



2018

Increasing Blacks' Representation and Utilization on the Bone Marrow Registry: An action-oriented needs assessment

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INCREASING BLACKS' REPRESENTATION AND UTILIZATION ON THE BONE
MARROW REGISTRY: AN ACTION-ORIENTED NEEDS ASSESSMENT

by

Indria Gillespie

A Dissertation Submitted to the

Graduate School

In Partial Fulfillment of the

Requirements for the Degree of

DOCTOR OF EDUCATION

Benerd School of Education

Educational and Organizational Leadership

University of the Pacific
Stockton, CA

2018

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INCREASING BLACKS' REPRESENTATION AND UTILIZATION ON THE BONE
MARROW REGISTRY: AN ACTION-ORIENTED NEEDS ASSESSMENT

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By

Indria Gillespie

Increasing Blacks' Representation and Utilization on the Bone Marrow Registry:
An Action-Oriented Needs Assessment.

Abstract

by Indria Gillespie

University of the Pacific
2018

The purpose of this action-oriented needs assessment was to ascertain the knowledge, motivation, and culture (KMC) needs of Blacks regarding joining the Be The Match bone marrow registry and participating in the bone marrow donation process. This needs assessment will be utilized to lay the foundation for an educational and research based nonprofit organization, Angels In Disguise, that I developed. This study will also be used to inform the bone marrow registry of the KMC needs of the Blacks who participated in this study. The data collection came from nine observations, four post-observation surveys, five donor interviews, two prototype development groups, and a prototype field test.

The formative results from the data collection partially aligned with the literature, which showed that a lack of knowledge resulted in Blacks not joining the Registry. An outlier materialized from the formative data, indicating that all five donor interviewees had joined the bone marrow registry without having knowledge of it, its processes, or the critical need for Blacks to join. On the other hand, the formative data supported the literature when the donor interviewees became a bone marrow match and were faced with the decision to move forward with the bone marrow donation process. All five donor interviewees sought and obtained

knowledge about the bone marrow registry prior to being able to move forward with the donation process. In contrast, the formative data around motivation fully aligned with the literature. Blacks who lacked motivation do not join the bone marrow registry or participate in the bone marrow donation process, whereas the literature stated that many Blacks do not join the bone marrow registry due to cultural attitudes and beliefs. Research indicates that the Black community distrusts the medical community due to their being used as medical guinea pigs in the past. Also, Blacks fear pain and their health being compromised due to bone marrow donation. Interestingly, the formative data results did not support or show a lack of support of the literature. Cultural attributes and beliefs did not manifest themselves in the formative data results.

The two prototype development groups participated in design thinking utilizing iterative brainstorming exercises, rapid prototyping, and assumption testing. The prototype development groups analyzed the data by categorizing and coding the data into themes through participatory research and collaborative analysis. The results of the two prototype development groups culminated into a final prototype. The final prototype was aimed at addressing the KMC needs of the Black participants, which were two-fold. First, the Registry needs to build a relationship with the Black community. Second, participants required knowledge about the Registry, the matching and donation processes, and the critical need for Blacks to join the Registry and participate in the donation process be provided to them in an educational setting, a symposium. The final prototype culminated into a bone marrow symposium that was tested in the field. The final prototype consisted of three videos about the bone marrow registry, a panel discussion with three Black bone marrow donors who had donated to non-relatives, and a pre- and post-prototype field test survey.

The summative findings of this study were the results of the pre- and post-prototype field test surveys and post prototype field test. The findings of the pre-prototype field test survey, regarding knowledge, indicate the participants knew nothing or very little about the bone marrow registry. After being exposed to the prototype, the participants indicated in the post-prototype field test survey they had learned by joining the bone marrow registry they could possibly save a life. They also indicated they did not need any additional information about the bone marrow registry in order to make a decision to join and participate in the bone marrow donation process. Regarding motivation, there was not much change between the pre- and post-prototype field test survey results. The participants had indicated in both the pre- and post-prototype field test surveys that they would be motivated to join the bone marrow registry and participate in the bone marrow donation process if it could save a life. With regard to culture, the participants indicated in both the pre- and post-prototype field test surveys that no beliefs would affect their decision to join the registry and participate in the bone marrow donation process.

