. This approach makes it possible for research subjects to be studied based on the interaction between the socio-physical environment and the genotypes (genetic constitutions or gene sequences) but not based on socio-physical environment and phenotypes (Olson et al., 2013). In addition, the DNA sequence of participants is continuously linked to their electronic medical records making follow up studies very easy (Gainer et al., 2016). Therefore, encouraging racial heterogeneity in biobanking studies will increase the likelihood that personalized medicine is available to all in the future (Buseh et al., 2012).
Barriers to Research Trial Accrual

Recruitment is an important first step to completing the NIH precision medicine initiative of 2015. Sites that experience recruitment challenges may face early termination, encounter completion delays, deplete their budgets, and have problems generalizing their findings due to loss of statistical power. Recruitment issues are common in population-based studies generally. In a cross-sectional study with 386 principal investigators (PIs), Cullati and colleague (2016) found that patient enrollment was the number one self-reported barrier to study completion. In a national survey of NIH-funded investigators, Durant and colleagues (2007) discovered that principal investigators (PIs) were more likely to fail their recruitment goals for minority participants (i.e., AAs, Asian Americans, and Hispanics) compared to whites. Even though PIs in this study experienced challenges in recruiting members from ethnic and minority groups, they were least successful at reaching their recruitment goals for AAs. Given the known problems of recruiting AAs into scientific studies, researchers need to be proactive in developing effective strategies to enhance the recruitment of this underserved population.

Socio-ecological Factors that Influence Participation in Biobanking (AAs)

Researchers face a myriad of barriers at multiple socio-ecological levels when attempting to recruit AAs into research studies. Challenges identified at the individual level include: lack of awareness of available studies, lack of scientific literacy among potential participants, negative attitudes about research, negative perceptions of sponsoring institutions, mistrust, inaccurate beliefs regarding community norms for participating in research, and general lack of interest (Buseh et al., 2013, Brown et al., 2016., Dang et al., 2014., Erwin et al., 2013; Gabriel et al., 2014., Scott et al., 2010., Hagiwara et al., 2014; Halverson et al., 2012 & McDonald et al., 2014).
Of the few biobanking studies that have included AAs, factors reported that inhibit their participation in biobanking include: skepticism, fear, medical mistrust, concerns regarding exploitation by medical researchers, discrimination, confidentiality, inequities between those benefiting from the research and those participating in research, failure of researchers to approach them for enrollment in studies, and a lack of direct benefit from the research or disinterest in genetic research (Buseh et al., 2013, Erwin et al., 2013; Gabriel et al., 2014; Hagiwara et al., 2014; Scott et al., 2010). Conversely, factors shown to facilitate their participation include altruism, personal benefits and collective health benefits (Streicher et al., 2011). Given that many of the determinants to participation in biobanking among AAs exist at the individual level, researchers might find answers using well-defined individual-level theories to investigate this issue. One particular theory that takes into account the influence of individual perceptions and social influences is the Theory of Reasoned Action (Ajzen & Fishbein, 1980).

**Theoretical Framework**

**The Theory of Reasoned Action (TRA)**

**TRA Overview.** The Theory of Reasoned Action (TRA) is a value-expectancy theory developed by two social psychologists, Martin Fishbein and Icek Ajzen (Ajzen & Fishbein, 1975). It was developed to help researchers better understand the relationship between attitude, intention, and behavior. Work on this theory grew from frustrations researchers were experiencing in the field regarding the low explanatory and predictive power of attitudes and behavior. The theory developers made methodological improvements in this area by refocusing attention from attitude toward an object to attitude toward the behavior. For example, attitude toward participation in biobanking is a much better predictor of donating biological specimens
along with PHI to a biobank than attitudes toward biobank. The TRA works best in situations where the behavior is under volitional control (Ajzen & Fishbein, 1980).

The TRA has eight major constructs that are categorized into groups of outcome and explanatory variables (See figure 2.1). Behavior and behavioral intention are the two outcome variables. The six explanatory variables include (1) attitudes, (2) subjective norm, (3) behavioral beliefs, (4) outcome evaluation, (5) normative beliefs, and (6) motivation to comply. The six explanatory/predictor constructs are classified as directly measured and indirectly measured constructs. The directly measured ones are attitude and subjective norms while the indirectly measured constructs are the behavioral belief, outcome evaluation, normative belief and motivation to comply. Only seven of the eight TRA constructs were measured in this research as the terminal construct, behavior, was excluded. Behavioral intention served as the proximal outcome to measure behavior. Nine criteria for the development of an instrument for the Theory of Planned Behavior published by Francis et al. (2004) were adapted to develop the survey to measure these seven constructs. The nine criteria are

[1) Defining the population of interest, 2) Using TACT principle to carefully define the behavior we are studying (TACT stands for Target, Action, Context and Time of the target behavior), 3) Deciding how best to measure intentions, 4) Determining the most frequently perceived advantages and disadvantages of performing the behavior, 5) Determining the most important people or groups of people who would approve and disapprove the behavior, 6) Determining the perceived barriers or facilitating factors which could make it easier or more difficult to adopt the behavior, 7) Including all items to measure all the needed constructs in the first draft of questionnaire, 8) Pilot testing the draft and rewording items if necessary and 9)
Using the test-retest method to assess the reliability of the indirect measures by administering the questionnaire twice to the same group of people with an interval of at least two weeks.

A brief description of each of the seven included constructs is provided below.

Figure 2.1. The TRA Constructs Matrix (Fishbein and Ajzen, 1980 in Glanz et al., 2008)

**Behavioral Intention.** Behavioral intention refers to the individual’s perceived willingness or not to perform a particular behavior. Behavioral intention is one of the theory’s two outcome variables. Intention is a proximal outcome that is used in studies that employ a
cross-sectional research design. Behavioral criteria must be defined for each behavioral intention being predicted. Behavioral criteria can be a single act (e.g., donate biospecimens or complete personal health information survey) or a behavior category (e.g., go to the clinic and get HIV screening) (Ajzen & Fishbein, 1980). However, participation in biobanking is defined as donating biospecimens along with PHI to a biobank (Mora et al., 2015, p.1116). Therefore, the two behaviors, donate biospecimens and complete PHI, together define a single act of participating in biobanking. Hence, in this dissertation, a single act behavior of intention to participate in biobanking (donate biospecimens along with PHI to a biobank) was investigated.

In order to ensure a high degree of correspondence between measures of intention and behavior, both constructs should each be clearly defined in terms of action, target, context and time (Ajzen & Fishbein, 1980). Action refers to the observable behavior to be performed. Target refers to the object at which the behavior under investigation is directed. Context is the place, circumstance or situation where the behavior is to be performed. Time is when the behavior is to be performed. Ajzen and Fishbein (1980), state that context and time are not always necessary when defining behavior criteria. The single act behavior investigated in this dissertation research is the intention to donate biospecimens along with PHI to a biobank over one’s lifetime. Therefore, in this dissertation, behavior refers to the intention to participate in biobanking, the action is to donate biospecimens and complete PHI, the target is biobank and the time is over one’s lifetime.

Behavioral intention is measured using Likert type, bipolar scaling (e.g., unlikely-likely scale or disagree-agree) (See Table 2.3). Behavioral intention response options can be on a 7-point (-3 to +3) or 5-point (-2 to +2) scale (Montano & Kasprzyk, 2008). Responses on the Likert scale vary in number based on the mode of data collection used in a study. The decision to use a
5 or 7-point scale is driven by the survey method. In situations where participants can view response options (self-administered surveys), 7-point scaling is used. Five-point scaling is best used for studies where participants cannot view response options (interview administered surveys). The current dissertation utilized self-administered surveys and, therefore, utilized a 7-point scaling.

**Attitude.** Attitude towards the behavior refers to an individual’s overall favorability or unfavorability about an object or behavior (Ajzen & Fishbein, 1980). Ajzen and Fisbein (1980) assert that behavioral intention is best predicted by the direct measurement of attitude when attitude corresponds to the behavior criteria (action, target, context and time) and measurement assesses attitude toward the behavior and not attitude toward the object or target at which the behavior is aimed. Attitude toward the behavior is measured directly or indirectly (See Table 2.3).

**Direct measurement of attitude.** Attitude is directly measured using a bipolar, semantic differential, 5 or 7-point Linkert type scaling (good-bad or wise-foolish). The scale for direct measurement of attitude usually ranges from (-2 to +2) or (-3 to +3) (Osgood, Suci, & Tannenbaum, 1975 as cited in Ajzen & Fishbein, 1980). Negative scores will be given to negatively evaluated items, positive scores are assigned to positively evaluated items and zero scores given to neutrally evaluated items. The scores for these items are summed to get a numerical value for attitude. According to Francis et al. (2004), attitude can also be measured directly using bipolar adjectives (e.g. wise-foolish), which are evaluative, using a 7-point unipolar scale. Unipolar 7-point scale usually ranges from 1 to 7, with scores less than 4 given to negatively evaluated items while positively evaluated items are assigned numbers greater than 4. The score of 4 is given to neutrally evaluated items.
Indirect measurement of attitude. Two explanatory constructs of TRA are used to indirectly measure attitude. The constructs are 1) behavioral belief and 2) outcome evaluation. A cross product of these two constructs is summed up across all outcomes of the behavior to arrive at the indirect score for attitude. Two different ranges of scale have been recommended for indirect measurement. These scales are bipolar (-3 to +3) and unipolar (+1 to +7). Bipolar (-3 to +3) is recommended for assessing outcome evaluations. The bipolar scale (-3 to +3) is useful in capturing double negative. “Capturing double negative ensures that belief that performing a behavior will not lead to a negative outcome will still yield a positive attitude” (Montano & Kasprzyk, 2008, p. 72). Unipolar (+1 to +7) can also be used in assessing behavioral beliefs.

The choice of direct or indirect measurement of attitude is dependent on the purpose of the study. If the focus of the study is predicting a behavior, the direct measurement will serve the purpose, however, if the focus is to explain behavior, both direct and indirect measurement of attitude is recommended. According to Ajzen and Fishbein (1975) as cited in Ross et al., (2007), a direct relationship between the direct measurement of attitude and indirect measurement of attitude will only exist if the indirect measurements of beliefs are salient. A correlation of at least 0.36 is expected between the direct and indirect measures if the identified behavioral beliefs were properly measured (Ajzen & Fishbein, 1975).

Salient beliefs can be considered from two angles, individual or group. Salient beliefs from an individual angle are those beliefs that are held by a person that are relevant in determining the individual’s attitudes. However, from a group perspective, salient beliefs are those beliefs that are widely held by members of a particular group. Ajzen and Fishbein (1975) recommend conducting an elicitation study to determine the salient beliefs of the priority population if indirect measures will be conducted in a study. The elicitation study will be done
for every single act in a behavior category. Researchers have developed standard non-leading questions that members of the study population should be asked to elicit salient beliefs. These questions can be presented as discussion points in focus groups, semi-structured interviews or open-ended questionnaires (Francis et al., 2004).
### Table 2.3. TRA Constructs and Measurements

<table>
<thead>
<tr>
<th>Modifiers</th>
<th>The Theory of Reasoned Action Constructs</th>
<th>Construct Measurements</th>
<th>Aims Answered</th>
<th>Hypotheses Answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Intention</td>
<td></td>
<td>Bipolar unlikely-likely scale; scored −3 to +3</td>
<td>AIM2:</td>
<td>1, 2, 3, and 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>AIM2:</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>AIM2:</td>
<td>1 and 3</td>
</tr>
<tr>
<td></td>
<td>Instrumental and Experiential Attitude (Direct Measure)</td>
<td>Semantic differential scales: for example, good-bad; wise-foolish</td>
<td>AIM2:</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Behavioral belief (Indirect Measure)</td>
<td>Bipolar unlikely-likely scale; scored −3 to +3</td>
<td>AIM2:</td>
<td>2 and 4</td>
</tr>
<tr>
<td></td>
<td>Evaluation (Indirect Measure)</td>
<td>Bipolar bad-good scale; scored −3 to +3</td>
<td>AIM2:</td>
<td>2</td>
</tr>
<tr>
<td>Subjective norm</td>
<td>Subjective (Injunctive) Norm (Direct Measure)</td>
<td>Bipolar disagree-agree scale; scored −3 to +3</td>
<td>AIM2:</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Normative belief (Indirect Measure)</td>
<td>Bipolar disagree-agree scale; scored −3 to +3</td>
<td>AIM2:</td>
<td>2 and 4</td>
</tr>
<tr>
<td></td>
<td>Motivation to comply (Indirect measure)</td>
<td>Unipolar unlikely-likely scale; scored 1 to 7</td>
<td>AIM2:</td>
<td>2</td>
</tr>
</tbody>
</table>

Source: Adapted from Glanz et al, 2008.
**Subjective norms.** Subjective norms refer to what individuals think important persons in their lives expect they should do regarding the behavior and their motivation to comply with this expectation (Montano & Kasprzyk, 2008). The beliefs of what important persons think are subjective beliefs. Subjective norms can be measured directly and indirectly (See Table 2.3). Like in attitude, the purpose of the research determines the choice of measurements undertaken. If the focus of the study is predicting a behavior, the direct measurement will serve the purpose, however; if the focus is to explain behavior, both direct and indirect measurements of subjective norms are recommended.

Direct measurement of the subjective norm: Subjective norm can be measured directly using a bipolar or a unipolar scale. A bipolar, unlikely-likely, 7 or 5-point Likert scale ((-3 to +3) or (-2 to +2)) can be used to directly measure subjective norm using a single question item. Unlikely responses are given negative numerical values, likely responses get positive numerical values and zero is given to neutral response. Similarly, a unipolar strongly disagree-strongly agree, 7-point scale can also be used (Francis et al.; 2004)

Indirect measurement of the subjective norm: Two predictor variables are used to indirectly measure subjective norms. These include 1) normative beliefs, 2) motivation to comply. There are two recommended scaling methods for the indirect measurement of subjective norms. First, a bipolar Likert scale (-3 to +3) is recommended to measure both normative beliefs and motivation to comply. The second scaling method uses a unipolar (+1 to +7) to measure motivation to comply while bipolar (-3 to +3) is used to measure normative beliefs. According to Fishbein (1976), as cited in Ross et al., 2007, researchers should use the second scaling method as most people will be motivated to comply with their important others. This makes the idea of capturing double negatives with the first scaling method unnecessary.
Similar to attitude, salient normative beliefs must be pertinent for there to be a direct relationship between the indirect and direct measures of the subjective norm. A correlation of at least 0.36 is expected between the direct and indirect measures if the identified normative references were properly measured. This guarantees accurate prediction of behavioral intention. Salient normative beliefs can be elicited from the study population using the same method recommended for attitude.

**Theory of Reasoned Action (TRA) and College Students**

Several behaviors have been investigated among college students using TRA. Behaviors that have been investigated with valid and reliable results included cyberbullying, smoking, condom use, gambling, and binge drinking. For example, Doane, Pearson, & Kelley, (2014) used TRA to explain cyberbullying behavior among 375 college students. Results from the study showed that those with a favorable attitude toward cyberbullying had higher predicted intention to cyberbully and higher cyberbullying intention was significantly associated with frequent cyberbullying behavior. Subjective norms also predicted the intention to perpetrate different forms of cyberbullying such as malice and unwanted contact behaviors.