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Chapter 1: Introduction

The primary focus of the National Marrow Donor Program's (NMDP) Be The Match Registry (Registry) is to match volunteer donors with those in need of a bone marrow transplant. Blacks are underrepresented on the Registry (Fingrut, 2015; Laver et al., 2001; Yancey, Coppo, & Kawanishi, 1997) and underutilized as participants in the bone marrow donor process (Fingrut, 2015; Johansen, Schneider, McCaffree, & Woods, 2008; Laver et al., 2001; National Marrow Donor Program [NMDP], 2013; Onitilo et al., 2004; Switzer, Bruce et al., 2013). It is critical to the Registry's success to increase its Black donor-recipient bone marrow matches and lower its post-match attrition rates. Post-match attrition occurs when the potential donor decides not to donate bone marrow after being identified as a bone marrow match.

This inquiry provides a deeper understanding of the needs related to Blacks registering on the Registry and participating in the bone marrow donation process. Such understanding will help enable the Registry to develop and implement more targeted marketing, recruitment, and educational efforts in the Black community, which will allow the Registry to increase the number of Black registrants and the number participating in the bone marrow donation process. Additionally, this inquiry provides the Registry with data needed to increase their post-match retention rates within the Black community.

Background

The NMDP's Registry is a nonprofit organization founded with congressional support in 1987 by a conglomeration of people and organizations like Dr. Robert Graves whose daughter was the first to undergo a bone marrow transplant, doctors, the United States Navy, and patient families (Be The Match, n.d.1). The Registry maintains a worldwide database of potential volunteer bone marrow, also called stem cells, donors for recipients with a blood-borne cancer

(Be The Match, n.d.j). Bone marrow is the soft, fatty tissue that fills the bone cavity. This is also where all blood cells are created (NMDP, 2011). Immature blood cells, also called stem cells, are located in the bone marrow and in the blood stream (American Cancer Society, n.d.; NMDP, 2011). The terms “bone marrow” and “stem cells” are used interchangeably (NMDP, 2011, 2016).

The main focus of the Registry is to match a recipient with a potential bone marrow donor. Currently, 11 million potential donors are on the Registry (Be The Match, n.d.j). On average, the Registry performs 6,000 to 7,000 searches per day (Vasconcellos, Nunes, & Feller, 2011), and the Registry coordinates over 5,000 transplants every year (Vasconcellos et al., 2011). Since 1987, the Registry has located and coordinated more than 50,000 bone marrow transplantations (Switzer, Bruce et al., 2013). The matching and donation processes and the critical need for Blacks to join the Registry are discussed in more detail later in this chapter.

Problem of Practice

Currently, every three minutes, someone is diagnosed with a blood-borne cancer (NMDP, 2016). This has increased from every four minutes in 2014 (NMDP, 2014a, 2014b). If chemotherapy and/or radiation does not eradicate cancer cells, a patient with a blood-borne cancer finds themselves in need of a bone marrow transplant (American Society of Hematology, n.d.b; Johns Hopkins Medicine, n.d.b; NMDP, 2014b). Bone marrow is usually a patient’s last lifesaving chance at saving their lives; however, locating a bone marrow donor match is not easy. Less than 30% of Blacks in need of a match ever find one (Bergstrom, Garratt, & Sheehan-Connor, 2009; Glasgow & Bello, 2007; Laver et al., 2001; NMDP, 2011). Ninety percent of matches are found within the recipient’s ethnicity, according to Elaine Rock, an account manager at the Blood Source in Sacramento, a Registry affiliate (personal communication, June 9, 2017).

The Registry conducts outreach to the general community, educating potential registrants about the importance of joining the Registry. According to Bergstrom et al. (2009), the Registry needs to recruit 189,000 Blacks per year in order to reach an optimum number of registrants. Their current marketing, outreach, and bone marrow drives acquire approximately 30,000 new Black registrants per year. According to Bergstrom et al. (2009):

The probability that two randomly white Americans are of matching type is less than one in 10,000. About 20 percent of white Americans are of types that are shared by less than one person in a million. The probability that two randomly selected Blacks will match is less than one in 100,000. (p. 1309)

Thus, it is critical for more Blacks to join the Registry and participate in the bone marrow donation process.

Blacks are underrepresented and underutilized on the Registry. Blacks are underrepresented and underutilized on the Registry partially due to so few Blacks being on the Registry (“Be the Match Tells,” 2013; Fingrut, 2015; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013 Yancey et al., 1997). According to the Registry (2014), nearly 11 million potential donors are on the Registry. The ethnicity of the registrants is depicted in Table 1.

Table 1

Black Representation on the Be The Match Registry by Ethnicity, 2014

Ethnicity	Number of registrants ^a	Percentage of the	Percentage of U.S.
		Registry's	population
		10,595,000 million registrants ^b	308,758,105 July 1, 2010 census ^c
White	7.4 million	69.84	63.7
Hispanic	1.1 million	10.38	16.3
Asian	769,000	7.26	4.8
Black	746,000	7.04	13.3
Multi-racial	441,000	4.16	2.9
American Indian/Alaskan Native	122,000	1.15	.9
Native Hawaiian/Pacific Islander	17,000	.16	0.2
Total	10,595,000		

Note. This table was adapted for Black representation on the Registry from NMDP (2014) and the United States population by ethnicity from the United States Census Bureau (2010).