Similarly, Thrasher, Andrew, & Mahony (2007), in their study used TRA to investigate and explain gambling among 345 college students. Results from the study showed that attitudes toward gambling and subjective norm toward gambling predicted gambling intentions. In addition, there was also a significant and positive prediction of gambling behavior from gambling intention. These studies suggest that TRA is a reliable theory to study and explain behavior among college students.
Theory of Reasoned Action and Biobanking Participation

There is a paucity of research studies that specifically use the Theory of Reasoned Action to study intention to participate in a biobank. A thorough literature review yielded only one research study that utilized all constructs of TRA to predict intention to participate in biobanking and one study that partially used the constructs of TRA.

McDonald & colleagues (2014) used all constructs of TRA and TPB to predict the intention to donate biospecimens to a biobank in a national sample of 1033 AAs. The study result revealed that 33% were not at all likely, 18% were a little likely, 36% were somewhat likely, and 23% were very likely to donate to a biobank. On the other hand, in a cross-sectional study, Treweek, Doney, & Leiman, 2009, studied attitude toward donating leftover blood samples from clinical practice to biobanks among 2471 patients in two general practice lists. Although 61% of respondents (841) had an unequivocal positive attitude toward donating and storing of leftover blood samples, the partial use of the constructs of TRA makes it difficult to validate the results of this study as recommended by the developers of TRA.

A greater majority of studies utilized TRA to predict intention to donate blood for transfusion and intention to donate an organ or other tissues for transplantation (Brown, 2012; Ford, & Steele-Moses, 2011; Griffin & Grace, 2014; & Weber, Martin & Corrigan, 2007). This is different from donating to a biobank for biomedical research as biospecimens donated to biobanks are mainly used for genetic analysis and other biomedical research. In addition, unlike donors for transfusion and transplant, donors to biobanks may also not know how the donated samples may be used in the future.
Summary

Despite the studies that have shown that biobanking holds great promise for improved chronic disease prevention and treatments, representation of minority populations in biobanking and biomedical research remains very low. The reason for this low representation has increasingly become the focus of scientific research with no prevalent consensus yet. Public health professionals have a role to play in understanding the intention and behavior of minority populations with regard to participation in biobanking.

Many of the previous studies conducted so far on AA participation in biobanking and biomedical research were mostly non-theory-based studies, utilizing community-based participatory research. Few studies utilized individual-level theory such as the Theory of Reasoned Action to assess the willingness of individuals to participate in biobanking and biospecimen research. Hence, different research approaches should be utilized in order to understand this population’s intention about participation in biobanking.
CHAPTER 3

METHODS

The methods section includes information about the research design, study purpose, study aims, human subjects’ protection, participant recruitment and sampling procedures, instruments, data collection, and analysis methods. The goal of this research study is to identify factors that influence the intention to participate in biobanking among AA college students. The current research utilized an exploratory sequential mixed method study with an initial qualitative phase followed by a quantitative phase. A detailed description of the methods and processes used to answer research questions and hypotheses for each phase of the study are provided below.

Research Design (Phase I)

Phase I was an elicitation study to ascertain the salient behavioral beliefs and normative referents among AA college students. Elicitation study is required when an indirect measurement of attitude and subjective norms are to be conducted (Francis et al., 2004). An open-ended cross-sectional questionnaire methodology was used to gather this information.

Sample

The sub-population from which participants were recruited included all AA college students at Georgia Southern University (GSU), Statesboro campus, enrolled between the years of 2018 and 2019. Francis et al. (2004) recommend that a total of 25 participants be selected from the target population for the elicitation study. The current study recruited a total of 27 participants.
Inclusion criteria

All students of GSU Statesboro campus between the years of 2018 and 2019, born in the United States, who identified as AA, enrolled in graduate or undergraduate study, at least 18 years of age, could write and understand English were eligible to participate in the study. An AA is defined by the study as an individual who was born in the United States and self-identifies as AA.

Exclusion criteria

Members of the GSU AA community were excluded from participating if they were younger than 18 years, faculty members or staff of GSU Statesboro Campus between the years of 2018 and 2019, not students, students but not enrolled in graduate or undergraduate study and could not write or understand English.

Setting

Statesboro Campus. Georgia Southern University Statesboro campus is the largest school in Statesboro, with a student population of about 18,499 as at fall 2018 (Georgia Southern University, 2018). In 2017, the last year separate Statesboro campus data was reported, undergraduate students constituted 17,759 while graduate students made up 2,659 of the student population. A total number of 5066 students identified as black. Within GSU, there are more than 300 student organizations (Office of Student Activities, GSU, 2018). The primary sites for the study were student classrooms and AA students’ organizations registered with the Office of Multicultural Affairs. The average age of graduate students is 31 while that of the undergraduate is 21 (Office of the Strategic Research Analysis, GSU, 2018). Given that the study target population was young AAs in college, the large diverse college student population at Georgia
Southern University, Statesboro campus with predominately young undergraduate students, made it an appropriate setting for the study.

Data collection method.

Sampling. A purposive sampling methodology was used to recruit 27 GSU students who met the eligibility criteria for phase I of the study. Francis et al. (2004) recommended that, in order to guarantee saturation in an elicitation study, a sample of 25 persons from the target population should be recruited. Similarly, Kelleher et al. (2016) used a purposive sample of 25 undergraduate nursing and midwifery students in an elicitation study utilizing the Theory of Planned Behavior to predict intention in a university community.

Participants and Recruitment. Announcement and advertisement for the first phase of the study were done through flyers placed in approved strategic places on GSU, Statesboro campus that contained information about the study, eligible participants, incentives, and contact information of the researchers. AA college students willing to participate in the study were to call or email the researchers. However, all participants for phase I of the study were recruited through the Office of Multicultural Affairs (OMA). The OMA invited AA college students to our presentations at a conference room in Russell Union. We made two presentations on two different dates. Eligible participants who indicated interest to participate in the study were scheduled for appointments to complete the open-ended questionnaires in a designated library graduate room.

Employees at OMA also invited eligible AA college students to our designated library graduate room on days we scheduled appointments for participants recruited through our presentation. These randomly recruited students were showed a five-minute video on biobank,
some in groups and others individually, depending on how they came. A brief explanation of biobank and the purpose of the study was equally provided to them after which they were given an opportunity to ask questions. This was done so as to give them a similar experience as those that attended our presentation at the Russell Union. A total of 27 participants completed the open-ended questionnaire. A total of 14 females and 13 males.

**Data Collection Procedure.** All eligible individuals who indicate interest to participate in the study were requested to physically provide their school email address and phone numbers. Each participant agreed on a particular time with the researchers on when best they would make themselves available to complete the survey. At the appointed time, each participant signed an informed consent and a link from Qualtrics was sent to their email address where they had the option to re-watch a brief five-minute video on biobanking, then followed by electronic completion of an open-ended questionnaire (Qualtrics, 2018). The researchers believed that participants would be more likely to understand and complete the survey if participants were physically present. In addition, given that the sample size is small (27), collecting data through this method was expected not to be time intensive. Reminder email, text message, phone call or voice mail was sent to prospective participants two hours before the appointed time.

In the cases of no show, the researcher called or emailed the participant another final reminder. Participants who called or emailed back were rescheduled for survey appointment, otherwise, they were dropped from the recruitment list. Phone calls or emails were continually sent out weekly to eligible participants who were yet to book an appointment until the sample size of 27 was reached or the participant indicated he/she was no longer interested.

Qualtrics was used as a common pathway for all participants to complete the open-ended questionnaires so that data would be captured electronically. It also ensured the confidentiality of
information provided by participants. The emails from Qualtrics were sent out to participants from the researcher’s laptop but participants were allowed to use their personal electronic devices to watch the video and complete the questionnaires. According to Francis et al (2004), open-ended questionnaires in elicitation study can be presented to participants as a one-to-one interview, focus groups or as questionnaires. Similarly, many researchers have used open-ended questionnaires to collect salient beliefs and normative referents in the investigation of health promotion behaviors (Kelleher et al., 2016; Lederer et al., 2014; Pastor et al., 2015 & Stenius et al. 2016). These justified the use of open-ended questionnaires in the current study.

The open-ended questionnaire took approximately 15 to 20 minutes to complete. Participants were offered a $10 Walmart gift card each as an incentive for participating in phase I of the study. Survey administration in phase I of the study lasted for three weeks.

**Human Subjects Protection**

**Study approval.** The study protocols were reviewed by the Georgia Southern University Institutional Review Board and secured approval.

**Informed consent.** After eligibility was established, informed consent was read to the participant who then signs it before proceeding to complete the open-ended questionnaire online.

**Confidentiality.** To ensure confidentiality, each questionnaire was assigned a number. Participants were represented and identified with the number on their questionnaire. In addition, all questionnaires were delivered electronically through Qualtrics to participants’ emails to increase confidentiality.
Instrument, Measurements, and Variables

The Theory of Reasoned Action was used to guide the elicitation of salient behavioral beliefs and normative references among AA college students and how these beliefs and referents affect intention to participate in biobanking. These salient beliefs and normative referents were elicited for a single behavior act which implies participating in biobanking. The single behavior act was donating biological specimens along with PHI to biobanks over one’s lifetime.

Open-ended questionnaires to elicit salient beliefs and salient referents in the first phase of the study were adapted from TRA questionnaires tested and used by experts in the field (See Appendix I). Francis et al. (2004) gave two groups of three sample questions that can each be used to respectively identify salient beliefs and salient normative referents for behaviors when TRA is the theoretical framework in a study (See Appendix II). Questions for salient beliefs are: “What do you believe are the advantages of donating a biological specimen along with your PHI to a biobank? What do you believe are the disadvantages of donating a biological specimen along with your PHI to a biobank? Is there anything else you associate with donating a biological specimen along with your PHI to a biobank?” Questions for normative referents are: “Who, which people or groups, might approve or support you if you donate a biological specimen along with your personal health information to a biobank? Who, which people or groups, might disapprove if you donate a biological specimen along with your personal health information to a biobank? Is there anything else you associate with donating a biological specimen along with your personal health information to a biobank?”

According to Francis et al. (2004), these questions can be presented as a one-to-one interview, focus group or open-ended question. The current dissertation research presented the questions as open-ended electronic questionnaires to participants.
Screener questions. Questions that served as screeners to establish eligibility preceded the survey. They are (1) Year of birth (2) Are you a faculty or staff of GSU (3) Are you an AA born in the United States (4) Are you enrolled in graduate or undergraduate course at GSU Statesboro campus (5) Can you write and understand the English language? In addition, the researchers made sure to establish eligibility using the screener questions criteria before administering the surveys. Demographic variables. Demographic information collected were (1) Year of birth (2) Gender (3) Educational level (graduate or undergraduate) and (4) Department (major).

Elicitation study variables. Two variables were targeted for identification in phase one of the study. They were the salient beliefs and salient normative referents of AA college students concerning participation in biobanking.

Content Analysis and Coding

Questionnaire Transcripts and Data Cleaning Process. Responses were downloaded from Qualtrics in Microsoft Excel format and exported. The data in the Excel sheet were de-identified for confidentiality. Each question stem in the sheet was then copied into a Word document along with its corresponding responses for every participant. This process created a total of 27 transcripts in word document forms. Responses were converted into Microsoft Word document transcripts so as to make it possible to analyze them in MAXQDA. The transcripts were given to the members of the coding team to code.

Coding Team. There was a three-member coding team, made up of two doctoral students and one faculty member who served as the dissertation committee chair. The two doctoral students have training in qualitative data coding and analysis.
Coding occurred in three phases. The doctoral students, under the supervision of the dissertation committee chair, independently coded the 27 transcripts. Initially, the transcripts were manually coded independently by the doctoral students to identify salient behavioral and normative themes. The two students then met and synthesized their identified themes into one list. The aggregated list was sent to the dissertation committee chair who then reviewed and approved the themes after edits and corrections.

Using the approved harmonized behavioral and normative themes, each of the doctoral students re-coded the 27 transcripts in MAXQDA software. The coded responses were then analyzed in MAXQDA. Two analyses were run. The analyses were sub-code statistics and inter-coder agreement. Identified areas of disagreement were revisited by the coders and agreement was made where possible. Areas of common agreement were then re-coded again respectively by each coder. The sub-code statistics and inter-coder agreement analysis were again done. Using the results of the sub-code statistics the most frequently mentioned behavioral themes and normative beliefs were used to develop the second phase survey. A total of 75% of all mentioned behavioral and normative beliefs were used in drawing up the second phase survey.

Data Analysis

Descriptive data such as frequency and percentage were produced for the identified salient normative and behavioral beliefs themes.

Content analysis. The content analysis of the responses from the open-ended questionnaires enabled us to answer study Aim 1.

To answer Aim #1, responses from open-ended questionnaires were analyzed by the three-person team and coded into themes (behavioral beliefs and normative referents) and
labeled. The frequency of each theme was noted by listing them in order from the most frequently mentioned to the least mentioned. Thereafter, behavioral beliefs and normative referents that are most frequent were selected to construct questionnaires for the second quantitative phase. The recommendation is that 75% of all beliefs and referents mentioned should be selected to ensure adequate coverage (Francis et al., 2004). All statistical analysis was done with MAXQDA.

**Quality control.** The study ensured quality control by having the content of the responses analyzed by a three-person coding team made up of two doctoral students and a faculty member who supervised them. Francis et al., 2004 suggests that at least two researchers conduct the content analysis to increase validity. The faculty member is experienced in qualitative research.

**Content validity.** Attempts to ensure content validity by having at least two biobank research experts review the salient beliefs and the normative referents that have been extracted from the content analysis were not successful as all inquiries to the biobank research experts were not returned.

**Research Design (Phase II)**

The second phase of the study is an applied, correlational, quantitative research approach using a cross-sectional survey design. The study is applied because the researcher is not formulating any new theory. It is correlational because the researcher sought to discover if the behavioral beliefs and normative referents identified from the first phase of the study significantly influenced participation in biobanking among AA college students in GSU, Statesboro campus.
Sample

The study subpopulation included all AA college students of Georgia southern university (GSU) Statesboro campus between the years of 2018 and 2019.

Inclusion criteria

All students of Georgia Southern University (GSU) Statesboro campus between the years of 2018 and 2019, born in the United States, who identified as AA, enrolled in graduate or undergraduate study, at least 18 years of age, could write and understand English were eligible to participate in the study.

Exclusion criteria

Members of the GSU AA community were ineligible to participate if they were younger than 18 years, faculty members, or staff of GSU Statesboro Campus between the years of 2018 and 2019, not students, students but not enrolled in graduate or undergraduate study and could not write or understand English.

Setting

The setting is the same as in phase one of the study. The setting is Georgia Southern University, Statesboro campus.

Data collection method.

Sampling. A purposive sampling methodology was used to recruit GSU students who met the eligibility criteria for phase II of the study. There is currently a paucity of research studies that utilized individual-level theory such as TRA to analysis the intention to participate in biobanking. However, Stenius et al., (2015), who used The Theory of Planned Behavior to
investigate Knowledge sharing intention in the workplace, had 200 responses out of 685 workers invited to participate in the second phase of the study. During the second phase of this dissertation, a total of 209 AA College Students who met the study eligibility were invited to participate. A total of 105 completed the cross-sectional survey.

**Participants and Recruitment.** Announcement and advertisement for the second phase of the study were done through flyers placed on approved strategic places on GSU, Statesboro campus that contained information about the study, eligible participants, incentives, and contact information of the researchers. AA college students willing to participate in the study were to call or email the researchers. All participants for phase II of the study were recruited through the Office of Multicultural Affairs (OMA) and solicitation from students at Russel Union. Through the facilitation of OMA, the researchers made a presentation on biobanking to two AA students' organizations. The organizations are MOVE and Georgia Southern University chapter (Lambda Kappa) of the Alpha Kappa Alpha Sorority Incorporated. Eligible participants who indicated interest to participate in the study provided their school email addresses and a link to the survey was sent to each of them.

Most of the survey participants were recruited at Russel Union. These students recruited from Russel Union were showed a five-minute video on biobanking, some in groups and others individually, depending on how they came. A brief explanation of biobank and the purpose of our study was equally provided to them after which they were given an opportunity to ask questions. This was done so as to give them a similar experience as those that attended our presentation. Following the presentation, links to the survey question were sent to each of them. The survey period ran from January 24th, 2019, to February, 22nd, 2019. A total of 105 participants completed the survey, 37 males and 68 females.
Data Collection Procedure. All eligible individuals who indicate interest to participate in the study were requested to provide their school email address. A link from Qualtrics was sent to their email address where they electronically signed the informed consent form, had the option to re-watch a brief five-minute video on biobanking, and then electronically completed the cross-sectional survey (Qualtrics, 2018). Reminder emails from Qualtrics were continually sent out weekly to eligible participants who were yet to respond to the survey until the sample size of 105 was reached or the participant indicated he/she was no longer interested.

Qualtrics was used as a common pathway for all participants to complete the cross-sectional survey so that data would be captured electronically. It also ensured the confidentiality of information provided by participants. The emails from Qualtrics were sent out to participants from the researcher’s lab top but participants were allowed to use their personal electronic devices to watch the video and complete the survey. According to Francis et al., 2004, the second phase of the study using TRA should be presented to participants as a cross-sectional survey. Similarly, Stenius et al. (2016) used a cross-sectional survey to conduct the second phase of the TRA study to predict the intention to share knowledge among employees at the workplace.

The cross-sectional survey took approximately 15 to 20 minutes to complete. Participants were automatically entered into a lottery to possibly win a $50 Walmart gift card as an incentive for participating in phase two of the study. There were a total of ten $50 Walmart gift cards for the lottery. Survey administration in phase two of the study lasted for a month.

Human Subjects Protection
Study approval. The researcher submitted the study protocols to the Georgia Southern University Institutional Review Board and secured approval.

Informed consent. After eligibility was established, a link to the survey was sent to the participant's school email address where they signed the informed consent electronically before proceeding to complete the self-administered cross-sectional survey online.

Confidentiality. To ensure confidentiality, each survey was assigned a number. Participants were represented and identified with the number on their survey. In addition, all surveys were delivered electronically through Qualtrics to participants’ emails to increase confidentiality.

Instrument, Measurements, and Variables

The constructs of the Theory of Reasoned Action were used to guide the measurement of participation in biobanking among AA college students and how AA college students’ behavioral beliefs and normative referents affected their intention to participate in biobanking. The TRA has eight major constructs that are categorized into groups of outcome and explanatory variables (See figure 2.1). Behavior and behavioral intention are the two outcome variables. The six explanatory variables include (1) attitudes, (2) subjective norm, (3) behavioral beliefs, (4) outcome evaluation, (5) normative belief, and (6) motivation to comply. All the variables except behavior were measured for a single behavior act among AA college students. The single behavior act is donating biological specimens along with personal health information (PHI) to a biobank over one’s lifetime. Behavioral intention served as the proximal outcome to measure the behavior in this dissertation.
**Self-administered Online Cross-sectional Survey.** A self-administered online cross-sectional survey was used to measure all the variables. The instrument for phase II of the study was adapted from TRA questionnaires tested and used by experts in the field (See Appendix I) (Francis et al., 2004). Francis et al. (2004) gave sample questions that can be used to respectively measure each of the variables.

**Behavioral Intention.** The study measured general intention using three items. According to Francis et al. (2004), adequate internal consistency can be demonstrated using the three items. The items are; I expect to donate biospecimens along with my personal health information to a biobank over my lifetime, I want to donate biospecimens along with my personal health information to a biobank over my lifetime, and I intend to donate biospecimens along with my personal health information to a biobank over my lifetime. Each item was scored in a unipolar scale of Strongly disagree _1 _2 _3 _4 _5 _6 _7…Strongly agree. Mid-point score (4) is considered neutral. A sum of the three responses is the score for intention.

**Attitude.** Attitude was measured in two formats, directly and indirectly. **Direct Measurements of Attitude:** Four items were used to measure attitude directly. These items assessed the overall evaluation of the single behavior act under investigation. They include, “Donating biospecimens along with my personal health information to a biobank is….Harmful/Beneficial, Bad/Good, Unpleasant/Pleasant, and Worthless/Useful. Each was scored in a unipolar scale of 1 to 7. A mid-point score of 4 for each item is considered as neutral. The sum of the four responses represents the score for attitude.

**Indirect Measurement of Attitude:** Indirect measure of attitude used two explanatory variables to indirectly measure attitude. The explanatory variables are behavioral beliefs and outcome evaluation. Each behavioral belief response had a corresponding outcome evaluation
response. The total score for a belief is the product of belief response and outcome evaluation response (Belief Score = Belief response X Corresponding outcome evaluation response). Responses to the belief items were scored in a bipolar 7-point Likert scale of -3 to +3 while the corresponding outcome evaluation was scored in a bipolar Likert scale of -3 to +3. There was a total of 12 beliefs and 12 corresponding outcome evaluations in this dissertation. The sum of the product of each belief and the corresponding outcome evaluation for each of the entire 12 beliefs represents the score for indirect attitude measurements. For example, Belief1 Score = Response for belief1 X Response for Outcome evaluation1

Indirect Attitude = Belief1 Score+ Belief2 Score+…………… Belief12 Score.

The 12 beliefs and the corresponding outcome evaluations measured in this dissertation along with the scoring pattern are listed below:

1. If I donate biospecimens along with my personal health information to a biobank I will feel that I am making medical treatment better
   Unlikely…..-3 -2 -1 0 +1 +2 +3….Likely

2. Making medical treatment better is
   Extremely undesirable... -3 -2 -1 0 +1 +2 +3…Extremely desirable

3. If I donate biospecimens along with my personal health information to a biobank I will feel that I am helping researchers achieve scientific breakthroughs and medical advances
   Unlikely….–3 -2 -1 0 +1 +2 +3….Likely

4. Achieving scientific breakthroughs and medical advances are
   Extremely undesirable... -3 -2 -1 0 +1 +2 +3…Extremely desirable
5. If I donate biospecimens along with my personal health information to a biobank I will feel that I am increasing diversity in scientific data so as to make research results applicable to all populations

   Unlikely…-3 -2 -1 0 +1 +2 +3….Likely

6. Increasing diversity in scientific data so as to make research results applicable to all populations is

   Extremely undesirable… -3 -2 -1 0 +1 +2 +3…Extremely desirable

7. If I donate biospecimens along with my personal health information to biobank I will feel that I am helping to find cures for diseases

   Unlikely…..-3 -2 -1 0 +1 +2 +3….Likely

8. Finding cures to diseases is

   Extremely undesirable… -3 -2 -1 0 +1 +2 +3…Extremely desirable

9. If I donate biospecimens along with my personal health information to biobank I will feel that I am adding more knowledge to science

   Unlikely…..-3 -2 -1 0 +1 +2 +3…..Likely

10. Adding more knowledge to science is

    Extremely undesirable… -3 -2 -1 0 +1 +2 +3…Extremely desirable

11. If I donate biospecimens along with my personal health information to biobank I will feel that I am helping to find the causes of diseases

    Unlikely…..-3 -2 -1 0 +1 +2 +3…..Likely

12. Finding causes of diseases is

    Extremely undesirable… -3 -2 -1 0 +1 +2 +3…Extremely desirable
Subjective Norms. Subjective Norm was measured in two formats, directly and indirectly. Direct Measurement of Subjective Norm: This was conducted to measure what participants generally think is the opinion of important persons concerning participation in biobanking. Three items were used for this measurement. Each item was scored using a 7-point unipolar scale of 1 to 7. The sum of the scores for the three items represents the final score for the direct measurement of the subjective norm. The items used in this measurement are

1. Most people who are important to me think that
   I should….1 2 3 4 5 6 7…..I should not donate biospecimens along with my personal health information to a biobank

2. It is expected of me that I donate biospecimens along with my personal health information to a biobank
   Strongly disagree….1 2 3 4 5 6 7…Strongly agree

3. I feel under social pressure to donate biospecimens along with my personal health information to a biobank
   Strongly disagree….1 2 3 4 5 6 7……Strongly agree

Indirect Measurement of Subjective Norms: This was conducted to measure what participants believe are the opinion of individuals, groups or organizations who would likely apply social pressure with regards to participation in biobanking and participants willingness to comply with that pressure. Indirect measurement can be conducted for injunctive norms which reflects what important person thinks a person should do or descriptive norms which reflect what important people actually do (Francis et al; 2004). Injunctive norm of indirect measurement was conducted in this dissertation using ten important persons, groups or organizations (normative referents) identified in the study phase one. Two measurements were conducted about each of the ten
normative referents. The first measurement assessed if participants think each of the normative referents would approve or disapprove donating biospecimens along with their personal health information to a biobank (Normative belief or NB). This was measured using a unipolar 7-point scale of 1 to 7. This question was then immediately followed by the second measurement that assessed if participants valued what this important person thinks (Motivation to comply or MTC). The second item was also measured using a unipolar 7-point scale of 1 to 7. The product of the first measurement and second measurement represents the indirect subjective norm score for that normative referent. The sum of indirect subjective norm scores for each of the entire ten normative referents represents the value of indirect measurement of subjective norms.

For example, the indirect subjective norm score for normative referent 1 (NB1 Score = NB1 X MTC1). Therefore, for each participant, the Indirect Subjective Norm measurement = NB1 Score + NB2 Score + NB3 Score + …… + NB10 Score.

The ten normative referents with the questions that assessed the participants’ normative beliefs about these referents along with the corresponding motivation to comply are listed below.

1. Health professionals would disapprove….. 1 2 3 4 5 6 7…. approve of me donating biospecimens along with my personal health information to a biobank

2. What health professionals think I should do matters to me

   Not at all….1 2 3 4 5 6 7…Very much

3. Academic researchers would disapprove….. 1 2 3 4 5 6 7….approve of me donating biospecimens along with my personal health information to a biobank

4. What academic researchers think I should do matters to me

   Not at all….1 2 3 4 5 6 7…Very much
5. My family would disapprove..... 1 2 3 4 5 6 7….approve of me donating biospecimens along with my personal health information to a biobank

6. What my family think I should do matters to me

   Not at all….1 2 3 4 5 6 7…Very much

7. Hospitalized individuals (those in need) would disapprove.1 2 3 4 5 6 7...approve of me donating biospecimens along with my personal health information to a biobank

8. What hospitalized individuals (those in need) think I should do matters to me

   Not at all….1 2 3 4 5 6 7…Very much

9. Other African Americans would disapprove..... 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

10. What other African Americans think I should do matters to me

    Not at all….1 2 3 4 5 6 7…Very much

11. My parents would disapprove..... 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

12. What my parents think I should do matters to me

    Not at all….1 2 3 4 5 6 7…Very much

13. My peers would disapprove..... 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

14. What my peers think I should do matters to me

    Not at all….1 2 3 4 5 6 7…Very much

15. My friends would disapprove..... 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

16. What my friends think I should do matters to me
17. My grandparents would disapprove.….. 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

18. What my grandparents think I should do matters to me

Not at all….1 2 3 4 5 6 7…Very much

19. My coworkers would disapprove.….. 1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

20. What my coworkers think I should do matters to me

Not at all….1 2 3 4 5 6 7…Very much

**Screener questions.** Questions that served as screeners to establish eligibility preceded the survey. They were (1) Year of birth (2) Are you a faculty or staff of GSU (3) Are you an AA born in the United States (4) Are you enrolled in graduate or undergraduate course at GSU Statesboro campus (5) Can you write and understand the English language? In addition, the researchers made sure to establish eligibility using the screener questions criteria before administering the surveys. **Demographic variables.** Demographic information collected were (1) Year of birth (2) Gender (3) Educational level (graduate or undergraduate) and (4) Department (major).

**Phase two study variables.** Seven variables concerning participation in biobanking among AA were targeted for measurement in phase two of the study. They were the Behavioral intention, Attitude, Behavioral belief, Outcome evaluation, Subjective norm, Normative belief and Motivation to comply.
Data Cleaning Process

Responses were downloaded from Qualtrics in Microsoft Excel format and exported. The data in the Excel sheet were de-identified for confidentiality. During the indirect measurement of subjective norms in this second phase, the normative beliefs were scored in a unipolar 7-point scale of 1 to 7. However, before the analysis of data was conducted, the scores for normative beliefs were converted from a unipolar 7-point scale (1 to 7) to a bipolar 7-point Likert scale (-3 to +3) using SAS software.

Data Analysis

Descriptive data such as frequency and percentage were produced for the variables. The analysis of the responses from the self-administered cross-sectional survey enabled us to answer study Aim 2.

Quality control. The study ensured quality control by pilot testing the cross-sectional survey instrument. The test-retest reliability method was used. A purposive convenient sample of six students was recruited from student interns at the Office of Multicultural Affairs. The draft cross-sectional survey was administered twice to a group of six AA college student interns at OMA over a two-week interval. A total of six students responded to the first wave of this test-retest reliability procedure. During the second wave, after two weeks, four students responded to the retest. These students were equally asked to comment if they had difficulty understanding or answering the question. Students commented that the survey was clear and easily understandable. Francis et al., 2004 suggested that the second phase survey be administered to a group of five participants to answer the questions during pilot testing.
**Content Validity.** To ensure the validity of the second phase survey instrument, materials that have been used, tested and considered valid by experts in measuring the constructs of the TRA was used to develop the survey. The material, authored by Francis et al., 2004, recommended steps that should be followed in the development of the second phase survey instrument for the TRA construct measurements. These steps were strictly followed during this dissertation to ensure validity. [The steps are]

1. Define the population of interest
2. Carefully define the behavior under study (explained using the TACT principle)
3. Decide how best to measure intention
4. Determine the most frequently perceived advantages and disadvantages of performing the behavior
5. Determine the most important people or groups of people who would approve or disapprove of the behavior
6. Include items to measure all the constructs of TRA in the first draft of the questionnaire
7. Pilot test the draft and re-word items if necessary
8. Assess the test-retest reliability of the indirect measures by administering the questionnaire twice to the same group of people, with an interval of at least two weeks].