^aThe number of registrants is rounded off to the nearest thousandth was taken from the NMDP (2014).

^bThe percentage of registrants on the Registry by ethnicity was calculated based on 10,595,000. This table represents the total number of registrants on the Registry per data collected from the Registry.

^cThe total percentage of the United States population equals 101.4% because the percentages were rounded off to the nearest tenth. These tables were taken from the July 1, 2010 U.S. Census.

Unfortunately, not nearly as many potential donors of African descent are on the Registry as needed. According to the U.S. Census (2010), Blacks represent 13.3% of the population; however, they represent less than 7% of the potential donors on the Registry (NMDP, 2014b).

Blacks underrepresented and underutilized as blood and organ donors.

Traditionally, Blacks are also underrepresented and underutilized as both blood and organ donors. According to Shaz et al. (2009), Blacks are underrepresented as blood donors. Shaz et al. conducted a study regarding the motivators and barriers to blood donations in Blacks in Atlanta, Georgia. The study showed that Blacks represent 35% of the population in Atlanta; however, they only donate 14% of the blood donated (Shaz et al., 2009). Additionally, very few Blacks are registered organ donors and do not participate in the organ donation process (Arriola, Perryman, Doldren, Warren, & Robinson, 2007; DuBay et al., 2014; Minniefield, Yang, & Muti, 2001; Moore, 2007; Morgan & Cannon, 2003). Many of these studies focus on post-life organ donations; however, very few studies focus on unrelated live donations.

Blacks' views about the Registry. Many studies have been conducted on the limitations preventing Blacks from joining the Registry (Ballen et al., 2012; DuBay et al., 2014; Durand, Decker, & Bruder, 2002; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Dew, Butterworth, Simmons, & Schimmel, 1997; Switzer, Bruce et al., 2013). Many of the limitations fall into three categories: (a) a lack of knowledge; (b) motivation; and (c) conflicts with cultural attitudes and beliefs. Blacks have shown a lack of knowledge regarding the Registry (Johansen et al., 2008; Kaster, Rogers, Jeon, & Rosen, 2014; Laver et al., 2001; Onitilo et al., 2004; Yancey et al., 1997), the bone marrow matching process (Glasgow & Bello, 2007; Kaster et al., 2014), the bone marrow donation process (Johansen et al., 2008; Laver et al., 2001), and the critical need for Blacks to join the Registry (Laver et al., 2001; Onitilo et al., 2004). Some studies have found that Blacks are not motivated to join the Registry due to fear of pain or health risk and a mistrust of the medical community (Glasgow & Bello, 2007; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013; Tanner, Hunt, &

Eppright, 1991; Yancey et al., 1997). Other studies indicate that Black cultural attitudes and beliefs act as catalysts toward their decision to not join the Registry (Ballen et al., 2012; DuBay et al., 2014; Durand et al., 2002; Onitilo et al., 2004; Quick, LaVoie, Reynolds-Tylus, Bosch, & Morgan, 2016; Roark, 1999; Switzer, Dew, Butterworth et al., 1997; Wittig, 2001; Yates & Oliveira, 2016). No studies have conducted an examination of the Black community to specifically ascertain the needs of Blacks in the areas of knowledge, motivation, and culture that would allow them to make an informed decision regarding joining the Registry.

Purpose and Questions for Inquiry

The purpose of this study was to increase the number of Blacks on the Registry by decreasing the critical knowledge, motivational, and cultural gaps preventing Blacks from joining the Registry and participating in the bone marrow donation process. Participants of prototype development groups one and two and donor interviews actively engaged in the data collection, data analysis, and the development of a solution. This study employed Liedtka and Ogilvie's Design Thinking Model (2011) as a guide. The participants developed a prototype modeling the solution, which was designed to decrease gaps in Blacks' knowledge, motivation, and cultural conflicts. The prototype will provide the Registry with data to assist them with the development of a more targeted marketing, recruitment, and educational plan within the Black community. The prototype is discussed in more detail in Chapter 3.

This study is important because more Blacks need to join the Registry to increase Black donor-recipient bone marrow match rates. To accomplish a match rate increase, this study answered inquiry questions based on knowledge, motivation, and culture (KMC).