An attempt was made to ensure content validity by having at least two biobank research experts review the salient beliefs and the normative referents used to construct the second phase survey instrument but it was unsuccessful as all inquiries to the biobank research experts were answered.
CHAPTER 4

RESULTS

Phase I Results

A total of twenty-seven AA college students in Georgia southern university responded to an open-ended questionnaire administered in July 2018. There was a total of thirteen males and fourteen females. Participants’ years of birth fell within a narrow range of between 1994 to 2000 with a majority of them (12) being born in 1996 followed by 1998, (4) and 1997, (4). A majority (25) are undergraduate students. Academic majors were spread across the entire participants with no clear majority.

Data Reduction (Behavioral beliefs and Normative Referents)

Data abstraction from response transcripts was carried out in three rounds. The 27 transcripts from the open-ended survey were subjected to three rounds of coding. The first round of coding was independently done manually by each of the two student coders to identify common themes. The two students met and synthesized a common list of themes. The synthesized list was reviewed and approved by a dissertation committee member and was used for the second round of coding in MAXQDA. After the second round of coding, an initial sub-code statistics and inter-coder agreement analysis were conducted, and areas of disagreement noted. Areas of disagreement were then resolved. Subsequently, the transcripts were subjected to the third round of coding. A final sub-code statistics and inter-coder agreement were then conducted. Following these two analyses, a total of 8 behavioral beliefs of advantages and 9 behavioral beliefs of disadvantages of donating biospecimens along with PHI to a biobank were initially identified. Similarly, 12 normative referents that would approve of donating
biospecimens along with PHI to a biobank and 10 normative referents that would disapprove of donating biospecimens along with PHI to a biobank were initially identified. Results from the sub-code statistic and inter-coder agreements are presented in Tables 4.1, 4.2, 4.3 and 4.4 which showed the frequency with which participants mentioned each of these themes in responses to the open-ended questionnaires.

Some themes were not eventually recognized in the response transcripts during the final third round of coding. A total of 75% of the most frequently mentioned themes from each of the four categories of advantages, disadvantages, individuals/group approving and individuals/group disapproving of donating biospecimens to biobanks were used to develop phase two survey instrument.
Table 4.1. Frequency of Advantages of donating to a Biobank

<table>
<thead>
<tr>
<th>Advantages of donating biospecimens along PHI to a biobank</th>
<th>Transcripts</th>
<th>Percentage</th>
<th>Percentage (valid)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better medical treatment (Personalized medicine)</td>
<td>22</td>
<td>40.74</td>
<td>42.31</td>
</tr>
<tr>
<td>Medical Advances</td>
<td>18</td>
<td>33.33</td>
<td>34.62</td>
</tr>
<tr>
<td>Generalizability or Diversity</td>
<td>16</td>
<td>29.63</td>
<td>30.77</td>
</tr>
<tr>
<td>More knowledge</td>
<td>8</td>
<td>14.81</td>
<td>15.38</td>
</tr>
<tr>
<td>Finding cures for diseases</td>
<td>8</td>
<td>14.81</td>
<td>15.38</td>
</tr>
<tr>
<td>Finding causes of diseases</td>
<td>4</td>
<td>7.41</td>
<td>7.69</td>
</tr>
<tr>
<td>Disease prevention</td>
<td>4</td>
<td>7.41</td>
<td>7.69</td>
</tr>
<tr>
<td>Discovery of new personal health issues</td>
<td>4</td>
<td>7.41</td>
<td>7.69</td>
</tr>
<tr>
<td>TRANSCRIPTS with code(s)</td>
<td>52</td>
<td>96.30</td>
<td>100.00</td>
</tr>
<tr>
<td>TRANSCRIPTS without code(s)</td>
<td>2</td>
<td>3.70</td>
<td>-</td>
</tr>
<tr>
<td>ANALYZED TRANSCRIPTS</td>
<td>54</td>
<td>100.00</td>
<td>-</td>
</tr>
</tbody>
</table>
Table 4.2. Frequency of Disadvantages of Donating to a Biobank

<table>
<thead>
<tr>
<th>Disadvantages of donating biospecimens along PHI to a biobank</th>
<th>Transcripts With code</th>
<th>Percentage</th>
<th>Percentage (valid)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of breach of personal health information</td>
<td>24</td>
<td>44.4</td>
<td>57.1</td>
</tr>
<tr>
<td>Abuse of personal health information</td>
<td>18</td>
<td>33.3</td>
<td>42.9</td>
</tr>
<tr>
<td>Mistrust</td>
<td>13</td>
<td>24.1</td>
<td>30.9</td>
</tr>
<tr>
<td>Inability to retract consent</td>
<td>6</td>
<td>11.1</td>
<td>14.3</td>
</tr>
<tr>
<td>Exploitation for profit</td>
<td>4</td>
<td>7.4</td>
<td>9.5</td>
</tr>
<tr>
<td>Lack of knowledge</td>
<td>4</td>
<td>7.4</td>
<td>9.5</td>
</tr>
<tr>
<td>Getting back an unpleasant result to me</td>
<td>4</td>
<td>7.4</td>
<td>9.5</td>
</tr>
<tr>
<td>Fear of stereotype</td>
<td>2</td>
<td>3.7</td>
<td>4.8</td>
</tr>
<tr>
<td>Abuse by employers</td>
<td>2</td>
<td>3.7</td>
<td>4.8</td>
</tr>
<tr>
<td>TRANSCRIPTS with code(s)</td>
<td>42</td>
<td>77.8</td>
<td>100.0</td>
</tr>
<tr>
<td>TRANSCRIPTS without code(s)</td>
<td>12</td>
<td>22.2</td>
<td>-</td>
</tr>
<tr>
<td>ANALYZED TRANSCRIPTS</td>
<td>54</td>
<td>100.0</td>
<td>-</td>
</tr>
</tbody>
</table>
Table 4.3. Frequency of Individuals or Group Approving Donating to a Biobank

<table>
<thead>
<tr>
<th>Individuals or Groups Approving Donating to a biobank</th>
<th>Transcripts</th>
<th>Percentage</th>
<th>Percentage (valid)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Professionals</td>
<td>30</td>
<td>55.56</td>
<td>62.50</td>
</tr>
<tr>
<td>Academic Researchers</td>
<td>11</td>
<td>20.37</td>
<td>22.92</td>
</tr>
<tr>
<td>My family</td>
<td>10</td>
<td>18.52</td>
<td>20.83</td>
</tr>
<tr>
<td>Hospitalized individuals (Those in need)</td>
<td>6</td>
<td>11.11</td>
<td>12.50</td>
</tr>
<tr>
<td>Educated People</td>
<td>4</td>
<td>7.41</td>
<td>8.33</td>
</tr>
<tr>
<td>African Americans</td>
<td>4</td>
<td>7.41</td>
<td>8.33</td>
</tr>
<tr>
<td>My parent</td>
<td>4</td>
<td>7.41</td>
<td>8.33</td>
</tr>
<tr>
<td>Caucasian people</td>
<td>2</td>
<td>3.70</td>
<td>4.17</td>
</tr>
<tr>
<td>Spouse</td>
<td>2</td>
<td>3.70</td>
<td>4.17</td>
</tr>
<tr>
<td>Self</td>
<td>2</td>
<td>3.70</td>
<td>4.17</td>
</tr>
<tr>
<td>Peers</td>
<td>2</td>
<td>3.70</td>
<td>4.17</td>
</tr>
<tr>
<td>Altruistic individuals</td>
<td>2</td>
<td>3.70</td>
<td>4.17</td>
</tr>
<tr>
<td>TRANSCRIPTS with code(s)</td>
<td>48</td>
<td>88.89</td>
<td>100.00</td>
</tr>
<tr>
<td>TRANSCRIPTS without code(s)</td>
<td>6</td>
<td>11.11</td>
<td>-</td>
</tr>
<tr>
<td>ANALYZED TRANSCRIPTS</td>
<td>54</td>
<td>100.00</td>
<td>-</td>
</tr>
</tbody>
</table>
Table 4.4. Frequency of Individuals or Group Disapproving Donating to a Biobank

<table>
<thead>
<tr>
<th>Individuals or Groups Disapproving Donating to a biobank</th>
<th>Transcripts with code</th>
<th>Percentage</th>
<th>Percentage (valid)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family</td>
<td>10</td>
<td>18.52</td>
<td>35.71</td>
</tr>
<tr>
<td>Friends</td>
<td>8</td>
<td>14.81</td>
<td>28.57</td>
</tr>
<tr>
<td>Minority groups</td>
<td>4</td>
<td>7.41</td>
<td>14.29</td>
</tr>
<tr>
<td>Grandparents</td>
<td>4</td>
<td>7.41</td>
<td>14.29</td>
</tr>
<tr>
<td>My parent</td>
<td>4</td>
<td>7.41</td>
<td>14.29</td>
</tr>
<tr>
<td>Coworker</td>
<td>3</td>
<td>5.56</td>
<td>10.71</td>
</tr>
<tr>
<td>Peers</td>
<td>2</td>
<td>3.70</td>
<td>7.14</td>
</tr>
<tr>
<td>African Americans</td>
<td>2</td>
<td>3.70</td>
<td>7.14</td>
</tr>
<tr>
<td>TRANSCRIPTS with code(s)</td>
<td>28</td>
<td>51.85</td>
<td>100.00</td>
</tr>
<tr>
<td>TRANSCRIPTS without code(s)</td>
<td>26</td>
<td>48.15</td>
<td>-</td>
</tr>
<tr>
<td>ANALYZED TRANSCRIPTS</td>
<td>54</td>
<td>100.00</td>
<td>-</td>
</tr>
</tbody>
</table>

**Phase II Results**

During phase II of the study, a total of twelve behavioral beliefs and ten normative referents identified in study phase I were used to drawing up a cross-sectional survey administered AA college students. A total of one hundred and five AA college students responded to the cross-sectional survey in phase two. Most of the participants (97.14%) were undergraduates, and the majority were females (64.76%). The overwhelming majority had no prior knowledge of biobanking (82.69%) and had never donated before to a biobank (97.12%). The majority of the participants also had no intention to donate biospecimens along with their PHI to biobanks over their lifetimes (58.10%) (Table 4.5) Participants’ years of birth had a
narrow range of 1992 to 2000, with the majority being born in 1999 (27.62%). Participants were scattered over several majors with no clear majority concentration in any major.

**Descriptive Statistics of Participants in Study Phase II**

Table 4.5. Demographic characteristics (n = 105)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Student</strong></td>
<td></td>
</tr>
<tr>
<td>Graduate</td>
<td>3 (2.86)</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>102 (97.14)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37 (35.24)</td>
</tr>
<tr>
<td>Female</td>
<td>68 (64.76)</td>
</tr>
<tr>
<td>Non-Binary</td>
<td></td>
</tr>
<tr>
<td><strong>Prior Knowledge about Biobanking</strong></td>
<td></td>
</tr>
<tr>
<td>Nothing at all</td>
<td>86 (82.69)</td>
</tr>
<tr>
<td>A little</td>
<td>18 (17.31)</td>
</tr>
<tr>
<td>A lot</td>
<td></td>
</tr>
<tr>
<td><strong>Prior Donation to a Biobank</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (2.88)</td>
</tr>
<tr>
<td>No</td>
<td>101 (97.12)</td>
</tr>
<tr>
<td><strong>Behavioral Intention</strong></td>
<td></td>
</tr>
<tr>
<td>Non-intenders</td>
<td>61 (58.10)</td>
</tr>
<tr>
<td>Intenders</td>
<td>29 (27.62)</td>
</tr>
<tr>
<td>Neutral</td>
<td>15 (14.29)</td>
</tr>
</tbody>
</table>
The overall attitude of the participants was positive towards donating biospecimens along with PHI to biobanks (Mean of direct attitude was 19.23 and indirect attitude was 31.76). Overall, participants were neutral about their subjective norms with respect to donating biospecimens along with PHI to biobanks. The mean of subjective norms was 8.92 (direct) and 0.064 (indirect). Similarly, overall behavioral intention to donate biospecimens along with PHI to biobanks was neutral with a mean of 10.69 (See Table 4.6).

Table 4.6. Overall Intention, Attitude, and Subjective Norms Predictions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Intention</td>
<td>10.69 (3 to 21)</td>
<td>4.7</td>
</tr>
<tr>
<td>Overall (Direct) Attitude</td>
<td>19.23 (4 to 28)</td>
<td>4.67</td>
</tr>
<tr>
<td>Indirect Attitude</td>
<td>31.76 (-108 to +108)</td>
<td>30.71</td>
</tr>
<tr>
<td>Overall (Direct) Subjective Norms</td>
<td>8.92 (3 to 21)</td>
<td>2.79</td>
</tr>
<tr>
<td>Indirect Subjective Norms</td>
<td>0.06 (-210 to +210)</td>
<td>51.87</td>
</tr>
</tbody>
</table>

Correlation Models

Several correlation models were conducted. A correlation between composite normative beliefs (Normative belief X Motivation to comply) and the direct subjective norm was conducted. The result showed that none of the composite normative beliefs significantly correlated with direct measurement of subjective norms as shown by their p-value (p-values > .05) (Table 4.7). In order to understand why there was no correlation between composite normative beliefs and direct subjective norms, the researchers calculated the individual mean for each of the normative beliefs and each of the motivations to comply. The results of the mean showed that participants did not believe that the normative referents in this study had any opinion in approving or disapproving donating biospecimens along with PHI to biobanks as the
mean for each of the normative beliefs were close to the neutral point of “0” (Range -3 to +3). (See Tables 4.9 and 4.10). This may explain why composite normative beliefs did not show any statistically significant correlation with subjective norms.

Correlation between composite behavioral beliefs (Behavioral belief X Outcome evaluation) and direct attitude was also conducted. The result revealed that all the behavioral beliefs (BB) except one (BB12) had statistically significant positive correlations with direct attitude (Table 4.8). The \( p \)-value for the composite behavioral beliefs are BB1 (0.00), BB2 (0.00), BB3 (0.00), BB4 (0.00), BB5 (0.00), BB6 (0.00), BB7 (0.02), BB8 (0.00), BB9 (0.04), BB10 (0.01), BB11 (0.01), BB12 (0.39). These results showed that these behavioral beliefs except BB12 determined the attitude of participants towards donating biospecimens along with PHI to biobanks in this study. The directionality of the correlation (positive) also implies that as the value placed on these beliefs increased (strongly held beliefs) so did the value of attitude increase. The mean of the individual behavioral beliefs and outcome evaluation was also calculated. The results were displayed in Tables 4.11 and 4.12.
Table 4.7 Correlation Between Weighted Composite Normative Beliefs and Direct Subjective Norms

<table>
<thead>
<tr>
<th>Normative Beliefs (NB) and Motivation to Comply (MTC)</th>
<th>Mean</th>
<th>SD</th>
<th>Correlation with Direct Subjective Norm</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>NB1 Health professionals would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>1.57</td>
<td>9.31</td>
<td>-0.041</td>
<td>0.69</td>
</tr>
<tr>
<td>MTC1 What health professionals think I should do matters to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NB2 Academic researchers would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>2.73</td>
<td>7.52</td>
<td>-0.039</td>
<td>0.70</td>
</tr>
<tr>
<td>MTC2 What academic researchers think I should do matters to me X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NB3 My family would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>-0.35</td>
<td>10.10</td>
<td>-0.041</td>
<td>0.70</td>
</tr>
<tr>
<td>MTC3 What my family think I should do matters to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.7 cont

<table>
<thead>
<tr>
<th>Normative Beliefs (NB) and Motivation to Comply (MTC)</th>
<th>Mean</th>
<th>SD</th>
<th>Correlation with direct Subjective Norm</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalized individuals (those in need) would disapprove/approve of me donating biospecimens along with my PHI to a biobank</td>
<td>3.61</td>
<td>8.72</td>
<td>-0.099</td>
<td>0.34</td>
</tr>
<tr>
<td>Other African Americans would disapprove/approve of me donating biospecimens along with my PHI to a biobank</td>
<td>-0.86</td>
<td>6.65</td>
<td>0.130</td>
<td>0.21</td>
</tr>
<tr>
<td>My parents would disapprove/approve of me donating biospecimens along with my PHI to a biobank</td>
<td>-2.21</td>
<td>10.00</td>
<td>0.087</td>
<td>0.40</td>
</tr>
<tr>
<td>My peers would disapprove/approve of me donating biospecimens...... X</td>
<td>-0.05</td>
<td>6.41</td>
<td>-0.005</td>
<td>0.96</td>
</tr>
</tbody>
</table>

MTC4  What hospitalized individuals (those in need) think I should do matters to me
MTC5  What other African Americans think I should do matters to me
MTC6  What my parents think I should do matters to me
MTC7  What my peers think I should do matters to me
Table 4.7 cont

<table>
<thead>
<tr>
<th>Normative Beliefs (NB) and Motivation to Comply (MTC)</th>
<th>Mean</th>
<th>SD</th>
<th>Correlation with direct Subjective Norm</th>
<th>Correlation P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>NB8 My friends would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>-0.49</td>
<td>8.50</td>
<td>-0.088</td>
<td>0.40</td>
</tr>
<tr>
<td>MTC4 What my friends think I should do matters to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NB9 My grandparents would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>-2.21</td>
<td>9.87</td>
<td>0.134</td>
<td>0.20</td>
</tr>
<tr>
<td>MTC9 What my grandparents think I should do matters to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NB10 My coworkers would disapprove/approve of me donating biospecimens along with my PHI to a biobank X</td>
<td>-0.74</td>
<td>5.07</td>
<td>-0.026</td>
<td>0.80</td>
</tr>
<tr>
<td>MTC10 What my coworkers think I should do matters to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.8. Correlation Between Weighted Composite Beliefs and Direct Attitude

<table>
<thead>
<tr>
<th>Behavioral Beliefs (BB) and Outcome Evaluations (OE)</th>
<th>Mean</th>
<th>SD</th>
<th>Correlation with attitude</th>
<th>Correlation P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BB1       I am making medical treatment better X</td>
<td>4.49</td>
<td>3.52</td>
<td>0.63</td>
<td>0.00</td>
</tr>
<tr>
<td>BB2       I am helping researchers achieve scientific breakthroughs and medical advances X</td>
<td>4.72</td>
<td>3.75</td>
<td>0.41</td>
<td>0.00</td>
</tr>
<tr>
<td>BB3       I am increasing diversity in scientific data so as to make research results applicable to all populations X</td>
<td>5.18</td>
<td>3.76</td>
<td>0.56</td>
<td>0.00</td>
</tr>
<tr>
<td>OE1       Making medical treatment better is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OE2       Achieving scientific breakthroughs and medical advances are</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OE3       Increasing diversity in scientific data so as to make research results applicable to all populations is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.8. Correlation Between Weighted Composite Beliefs and Direct Attitude

<table>
<thead>
<tr>
<th>Behavioral Beliefs (BB) and Outcome Evaluations (OE)</th>
<th>Mean</th>
<th>SD</th>
<th>Correlation with attitude</th>
<th>Correlation P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BB4 I am helping to find cures for diseases X</td>
<td>5.31</td>
<td>3.58</td>
<td>0.58</td>
<td>0.00</td>
</tr>
<tr>
<td>OE4 Finding cures to diseases is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB5 I am adding more knowledge to science X</td>
<td>5.59</td>
<td>3.32</td>
<td>0.47</td>
<td>0.00</td>
</tr>
<tr>
<td>OE5 Adding more knowledge to science is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB6 I am helping to find the causes of diseases X</td>
<td>5.35</td>
<td>3.29</td>
<td>0.51</td>
<td>0.00</td>
</tr>
<tr>
<td>OE6 Finding causes of diseases is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB7 Will result in a breach of my personal health</td>
<td>-0.36</td>
<td>5.12</td>
<td>0.24</td>
<td>0.02</td>
</tr>
<tr>
<td>information X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OE Breaching my personal health information is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.8. Correlation Between Weighted Composite Beliefs and Direct Attitude

<table>
<thead>
<tr>
<th>Behavioral Beliefs (BB) and Outcome Evaluations (OE)</th>
<th>Mean (−9 to +9)</th>
<th>SD</th>
<th>Correlation with attitude</th>
<th>Correlation P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BB8 Will result in abuse or wrongful use of my personal health information X</td>
<td>1.88</td>
<td>4.92</td>
<td>0.33</td>
<td>0.00</td>
</tr>
<tr>
<td>OE8 Abusing or making wrongful use of my biospecimens and personal health information in a biobank is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB9 Untrustworthy researchers may have access to my personal health information X</td>
<td>-1.04</td>
<td>5.45</td>
<td>0.21</td>
<td>0.04</td>
</tr>
<tr>
<td>OE9 Allowing untrustworthy researchers to have access to my personal health information in a biobank is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral Beliefs (BB) and Outcome Evaluations (OE)</td>
<td>Mean ((-9 \text{ to } +9))</td>
<td>SD</td>
<td>Correlation with direct attitude</td>
<td>Correlation (P)-value</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-----------------</td>
<td>-----</td>
<td>-------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>BB10 Will result in my inability to retract my biospecimens along with PHI X</td>
<td>-0.06</td>
<td>4.36</td>
<td>0.27</td>
<td>0.01</td>
</tr>
<tr>
<td>OE10 Inability to retract my biospecimens and my PHI in biobank is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB11 Will result in exploitation of my PHI for profit X</td>
<td>0.18</td>
<td>4.90</td>
<td>0.28</td>
<td>0.01</td>
</tr>
<tr>
<td>OE11 Exploiting my biospecimens and PHI in biobanks for profit is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BB12 Will result in unpleasant findings of which researchers will notify me X</td>
<td>1.28</td>
<td>4.03</td>
<td>0.09</td>
<td>0.39</td>
</tr>
<tr>
<td>OE12 Getting back unpleasant findings from biobank to me is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.9. Mean of Individual Normative Beliefs

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(Range -3 to +3)</td>
</tr>
<tr>
<td>NB1</td>
<td>0.35</td>
<td>1.74</td>
</tr>
<tr>
<td>NB2</td>
<td>0.60</td>
<td>1.63</td>
</tr>
<tr>
<td>NB3</td>
<td>-0.06</td>
<td>1.70</td>
</tr>
<tr>
<td>NB4</td>
<td>0.86</td>
<td>1.74</td>
</tr>
<tr>
<td>NB5</td>
<td>-0.25</td>
<td>1.71</td>
</tr>
<tr>
<td>NB6</td>
<td>-0.39</td>
<td>1.67</td>
</tr>
<tr>
<td>NB7</td>
<td>-0.14</td>
<td>1.40</td>
</tr>
<tr>
<td>NB8</td>
<td>-0.12</td>
<td>1.62</td>
</tr>
<tr>
<td>NB9</td>
<td>-0.42</td>
<td>1.78</td>
</tr>
<tr>
<td>NB10</td>
<td>-0.47</td>
<td>1.62</td>
</tr>
</tbody>
</table>
Table 4.10. Mean of Individual Motivation to Comply

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (Range 1 to 7)</td>
<td>SD</td>
</tr>
<tr>
<td>MTC1</td>
<td>4.77</td>
<td>1.73</td>
</tr>
<tr>
<td>MTC2</td>
<td>3.97</td>
<td>1.85</td>
</tr>
<tr>
<td>MTC3</td>
<td>5.62</td>
<td>1.34</td>
</tr>
<tr>
<td>MTC4</td>
<td>4.16</td>
<td>1.64</td>
</tr>
<tr>
<td>MTC5</td>
<td>3.55</td>
<td>1.67</td>
</tr>
<tr>
<td>MTC6</td>
<td>5.71</td>
<td>1.51</td>
</tr>
<tr>
<td>MTC7</td>
<td>3.49</td>
<td>1.77</td>
</tr>
<tr>
<td>MTC8</td>
<td>4.41</td>
<td>1.54</td>
</tr>
<tr>
<td>MTC9</td>
<td>5.25</td>
<td>1.70</td>
</tr>
<tr>
<td>MTC10</td>
<td>2.53</td>
<td>1.64</td>
</tr>
<tr>
<td>Variable</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>-----</td>
</tr>
<tr>
<td>BB1</td>
<td>1.58</td>
<td>1.33</td>
</tr>
<tr>
<td>BB2</td>
<td>1.74</td>
<td>1.30</td>
</tr>
<tr>
<td>BB3</td>
<td>1.96</td>
<td>1.31</td>
</tr>
<tr>
<td>BB4</td>
<td>1.81</td>
<td>1.18</td>
</tr>
<tr>
<td>BB5</td>
<td>2.12</td>
<td>1.15</td>
</tr>
<tr>
<td>BB6</td>
<td>1.80</td>
<td>1.24</td>
</tr>
<tr>
<td>BB7</td>
<td>0.66</td>
<td>1.70</td>
</tr>
<tr>
<td>BB8</td>
<td>-0.16</td>
<td>1.84</td>
</tr>
<tr>
<td>BB9</td>
<td>0.61</td>
<td>1.89</td>
</tr>
<tr>
<td>BB10</td>
<td>0.14</td>
<td>1.68</td>
</tr>
<tr>
<td>BB11</td>
<td>0.09</td>
<td>1.80</td>
</tr>
<tr>
<td>BB12</td>
<td>0.28</td>
<td>1.64</td>
</tr>
</tbody>
</table>
Table 4.12. Mean of Individual Outcome Evaluation

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Range -3 to +3)</td>
<td></td>
</tr>
<tr>
<td>OE1</td>
<td>2.31</td>
<td>1.10</td>
</tr>
<tr>
<td>OE2</td>
<td>2.17</td>
<td>1.29</td>
</tr>
<tr>
<td>OE3</td>
<td>2.11</td>
<td>1.18</td>
</tr>
<tr>
<td>OE4</td>
<td>2.73</td>
<td>0.79</td>
</tr>
<tr>
<td>OE5</td>
<td>2.28</td>
<td>1.14</td>
</tr>
<tr>
<td>OE6</td>
<td>2.60</td>
<td>0.88</td>
</tr>
<tr>
<td>OE7</td>
<td>-1.91</td>
<td>1.96</td>
</tr>
<tr>
<td>OE8</td>
<td>-1.99</td>
<td>1.87</td>
</tr>
<tr>
<td>OE9</td>
<td>-1.96</td>
<td>1.76</td>
</tr>
<tr>
<td>OE10</td>
<td>-1.70</td>
<td>1.53</td>
</tr>
<tr>
<td>OE11</td>
<td>-1.61</td>
<td>1.78</td>
</tr>
<tr>
<td>OE12</td>
<td>-0.75</td>
<td>2.09</td>
</tr>
</tbody>
</table>

Regression Models

Three multiple linear regression models were built to answer research AIM2. First, in model I, two explanatory variables of the TRA (Direct Attitude and Direct Subjective Norm) were regressed on the outcome variable (Behavioral Intention) (See Figure 2.1) to determine the construct of TRA that was most significantly associated with behavioral intention. In the model I, the independent variables were direct attitude and direct subjective norm while the dependent variable was the behavioral intention. The results of the model I were displayed in Table 4.13. It
showed that only direct attitude had a significant association with behavioral intention, with a $P$-value <.0001. This suggests that attitude was the single most significant construct that determined behavioral intention in this study. In addition, the parameter estimate of direct attitude (0.68) signifies that as attitude increases, behavioral intention also increases.

Model I: Behavioral Intention = Direct Attitude + Direct Subjective Norms

Table 4.13. Multiple Linear Regression Analysis for Variables Predicting Behavioral Intention

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>$P$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-3.7185</td>
<td>2.13705</td>
<td>0.0852</td>
</tr>
<tr>
<td>Direct Attitude</td>
<td>0.68401</td>
<td>0.0833</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Direct S norm</td>
<td>0.12685</td>
<td>0.1391</td>
<td>0.3641</td>
</tr>
</tbody>
</table>

Model II regressed the twelve weighted composite behavioral beliefs (Behavioral Belief X Outcome Evaluation) on direct attitude to determine which of the specific behavioral beliefs had a significant impact in determining the attitude of participants in this study. The dependent variable in model II was the direct attitude while the independent variables were the twelve weighted composite beliefs ((Behavioral Belief1 X Outcome Evaluation1) + (Behavioral Belief2 X Outcome Evaluation3) ........... (Behavioral Belief12 X Outcome Evaluation12)).

Therefore, to build model II, let Belief 1 = Behavioral Belief1 X Outcome Evaluation1, Belief 2 = Behavioral Belief2 X Outcome Evaluation2 ........... to Belief 12 = Behavioral Belief12 X Outcome Evaluation12.
Model II: Direct Attitude = Belief 1 + Belief 2 + Belief 3 + Belief 4 …… +Belief 12.

The results from model II were displayed in Table 4.14. It showed that two beliefs, Belief 1 (P-value <.0001) and Belief 4 (P-value <.0004), were significantly associated with direct attitude. Belief 1 is that donating biospecimens along with PHI to biobanks will help in making medical treatment better while belief 4 is that donating biospecimens along with PHI to biobanks will help in finding cures to diseases. This suggests that these two beliefs were the most important specific behavioral beliefs that determined the attitude of participants in this study.
### Table 4.14. Multiple Linear Regression Analysis for Variables Predicting Direct Attitude

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter</th>
<th>Standard Error</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>14.6542</td>
<td>0.73945</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>belief1 (BO1)</td>
<td>0.5903</td>
<td>0.14727</td>
<td>0.0001</td>
</tr>
<tr>
<td>belief2 (BO2)</td>
<td>-0.178</td>
<td>0.14292</td>
<td>0.2168</td>
</tr>
<tr>
<td>belief3 (BO3)</td>
<td>0.1857</td>
<td>0.15375</td>
<td>0.2306</td>
</tr>
<tr>
<td>belief4 (BO4)</td>
<td>0.5227</td>
<td>0.14312</td>
<td>0.0004</td>
</tr>
<tr>
<td>belief5 (BO5)</td>
<td>0.0629</td>
<td>0.20167</td>
<td>0.7561</td>
</tr>
<tr>
<td>belief6 (BO6)</td>
<td>-0.219</td>
<td>0.23389</td>
<td>0.3517</td>
</tr>
<tr>
<td>belief7 (BO7)</td>
<td>0.0678</td>
<td>0.08726</td>
<td>0.4393</td>
</tr>
<tr>
<td>belief8 (BO8)</td>
<td>0.0166</td>
<td>0.12134</td>
<td>0.8916</td>
</tr>
<tr>
<td>belief9 (BO9)</td>
<td>0.0554</td>
<td>0.08743</td>
<td>0.5283</td>
</tr>
<tr>
<td>belief10 (BO10)</td>
<td>0.0942</td>
<td>0.09266</td>
<td>0.3121</td>
</tr>
<tr>
<td>belief11 (BO11)</td>
<td>0.017</td>
<td>0.10358</td>
<td>0.8702</td>
</tr>
<tr>
<td>belief12 (BO12)</td>
<td>-0.034</td>
<td>0.10027</td>
<td>0.7385</td>
</tr>
</tbody>
</table>

Note: B = Behavioral Belief    O = Corresponding Outcome evaluation

Model III regressed the ten weighted composite normative beliefs (Normative Belief X Motivation to Comply) on direct subjective Norm to determine the specific normative beliefs or referents that had a significant impact in determining the subjective norms of participants in this study. The dependent variable in model III was the direct subjective norm while the independent variables were the ten weighted composite normative beliefs ((Normative Belief X Motivation
to Comply1) + (Normative Belief2 X Motivation to Comply2) + (Normative Belief3 X
Motivation to Comply3) ……. + (Normative Belief10 X Motivation to Comply10)).

Therefore, to build model III, let $S_{norm}^1 = \text{Normative Belief}_1 \times \text{Motivation to Comply}_1$, $S_{norm}^2 = \text{Normative Belief}_2 \times \text{Motivation to Comply}_2$ …….. to $S_{norm}^{10} = \text{Normative Belief}_{10} \times \text{Motivation to Comply}_{10}$. 

Model III: Direct subjective norm = $S_{norm}^1 + S_{norm}^2 + S_{norm}^3 + \ldots + S_{norm}^{10}$.

The results from model III were displayed in Table 4.15. It showed that none of the independent variables had a statistically significant association with direct subjective norm. Their $P$-value was each greater than .05. It means that normative beliefs or referents measured most likely had no impact in determining the subjective norms of participants in this study. This result was similar to what we got in correlation analysis, where none of the composite normative beliefs showed statistically significant correlation with direct subjective norms. Similarly, the mean scores of beliefs of participants in normative referents in this study had shown that the participants did not believe that anybody or group can tell them what do concerning donating biospecimens along with PHI to biobanks. The mean scores of responses for what participants believe important individuals or groups (normative referents) think about donating to biobanks, were all close to the neutral point of "0" (Range -3 to +3, see Table 4.9). This lack of belief in normative referents may explain why regressing composite normative beliefs on direct subjective norms was not yielding any statistically significant results.
Table 4.15. Multiple Linear Regression Analysis for Variables Predicting Subjective Norms

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter</th>
<th>Standard Error</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>9.12776</td>
<td>0.32782</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>snorm1 (NB1 X MTC1)</td>
<td>0.0194</td>
<td>0.03934</td>
<td>0.6226</td>
</tr>
<tr>
<td>snorm2 (NB2 X MTC2)</td>
<td>0.0157</td>
<td>0.05014</td>
<td>0.7555</td>
</tr>
<tr>
<td>snorm3 (NB3 X MTC3)</td>
<td>-0.061</td>
<td>0.03958</td>
<td>0.1248</td>
</tr>
<tr>
<td>snorm4 (NB4 X MTC4)</td>
<td>-0.022</td>
<td>0.03867</td>
<td>0.5687</td>
</tr>
<tr>
<td>snorm5 (NB5 X MTC5)</td>
<td>0.0553</td>
<td>0.05826</td>
<td>0.3454</td>
</tr>
<tr>
<td>snorm6 (NB6 X MTC6)</td>
<td>0.0461</td>
<td>0.04694</td>
<td>0.3284</td>
</tr>
<tr>
<td>snorm7 (NB7 X MTC7)</td>
<td>-0.017</td>
<td>0.07718</td>
<td>0.8306</td>
</tr>
<tr>
<td>snorm8 (NB8 X MTC8)</td>
<td>-0.067</td>
<td>0.06283</td>
<td>0.2925</td>
</tr>
<tr>
<td>snorm9 (NB9 X MTC9)</td>
<td>0.0477</td>
<td>0.03816</td>
<td>0.215</td>
</tr>
<tr>
<td>snorm10 (N10 X MTC10)</td>
<td>0.018</td>
<td>0.07256</td>
<td>0.8049</td>
</tr>
</tbody>
</table>

Note: NB = Normative belief or referent. MTC = Motivation to comply.

Analyses to Test Study Hypotheses

Four different correlation analyses were conducted to test the study hypotheses (Table 4.16). The results showed that there was a statistically significant positive correlation between direct attitude and behavioral intention (Research hypothesis 1), and a statistically significant positive correlation between indirect attitude and direct attitude (Research hypothesis 3). Hence, research hypotheses 1 and 3 were accepted. There was no statistically significant positive correlation between direct subjective norm and behavioral intention (Research hypothesis 2) and between direct subjective norms and indirect subjective norms (Research hypothesis 4). Hence,
research hypotheses 2 and 4 were rejected. Hence, acceptance of hypothesis 1 suggests that attitude was the single most important construct that determined intention to participate in biobanking in this study, and as the value of attitude increased, the value of behavioral intention also increased. Similarly, acceptance of hypothesis 3 suggests that the behavioral beliefs investigated in this study actually determined the attitude of the participants. In addition, the stronger a participant held a behavioral belief, the greater was the impact on the attitude. Hypotheses 2 and 4 could not be proved probably because of the results which showed that participants did not believe in normative referents in this study. Hence, the subjective norm was irrelevant in the current behavior under investigation. The study hypotheses were:

1. There will be a positive relationship between measures of attitudes toward participation in biobanking and behavioral intention.
2. There will be a positive relationship between measures of subjective norm regarding participation in biobanking, and behavioral intention.
3. Indirect measures of attitudes (behavioral beliefs x outcome evaluations) toward participation in biobanking will be positively related to direct measures of attitudes toward the behavior.
4. Indirect measures of the subjective norm (normative beliefs x motivation to comply) for participation in biobanking, will be positively related to direct measures of subjective norm regarding the behavior.
Table 4.16. Correlation Among the TRA Constructs to Test Study Hypotheses

<table>
<thead>
<tr>
<th>Variable</th>
<th>Behavioral Intention</th>
<th>Direct Attitude</th>
<th>Indirect Attitude</th>
<th>Direct Subjective Norm</th>
<th>Indirect Subjective Norm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Intention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct</td>
<td>0.65*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude</td>
<td></td>
<td>0.56*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect</td>
<td></td>
<td></td>
<td>0.56*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct</td>
<td>0.024</td>
<td></td>
<td></td>
<td>0.024</td>
<td></td>
</tr>
<tr>
<td>Subjective Norm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect</td>
<td></td>
<td></td>
<td></td>
<td>0.038</td>
<td></td>
</tr>
<tr>
<td>Subjective Norm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Significant positive correlation values (p < 0.05)
CHAPTER 5

DISCUSSION

The purpose of this research was two-fold. The first was to identify factors that influence the intention to participate in biobanking among AA college students. Secondly, to examine the applicability of the TRA as a model to explain intentions to participate in biobanking. This purpose was achieved by using the Theory of Reasoned Action (TRA) as the theoretical lens through which the influence of these factors on intention could be understood (Ajzen & Fishbein, 1980). When utilizing the TRA as a theoretical framework, the first step is to identify the salient behavioral and normative beliefs of the priority population for the behavior being investigated. Steps specified by experts on the TRA in a manual for measurement of the TRA constructs guided the efforts to identify these specific beliefs (Francis et al, 2004). The second step is to use these identified beliefs to measure the TRA constructs. The first and second steps were conducted as phase one and phase two of this dissertation, respectively.

Discussion-Study Phase I Discussion: Following the steps prescribed by Francis et al (2004), a total of seventeen behavioral beliefs (8 advantages and 9 disadvantages) and twenty normative beliefs were identified. The behavioral beliefs were classified into advantages (total of 8) and disadvantages (total of 9) of donating biospecimens along with PHI to biobanks (see tables 4.1 and 4.2). Following the data reduction process that required a review of these beliefs by the dissertation committee and subsequent selecting of 75% of the most frequently mentioned advantages and disadvantages, the behavioral beliefs were reduced to 12 most frequently mentioned relevant beliefs. This 75% of the most frequently mentioned beliefs were selected after the committee members met and agreed on which beliefs were relevant to the study. Some themes were deleted as non-relevant. There was a total of six advantages and six disadvantages.
The six behavioral belief advantages mentioned by participants in this study phase one were as follows; participants felt that if they donate biospecimens along with their PHI to biobanks they were making medical treatment better, helping researchers achieve scientific breakthroughs and medical advances, increasing diversity in scientific data so as to make research results applicable to all populations, helping to find cures for diseases, adding more knowledge to science, and helping to find causes of diseases. These were included in the second phase survey instrument (see Appendix II). Streicher et al (2011), previously reported in the literature that altruism, personal benefits, and collective health benefits were major motivating beliefs that facilitates AA participation in biobanking.

On the other hand, the following six behavioral disadvantages were mentioned in this study. Participants felt that it was disadvantageous to donate biospecimens along with PHI to biobanks because it would result in a breach of their PHI, abuse or wrongful use of their PHI, untrustworthy researchers having access to their PHI, their inability to retract their biospecimens along with PHI from biobanks, exploitation of their PHI for profit, and unpleasant findings of which researchers would notify them. These were included in the second phase survey instrument (see Appendix II). These findings agreed with what previous researchers had reported in the literature as inhibiting factors to participation in biobanking among AA. Previous researchers identified skepticism, fear, medical mistrust, concerns regarding exploitation by medical researchers, discrimination, confidentiality, and inequities between those benefiting from the research and those participating in research as factors constituting barriers to AA participation in biobanking studies (Buseh et al., 2013, Erwin et al., 2013; Gabriel et al., 2014; Hagiwara et al., 2014; Scott et al., 2010).
The normative beliefs (normative referents) identified in phase I of the study were also classified as those that would approve and those that would disapprove donating biospecimens along with PHI to biobanks. There was a total of twelve normative referents mentioned that would approve of donating to biobanks and eight normative referents that would disapprove of it (see tables 4.3 and 4.4). Following the data reduction process that required a review of the referents by the dissertation committee and subsequent selecting of the 75% of the most frequently mentioned normative referents approving and disapproving donation to biobanks, the normative referents were reduced to 10 most frequently mentioned relevant referents. This 75% of the most frequently mentioned referents were selected after the committee members met and agreed on which referents were relevant to the study. Some themes were deleted as non-relevant. Two of the normative referents were mentioned as capable of both approving and disapproving donating biospecimens along with PHI to biobanks. The two normative referents were my family and my parents. Three of the normative referents were identified to be capable of only disapproving donating to biobanks. The three were grandparents, my friends, and coworkers. Five normative referents were identified as capable of only approving donating biospecimens along with PHI to biobanks. The five were health professionals, academic researchers, hospitalized individuals, other AAs, and my peers. These ten normative referents were included in the second phase survey instrument (see Appendix II).

**Inter-coder agreement**: During the coding process of the themes that yielded the above-mentioned behavioral beliefs and normative referents, the inter-coder agreement analysis revealed that the two coders agreed 100% in the interpretation of normative beliefs and behavioral beliefs expressed by participants in 24 out of the 27 transcripts coded. This high level
of the agreement shows that the participants clearly identified their behavioral beliefs and normative referents in an understandable manner free of ambiguity.

The three transcripts the coders differed, and on which they could not reconcile their differences were transcripts 1, 5 and 23. Hence, the inter-coder correlation result for transcript 1 was 85.71%, transcript 5 was 90.91% and transcript 20 was 80.00%. In transcript 1, while the first coder identified “academic researchers” as a normative referent that approved donating biospecimens to biobanks, the second coder did not see any role at all for academic researchers. In transcript 23, the two coders differed on whether hospitalized individuals (in two places), coworker (in one place) and health professional (in one place) would approve or disapprove donating biospecimens to biobanks. In transcript 5, the two coders could not agree that mistrust of researchers was expressed as a disadvantage from the transcript.

Conclusion-Phase I

Utilizing the guidelines provided by Francis et al (2004), theory-based measures to identify motivational factors for donating biospecimens along PHI to biobanks among AA college students were developed, effectively answering the study Aim 1. Dissertation committee rating of the clarity and relevance of items identified were favorable and inter-coder correlational results showed a high level of agreement between the two coders. In addition, motivational and inhibiting factors identified agreed with what have been reported previously in the literature. In phase two of this dissertation, the researchers developed a survey instrument with these behavioral beliefs and normative referents, pilot-tested it, and used it to measure the constructs of the TRA to determine which constructs, behavioral beliefs and normative referents had a statistically significant influence on the intention to participate in biobanking among AA college
students. In addition, the applicability of the TRA as a model to explain intentions to participate in biobanking was also examined.

**Discussion-Phase II Discussion:** The primary purpose of study phase two was to examine the applicability of the TRA as a model to explain intentions to participate in biobanking and to identify the construct of TRA that significantly influenced intention to participate in biobanking. It also provided an opportunity to identify the specific behavioral beliefs and normative referents that significantly acted as motivational factors to increase participation in biobanking among AA college students. These findings helped us to answer study Aim 2. Correlation analysis among the constructs of the TRA led to the acceptance of hypotheses 1 and 3 while hypotheses 2 and 4 were rejected. These correlation analysis findings proved that TRA was a good model to explain intentions to participate in biobanking.

The TRA is made up of eight constructs (See figure 1.1). However, in this study, the researchers excluded behavior and measured behavioral intention as the proximal outcome of behavior. According to Montaño and Kasprzyk (2008), the TRA asserts that behavioral intention is the most important determinant of a behavior. Hence, seven of the eight constructs of TRA were measured, excluding the behavior. The seven constructs were the behavioral intention, attitude, subjective norms, behavioral beliefs, outcome evaluation, normative beliefs and motivation to comply. Furthermore, the actual behavior was not measured because biobanking is a relatively new phenomenon in the US of which many members of the population have little to no knowledge about. This was confirmed in our current study where an overwhelming majority of participants admitted that they knew "nothing at all" of biobanking (82.69%) and had never donated before to biobanks (97.12%). Previously, Henderson et al., 2013, reported that over 58% of biobanks operating currently in the US were formed after the completion of the human
genomic project in 2001. In addition, the 2015-US national precision medicine initiative on biobanking is yet to kick off as the modalities are still being worked out. Hence, biobanking institutions in the US are currently few, thereby making the availability of donation sites to be scarce. The implication is that members of the society may not have had enough reasonable experiences to share about the ease or difficulty of performing the behavior. This also makes the constructs of perceived behavioral control not very relevant in this study.

The researchers also believed that, although there are physical and logistic barriers such as lack of sites for donation and transport difficulties to donation sites, such barriers can only inhibit volunteers from performing the actual behavior. The barriers would not prevent someone from having an intention to donate biospecimens to biobanks. Intention is a voluntary and free-will act that exists only in the mind and would not be hampered by physical barriers. Hence, the barriers would only be relevant to volunteers when they want to transition from intention to actual performance of the behavior. The current study, therefore, chose attitude and subjective norms as the relevant constructs in predicting behavioral intention in this behavior under investigation.

**Behavioral Intention:** Three items were used to measure general behavioral intention (scored 1 to 7). Therefore, the range of the total score of behavioral intention was between 3 to 21. The overall mean score of behavioral intention among the participants was 10.69 (See table 4.6). This suggests that the participants were generally undecided about donating biospecimens along with PHI to biobanks. However, individually, a slight majority (58.10%) of the participants have no intention to donate biospecimens along with their PHI to biobanks over their lifetimes (Table 4.5). A total of 27.62% had the intention to donate biospecimens along with PHI to biobanks over their lifetimes while 14.29% were neutral or undecided. There is a paucity of
literature that used all the constructs of TRA to predict the intention to donate biospecimens to biobanks. However, McDonald & colleagues (2014) had previously used all the constructs of the TRA and the TPB to predict the intention to donate biospecimens to biobanks in a national sample of 1033 AA. Unlike the current study, McDonald et al (2014) did not conduct an elicitation study, but found in their study that among the 1033 AA who participated in the study, 33% were not at all likely, 18% were a little likely, 36% were somewhat likely, and 23% were very likely to donate biospecimens to biobanks.

**Attitude:** Attitude was measured directly and indirectly. Direct attitude was measured with four items, scored 1 to 7 each. The mean of direct attitude was 19.23, with a possible range of scores of 4 to 28. This result means that the attitude of the participants was positive towards donating biospecimens along with PHI to biobanks. Indirect measurement of attitude was conducted using 24 items (12 behavioral beliefs and 12 corresponding outcome evaluations). The possible range of scores for indirect attitude from the 12 composite beliefs (Behavioral belief (score -3 to +3) X Outcome evaluation (scored -3 to +3)) is equal to (+3 X +3) X 12 = (-9 to +9) X 12 = -108 to +108 (Francis et al, 20014). The mean of the indirect attitude score was 31.76 which again suggests that the participants' attitude towards participating in biobank was positive (See table 4.6). We regressed attitude and subjective norm on behavioral intention. The multiple linear regression analysis showed that attitude was significantly associated with behavioral intention ($P$-value <.0001, Parameter estimate = 0.68). Association with subjective norms was not significant. Hence, attitude was the single most important construct that determined the behavioral intention of participants in this study. The parameter estimates also indicated that as attitude increased in value, the behavioral intention value also increased. In a cross-sectional study, Treweek, Doney, & Leiman (2009) had previously studied attitude toward
donating left-over blood samples from clinical practice to biobanks among 2471 patients in two
general practice lists. A total of 34.03% of respondents (841) had an unequivocal positive
attitude toward donating and storing of left-over blood samples to biobanks. However, the partial
use of the constructs of the TRA in their study makes it difficult to validate the results of the
study as recommended by the developers of the TRA. When we regressed the twelve composite
behavioral beliefs on direct attitude, the multiple linear regression analysis also showed that two
specific behavioral beliefs had a statistically significant association with direct attitude. The
results from table 4.14 showed that Belief 1 (P-value < .0001, Parameter estimate = 0.59) and
Belief 4 (P-value < .0004, Parameter estimate = 0.52) were both significantly associated with
direct attitude. Belief 1 is “making medical treatment better”. Belief 4 is “finding cures for
diseases”. Hence, these two beliefs had the strongest impact in determining the attitude of
participants in this study. In addition, the parameter estimates indicated that the stronger the
value a participant placed on these two beliefs, the greater would be the value of the participant's
positive attitude towards participation in biobanking.

**Subjective norms:** Subjective norm was measured directly and indirectly. Direct
subjective norm was measured with three-item score 1 to 7 each. The mean score of the direct
subjective norm was 8.92 with a possible range of scores of 3 to 21. Generally, this suggests that
normative referents identified among these participants did not influence their intention to
participate in biobanking. This was because the mean score of “8.92” was very close to the
neutral point of “9” (Range 3 to 21). Indirect measure of subjective norms was conducted with
20 items (10 Normative beliefs and 10 corresponding motivations to comply). The possible range
score for indirect subjective norm from the 10 composite normative beliefs (Normative belief
(score -3 to +3) X Motivation to comply (scored 1 to 7)) is equal to (+3 x 7) X 10 = -210 to 210
(Francis et al, 2004). The mean score of the indirect subjective norm was 0.06 (See table 4.6). Again, this suggests that normative referents identified in these participants did not influence their intention to participate in biobanking as the mean score of “0.06” is close to the neutral point of “0” (Range -210 to +210). We conducted a correlation between composite normative beliefs and direct subjective norms. The results of the correlation showed that none of the composite normative beliefs had a statistically significant correlation with direct subjective norms (See Table 4.7). In addition, when normative referents identified in the study were regressed on direct subject norms, none had a statistically significant association with direct subjective norms (All $P$-value >.05, Table 4.15). Following this result, the researchers calculated the individual mean for each of the normative beliefs and each of the motivations to comply. The results of the mean scores showed that participants did not believe that the normative referents in this study had any opinion in approving or disapproving donating biospecimens along with PHI to biobanks as the mean for each of the normative beliefs were close to the neutral point of “0” (Range -3 to +3). (See Tables 4.9 and 4.10). This may explain why composite normative beliefs were not significantly correlating with subjective norms in this study. Similarly, it may also explain why no composite normative referents showed statistically significant association with the direct subjective norm in regression analysis.

Four hypotheses derived from the TRA were tested to determine the relationships between the constructs of TRA. The four hypotheses were:

1. There will be a positive relationship between measures of attitudes toward participation in biobanking and behavioral intention.

2. There will be a positive relationship between measures of subjective norm regarding participation in biobanking, and behavioral intention.
3. Indirect measures of attitudes (behavioral beliefs x outcome evaluations) toward participation in biobanking will be positively related to direct measures of attitudes toward the behavior.

4. Indirect measures of the subjective norm (normative beliefs x motivation to comply) for participation in biobanking, will be positively related to direct measures of subjective norm regarding the behavior.

Hypotheses 1 and 3 were supported (See table 4.16). The correlation (Value = 0.65) between direct attitude and behavioral intention ($P$-value < .0001), and correlation (Value = 0.56) between indirect attitude and direct attitude ($P$-value < .0001) were both statistically significant as were shown by the $P$-values. According to Ajzen and Fishbein (1980), there must be a correlation of at least 0.36. This implies that the behavioral beliefs used in the indirect measurements of attitude accurately predicted attitude and those behavioral beliefs formed the formative factors that determined whatever attitude the participants in this study had. Hypotheses 2 and 4 were not supported. The correlation (Value = 0.024) between direct subjective norms and behavioral intention (Hypothesis 2) was not statistically significant ($P$-value, 0.82). Similarly, the correlation (Value = 0.038) between indirect subjective norms and direct subjective norms (Hypothesis 4) was not statistically significant ($P$-value, 0.72). The implication of rejecting hypotheses 2 and 4 was that, in this study, normative referents identified likely had no impact in determining the subjective norms of the participants and the subjective norm of the participants most likely did not influence their intentions to participate in biobanking. Rejection of hypotheses 2 and 4 calls for additional research to possibly redefine the relationship between subjective norms and behavioral intention. It may also be that the construct of subjective norms is not relevant in certain behavior. The age and educational level of our participants may also
explain why subjective norm appeared irrelevant in this study. The participants were mostly young college adults, a group that typically show a high level of independence.

There were three multiple linear regression models built in this research. The first multiple linear regression was conducted to determine which TRA construct that was most significantly associated with behavioral intention. Results from Table 4.13 shows that only direct attitude was significantly associated with behavioral intention ($P$-value = <0.0001). This implies that attitude was the greatest determinant of behavioral intention in this study. Association with direct subjective norm was not significant. Although there was a lack of literature on studies that have used both elicitation study and phase two while using the TRA as a theoretical framework, Doane, Pearson, & Kelley, (2014) had previously used TRA to explain cyberbullying behavior among 375 college students. Results from the study showed that those with a favorable attitude toward cyberbullying had a higher predicted intention to cyberbully. Unlike in the current dissertation study, subjective norms predicted intention to perpetrate different forms of cyberbullying such as malice and unwanted contact behaviors in the study. Similarly, Thrasher, Andrew, & Mahony (2007), in their study used TRA to investigate and explain gambling among 345 college students. Results from the study showed that attitudes toward gambling and subjective norm toward gambling predicted gambling intentions. The reason for the lack of predictive value of subjective norm in the current study may be because of a lot of possible factors. This could be because of our participants who are college educated and young or probably because of differences in research design. The current dissertation study utilized an elicitation study to identify behavioral beliefs and normative referents to be used in predicting intention, unlike these previous studies.
The second multiple linear regression analysis was conducted to determine which composite behavioral belief (behavioral belief X outcome evaluation) most significantly associated with direct attitude. The results from table 4.14 showed that both Belief 1 (P-value <.0001) and Belief 4 (P-value <.0004) had a statistically significant association with direct attitude. Belief 1 is “making medical treatment better”. Belief 4 is “finding cures for diseases”. This suggests that participants’ positive attitudes towards participation in biobanking in this research were as a result of their belief that it will improve medical treatment provided to the general population. Similarly, it also suggests that participants’ positive attitude arose from their desire to help in finding cures for diseases. These findings agree with previous literature. Streicher et al. (2011) had previously reported that factors that facilitate participation in biobanking among AA included altruism, personal benefits, and collective health benefits. Hence, social marketing campaigns and other advertisements aimed at increasing the recruitment of this population into participation in biobanking should focus on the message of improving health care and finding cures for diseases. However, it is also possible that poor knowledge of biobanking among this population may have contributed to the fewer number of composite behavioral beliefs that had a statistically significant association with direct attitude. An overwhelming majority of the participants in this study (82.69%) said that they knew “nothing at all” about biobanking.

A third multiple linear regression model was conducted to determine which composite normative beliefs (normative belief X motivation to comply) most significantly associated with direct subjective norms. Table 4.15 shows that none of the normative beliefs had a statistically significant association with the direct subjective norm as indicated by their P-values which were each greater than 0.05.
Researchers conducted additional analysis to determine why hypotheses 2 and 4 were not supported and why none of the composite normative beliefs showed significant association with the direct subjective norm. The mean scores of the individual normative beliefs and motivation to comply were calculated. The results of the calculated means are shown in Table 9 and 10. The mean values for the ten normative beliefs fell between -0.47 to 0.86 which is close to the neutral point of “0” (score range = disapprove… -3 to +3 …. approve). This implies that generally, the participants did not believe that the normative referents have any opinion with regards to approving or disapproving donation to biobanks. The mean values for the corresponding ten motivations to comply fell between 2.53 to 5.71 (score range = not all….1 to 7…. very much) with a majority of the mean scores (60%) falling above the value of 4 (midpoint or neutral point). This implies that even though participants did not believe in the existence of normative referents' opinions or pressure, where such opinion exist, participants were likely to comply with it. The lack of belief, among participants on the existence of opinion, and therefore pressure, from the normative referents about whether to donate or not to donate biospecimens along with PHI to biobanks may explain why there was a low correspondence between subjective norm and behavioral intention.

Limitations

A major limitation to our study was the study design. The study design excluded the rest of the members of the AA community in Statesboro, using a convenient sample of AA college students. This poses generalizability challenges to the findings. In addition, the use of open-ended questionnaires instead of a focus group or face-to-face interview likely limited our ability to elicit additional behavioral beliefs and normative referents from participants during phase I of the study. In our study, the time frame for behavioral intention under the TACT principle of the
TRA was designated as “over one’s lifetime”. We acknowledge that such a long timeframe may not be most suitable to accurately predict sustainable or actionable behavioral intention that can be translated into the actual behavior.

**Conclusions**

This study generated a lot of results from which many conclusions were drawn by the researchers. The results revealed that behavioral beliefs were very relevant in determining the attitude of participants in this study. Out of a total of six behavioral belief advantages and a total of six behavioral beliefs disadvantages of donating to biobanks elicited in the study phase I, all but one had a statistically significant correlation with attitude during analysis in study phase II. Two of the beliefs had a statistically significant association with attitude in multiple regression. The twelve behavioral beliefs were:

1. Behavioral belief advantages were: (All had a statistically significant correlation with attitude)
   a. Making medical treatment better
   b. Helping researchers achieve scientific breakthroughs and medical advances
   c. Increasing diversity in scientific data to make research results applicable to all populations
   d. Helping to find cures for diseases
   e. Adding more knowledge to science
   f. Helping to find causes of disease.

2. The behavioral belief disadvantages were: (All except number “f” had a statistically significant correlation with attitude).
   a. Breaching of their PHI
b. Abuse or wrongful use of their PHI

c. Untrustworthy researchers having access to their PHI

d. Inability to retract their biospecimens along with PHI from biobanks

e. Exploitation of their PHI for profit

f. Unpleasant findings of which researchers would notify them

Overall, multiple linear regression analysis in phase II showed that two behavioral beliefs most significantly determined the attitude of participants in this study. These beliefs are: (1) Making medical treatment better and, (2) helping to find cures for diseases.

None of the ten elicited normative referents that can approve or disapprove donating biospecimens along with PHI to biobanks showed statistically significant influence in determining the subjective norms of the participants in this study. Therefore, the subjective norm was most likely no as relevant in investigating participation in biobanking as it would be in other behaviors.

The construct of TRA that most significantly determined the behavioral intention of participants in this study was the attitude. Multiple linear regression showed that attitude only had a statistically significant association with behavioral intention. Subjective norms had no statistically significant association with behavioral intention.

Correlation analysis among the seven constructs of the TRA led to the acceptance of research hypotheses 1 and 3. Research hypotheses 2 and 4 were rejected. Hence, TRA was a good model theory to explain the intention to participate in biobanking.
Next Steps, Future Research, and Personal challenges

Primarily, efforts would be made to share the findings of this research to the scientific community by publishing it in public health Journals and presenting it at American Public Health Association Annual Meeting and other relevant scientific conferences. This research also calls for additional studies to re-investigate and revalidate the association between subjective norms and behavioral intention to perform certain behaviors.

Giving the growing population of African immigrants in the United States and bearing in mind that African immigrants have homogenous experience and similar strong cultural beliefs, I would want to replicate this study among the population. There is also a possibility to expand the current study to include the perceived behavioral construct of the Theory of Planned Behavior.

Conducting this research enriched me personally from the challenges encountered. Research of this nature in which much was dependent on the responses and efforts of others requires that deadlines should be designated at least a month before the actual deadlines. There is also a need to continuously keep progress reports and document activities/methods that one is undertaking at every stage during the research. It is easy to forget what you have done. Just like most previous reports have stated, face to face administration of surveys yields the most response rate in survey administration. In the current research, most of the completed surveys were from those administered face to face with participants. We sent out severally emails to participants who agreed to participate and provided their email address, however, response rate rarely increase following such emails. A noticeable increase in response rate was only found during those periods that surveys were administered face to face to interested participants.
Implications for Public Health

The implication of this study for the scientific community is that there is a need to increase efforts to improve the recruitment of AA into biobanking studies. Results from the current study suggest that health promotional interventions to increase participation in biobanking especially among AA college students should focus on the attitude towards participation in biobanking. Analysis of the behavioral beliefs that determined the attitude of the participants suggests that the health promotion messages to increase participation in biobanking should target strengthening the beliefs that participation in biobanking will help improve medical treatment and find cures for diseases.

In addition, all normative referents elicited in this study did not have any statistically significant impact in determining the subjective norms of participants. Similarly, subjective norms did not show any statistically significant association in influencing the behavioral intention of participants in this study. Hence, subjective norms or social norms may not be as relevant for biobanking as they are for other behaviors. It could also be that additional research is needed to reexamine the relationship between subjective norms and behavioral intention.

Finally, proactively bringing biobanking information to young AA college students through health education might be helpful in improving participation in biobanking. A greater majority (86%) of participants in this study admitted that they knew “nothing at all” about biobanking. An increased biobanking health education among this population might improve their understanding of the importance of participation in biobanking research.


Banks, E., Herbert, N., Mather, T., Rogers, K., & Jorm, L. (2012). Characteristics of Australian cohort study participants who do and do not take up an additional invitation to join a long-term biobank: The 45 and Up Study *BMC Research Notes, 5*(655).


applications. *Transnational Research, 154*(6).


Lim, M. D., Dickherber, A., & Compton, C. C. (2011). Before you analyze a human specimen,
think quality, variability, and bias. *Analytical Chemistry*(1), 8.


New Jersey Association for Biomedical Research. (2016). Biomedical Research Definitions.


http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

APPENDICES

Appendix I: Survey Instrument for Study Phase I

(App adapted from The American Academy for Political and Social Science., 2012; Francis et al., 2004; Lederer, et al., 2014 & Pastor et al., 2015)

Biobank or Biorepository is a collection of human and animal samples such as urine, saliva, blood, tissue, cells, DNA, RNA, and protein and the accompanying background information systematically stored, “for a population or a large subset of a population” (Mora et al., 2015). These samples are referred to as biological specimens or biospecimen. In order to provide socioeconomic, environmental and biological context to the samples, personal health information (PHI) such as height, weight, family medical history, lifestyles and other health related available data that may have impact on health are recorded. The donated biological specimens along with the personal health information (PHI) is kept indefinitely or for many years to be used in biomedical research (HERG, Oxford University, 2014). Biobanks provide human biological specimens for biomedical research, such as genomic sequencing and analysis, which is currently being explored to offer a “good fit” treatment modalities for cancer patients, develop vaccines, and provide cure for many diseases.

However, research has shown that there are differences among racial groups in their willingness to participate in biobanking. Minority groups such as African American have been reported to have a very low percentage participation in biobanking. The current study seeks to find out factors that influence individuals’ willingness to participate in biobanking.

Therefore, we would kindly wish to get your thought on the questions below.

The five minutes video presentation below provides further clarification on what it means to participate in biobanking: Right click on the link below
1. Year of birth: _____________________________

2. Are you a faculty or staff of GS: Yes    No

3. Are you an African American born in United States: Yes    No

4. I am enrolled at GSU Statesboro campus as a
   A. graduate
   B. undergraduate
   C. Not enrolled as a graduate or undergraduate

5. Can you write and understand English language? Yes    No

DEMOGRAPHIC QUESTIONS

1. Gender: Male                              Female

2. Educational level
   a. Graduate
   b. Undergraduate

3. Department (major)_________________________

YOUR BEHAVIOURAL FACTORS

1. What do you believe are the advantages or good things about donating a biological specimen along with your personal health information to a biobank?
   a. …….
b. ....

c. ....

d. ....

2. What do you believe are the disadvantages or bad things about donating a biological specimen along with your personal health information to a biobank?
   a. ....
   b. ....
   c. ....
   d. ....

3. Is there anything else you associate with donating a biological specimen along with your personal health information to a biobank?
   a. ..... 
   b. ..... 
   c. ..... 
   d. ..... 
   e. 

YOUR NORMATIVE FACTORS

1. Who, which people or groups, might approve or support you if you donate a biological specimen along with your personal health information to a biobank?
   a. ....
2. Who, which people or groups, might disapprove if you donate a biological specimen along with your personal health information to a biobank?
   a. .......
   b. .......
   c. .......
   d. .......

3. Is there anything else you associate with donating a biological specimen along with your personal health information to a biobank?
   a. .......
   b. .......
   c. .......
   d. .......
Appendix II. Survey Instrument for Study Phase II

(Adapted: The American Academy for Political and Social Science., 2012; Francis et al., 2004; Lederer, et al., 2014 & Pastor et al., 2015)

Biobank, or Biorepository, is a collection of human and animal samples such as urine, saliva, blood, tissue, cells, DNA, RNA, and protein, as well as the accompanying background information systematically stored, “for a population or a large subset of a population” (Mora et al., 2015). These samples are referred to as biological specimens or biospecimens. In order to help understand how our personal characteristics, environment and our everyday life activities affects gene manifestations from birth onwards, personal health information (PHI) such as height, weight, family medical history, lifestyles and other health related available data that may have impact on health are recorded. The donated biological specimens along with the personal health information (PHI) are kept indefinitely or for many years to be used in scientific research such as DNA analysis (HERG, Oxford University, 2014). Currently DNA analysis is being explored to offer a “good fit” treatment options for cancer patients, develop vaccines, and provide cure for many diseases.

However, research has shown that there are differences among racial groups in their willingness to participate in biobanking. The current study seeks to find out factors that influence individuals’ willingness to participate in biobanking.

Therefore, we would kindly wish to get your response on the questions below. The five minutes video presentation below provides further clarification on what it means to participate in biobanking: Right click on the link below

https://www.youtube.com/watch?v=a6qLBidtW-Y.
Screener Questions

1. Year of birth: ____________

2. Were you born in United States?    Yes         No

3. Do you identify as Black or African American?    Yes               No

4. I am enrolled at GSU Statesboro campus as a
   1. Graduate
   2. Undergraduate
   3. Not enrolled as a graduate or undergraduate

5. Can you write and understand the English language?  Yes         No

Demographic Questions

6. What is your department (major)?     _________________

7. What is your gender?       Male     Female     Non-binary/third gender     Prefer not to say

Pre-Survey Questions

8. Prior to your participation in this study how much do you know about Biobanking?
   1. Nothing at all
   2. A little
   3. A lot

9. Have you ever donated a biospecimens along with your personal health information to a biobank before?
   1. Yes
   2. No
10. Donating to biospecimens along with my personal health information to a biobank is….

Harmful.....1  2  3  4  5  6  7  Beneficial

Bad ......1  2  3  4  5  6  7  Good

Unpleasant (for me).....1  2  3  4  5  6  7  Pleasant (for me)

Worthless.....1  2  3  4  5  6  7  Useful

11. If I donate biospecimens along with my personal health information to a biobank I will feel that I am making medical treatment better

Unlikely.....-3  -2  -1  0  +1  +2  +3....Likely

12. Making medical treatment better is

Extremely undesirable... -3 -2 -1  0  +1  +2  +3...Extremely desirable

13. If I donate biospecimens along with my personal health information to a biobank I will feel that I am helping researchers achieve scientific breakthroughs and medical advances

Unlikely.....-3  -2  -1  0  +1  +2  +3....Likely

14. Achieving scientific breakthroughs and medical advances is

Extremely undesirable... -3 -2 -1  0  +1  +2  +3...Extremely desirable

15. If I donate biospecimens along with my personal health information to a biobank I will feel that I am increasing diversity in scientific data so as to make research results applicable to all populations

Unlikely.....-3  -2  -1  0  +1  +2  +3.....Likely

16. Increasing diversity in scientific data so as to make research results applicable to all populations is

Extremely undesirable... -3 -2 -1  0  +1  +2  +3...Extremely desirable
17. If I donate biospecimens along with my personal health information to biobank I will feel that I am helping to find cures for diseases

Unlikely.....-3  -2  -1  0  +1  +2  +3.....Likely

18. Finding cures to diseases is

Extremely undesirable... -3  -2  -1  0  +1  +2  +3...Extremely desirable

19. If I donate biospecimens along with my personal health information to biobank I will feel that I am adding more knowledge to science

Unlikely.....-3  -2  -1  0  +1  +2  +3.....Likely

20. Adding more knowledge to science is

Extremely undesirable... -3  -2  -1  0  +1  +2  +3...Extremely desirable

21. If I donate biospecimens along with my personal health information to biobank I will feel that I am helping to find causes of diseases

Unlikely.....-3  -2  -1  0  +1  +2  +3.....Likely

22. Finding causes of diseases is

Extremely undesirable... -3  -2  -1  0  +1  +2  +3...Extremely desirable

23. Donating my biospecimens along with my personal health information (PHI) to a biobank will result in a breach of my personal health information

Unlikely.....-3  -2  -1  0  +1  +2  +3.....Likely

24. Breaching and stealing my personal health information in biobank is

Extremely undesirable... -3  -2  -1  0  +1  +2  +3...Extremely desirable

25. Donating my biospecimens along with my personal health information to a biobank will result in abuse or wrongful use of my personal health information
26. Abusing or making wrongful use of my biospecimens and personal health information in a biobank is

Extremely undesirable... -3 -2 -1 0 +1 +2 +3...Extremely desirable

27. If I donate biospecimens along with my personal health information to a biobank, then untrustworthy researchers may have access to my personal health information

Unlikely.....-3 -2 -1 0 +1 +2 +3.....Likely

28. Allowing untrustworthy researchers have access to my personal health information in a biobank is

Extremely undesirable... -3 -2 -1 0 +1 +2 +3...Extremely desirable

29. Donating a biospecimens along with my personal health information to a biobank will result in my inability to retract my biospecimens along with personal health information

Unlikely.....-3 -2 -1 0 +1 +2 +3.....Likely

30. Inability to retract my biospecimens and my personal health information in biobank is

Extremely undesirable... -3 -2 -1 0 +1 +2 +3...Extremely desirable

31. Donating biospecimens along with my personal health information to a biobank will result in exploitation of my personal health information for profit

Unlikely.....-3 -2 -1 0 +1 +2 +3.....Likely

32. Exploiting my biospecimens and personal health information in biobank for profit is

Extremely undesirable... -3 -2 -1 0 +1 +2 +3...Extremely desirable

33. Donating biospecimens along with my personal health information to a biobank will result in unpleasant findings of which researchers will notify me

Unlikely.....-3 -2 -1 0 +1 +2 +3.....Likely
34. Getting back unpleasant findings from biobank to me is

   Extremely undesirable... -3 -2 -1 0 +1 +2 +3...Extremely desirable

35. Most people who are important to me think that

   I should...1 2 3 4 5 6 7......I should not
donate biospecimens along with my personal health information to a biobank

36. It is expected of me that I donate biospecimens along with my personal health information to a biobank

   Strongly disagree....1 2 3 4 5 6 7...Strongly agree

37. I feel under social pressure to donate biospecimens along with my personal health information to a biobank

   Strongly disagree....1 2 3 4 5 6 7......Strongly agree

38. Health professionals would disapprove..... 1 2 3 4 5 6 7....approve of me donating biospecimens along with my personal health information to a biobank

39. What health professionals think I should do matters to me

   Not at all....1 2 3 4 5 6 7...Very much

40. Academic researchers would disapprove..... 1 2 3 4 5 6 7....approve of me donating biospecimens along with my personal health information to a biobank

41. What academic researchers think I should do matters to me

   Not at all....1 2 3 4 5 6 7...Very much

42. My family would disapprove..... 1 2 3 4 5 6 7....approve of me donating biospecimens along with my personal health information to a biobank

43. What my family think I should do matters to me

   Not at all....1 2 3 4 5 6 7...Very much
44. Hospitalized individuals (those in need) would disapprove. 1 2 3 4 5 6 7...approve of me donating biospecimens along with my personal health information to a biobank

45. What hospitalized individuals (those in need) think I should do matters to me

Not at all....1 2 3 4 5 6 7...Very much

46. Other African Americans would disapprove..... 1 2 3 4 5 6 7.....approve of me donating biospecimens along with my personal health information to a biobank

47. What other African Americans think I should do matters to me

Not at all....1 2 3 4 5 6 7...Very much

48. My parents would disapprove..... 1 2 3 4 5 6 7.....approve of me donating biospecimens along with my personal health information to a biobank

49. What my parents think I should do matters to me

Not at all....1 2 3 4 5 6 7...Very much

50. My peers would disapprove..... 1 2 3 4 5 6 7.....approve of me donating biospecimens along with my personal health information to a biobank

51. What my peers think I should do matters to me

Not at all....1 2 3 4 5 6 7...Very much

52. My friends would disapprove..... 1 2 3 4 5 6 7.....approve of me donating biospecimens along with my personal health information to a biobank

53. What my friends think I should do matters to me

Not at all....1 2 3 4 5 6 7...Very much

54. My grandparents would disapprove..... 1 2 3 4 5 6 7.....approve of me donating biospecimens along with my personal health information to a biobank

55. What my grandparents think I should do matters to me
Not at all….1 2 3 4 5 6 7….Very much

56. My coworkers would disapprove…..1 2 3 4 5 6 7…..approve of me donating biospecimens along with my personal health information to a biobank

57. What my coworkers think I should do matters to me

Not at all….1 2 3 4 5 6 7….Very much

58. I expect to donate biospecimens along with my personal health information to a biobank over my lifetime

Strongly disagree _1 2 3 4 5 6 7….Strongly agree

59. I want to donate biospecimens along with my personal health information to a biobank over my lifetime

Strongly disagree 1 2 3 4 5 6 7…..Strongly agree

60. I intend to donate biospecimens along with my personal health information to a biobank over my lifetime

Strongly disagree 1 2 3 4 5 6 7……Strongly agree
Appendix III. Recruitment Flyer

Are you a GSU college student in Statesboro, born in America and identify as African American?

If yes, then share what you think in a 15-minute survey about donating bodily fluid and parts to institutions for research (BIOBANKING) and receive a $10 WALMART GIFT CARD

**BANKING OUR BODY FLUID AND PARTS FOR RESEARCH**

…..And help in………..

- Providing information to CURE CANCER
- Providing information to DEVELOPE VACCINE
- Providing information to CURE CHRONIC DISEASES
- Providing information to HELP OUR POPULATION STAY HEALTHY