1. What knowledge do Blacks need about the Registry, the matching process, the donation process, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process?
2. What are the motivational needs of Blacks that would galvanize them to join the Registry and participate in the bone marrow donation process?
3. What are the cultural needs of Blacks that would allow them to overcome adverse cultural attitudes and beliefs towards joining the Registry and participating in the bone marrow donation process?

This study answered the questions utilizing the KMC theoretical framework, discussed in more detail in Chapter 2.

Additionally, the goal was to start a non-profit organization geared towards conducting research and creating awareness nationwide about the Registry in the African-American, Hispanic, and Native American communities. I was led to this career pathway after joining the Registry in 1994 during a bone marrow drive. Since then, I have been a two-time donor-recipient match undergoing both the bone marrow surgical donation and more recently, the PBSC non-surgical process. After my first donation in 2001, I began to volunteer for the Registry giving presentations about my experience as a bone marrow donor, writing op-ed articles for newspapers with a large Black audience, working at bone marrow drives, and answering potential registrants' questions. I began to conduct independent research to better prepare myself for volunteerism engagements when I discovered Blacks are underrepresented and underutilized on the Registry, which has led me to want to do more. Thus, I am starting a non-profit organization, Angels in Disguise. The results of this inquiry will provide both the Registry and Angels in Disguise with the KMC needs of Blacks. This needs assessment will

assist the Registry and Angels in Disguise, working collaboratively, to decrease Blacks' KMC gaps by creating and implementing more targeted marketing, recruitment, and educational efforts.

Methods of Inquiry: Needs Assessment and Design Thinking

This study addresses the aforementioned inquiry questions utilizing a project-based needs assessment. A needs assessment “is a systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources” (Witkin & Altschuld, 2011, p. 4). The focus of this study was obtaining an understanding of the KMC needs of Blacks, which will assist them to overcome their KMC limitations preventing them from joining the Registry and participating in the bone marrow donation process. An understanding of these needs will also enable the Registry to develop a more targeted marketing, recruitment, and educational effort in the Black community. The needs assessment was conducted through four phases using Liedtka and Ogilvie’s Design Thinking Model (2011).

According to Liedtka and Ogilvie (2011), design thinking is a systematic approach to problem solving that uses experimentation aimed at iterating toward a better answer or solution. This study used Liedtka and Ogilvie’s Design Thinking Model, which focuses on answering four distinct questions. The first question is *What is?* *What is* identifies the current situation or reality (Liedtka & Ogilvie, 2011), the here and the now. The second question asks *What if?* New ideas and concept development are the focus during this stage (Liedtka & Ogilvie, 2011); the needs assessment was conducted during this stage. The purpose of the *what if* stage is to collect data that will ultimately be used to decrease the critical gaps of this study, which is used to transform the reality of *what is*. The third question is *What wows?*; this is when assumption testing and

rapid prototyping occur. The prototype or solution is developed during this stage. The final question asks *What works?* Customer co-creation and the final prototype launch occur during this stage.

The *what is* has already been identified in the literature review in Chapter 2. The observations, surveys, and donor interviews also support the literature review findings defining the *what is* stage. The *what is* stage represents the limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process. The identified limitations fall within the KMC framework categories. This study focused on the *what is*, *what if*, *what wows*, and *what works* design thinking stages, in which new ideas and solutions were developed. Prototypes were created and tested before a final prototype (solution) was selected.

Chapter Summary

The purpose of this study was to understand the needs, within the context of the KMC framework, related to Blacks registering on the Registry and participating in the bone marrow donation process. The study will help enable the Registry to develop and implement more targeted marketing, recruitment, and educational efforts in the Black community. Additionally, this study will provide the Registry with data needed to increase their post-match retention rates within the Black community. Following a definition of terms used, the next chapter discusses the theoretical framework and the limitations preventing Blacks from joining the Registry and participating in the bone marrow donor process.

Definition of Terms

Acute Lymphocytic Leukemia (ALL)

A cancer that affects the white blood cells in the bone marrow. Generally, the cancerous cells spread through the blood stream to other organs and tissues (Cancer Treatment Centers of America, n.d.a).

Acute

Acute leukemias are rapidly growing cancers (American Society of Hematology, n.d.c).

Acute Myeloid Leukemia (AML)

A fast-growing leukemia located in the bone marrow where immature white blood cells prevent the infected from fighting infections (Cancer Treatment Centers of America, n.d.b). This type of leukemia is most prevalent among adults (Johns Hopkins Medicine, n.d.a).

Anesthesia

Treatment used to prevent the patient from feeling pain during the bone marrow donation process. It is administered as a general anesthesia causing unconsciousness or regionally numbing the region in which the surgical process will take place (NMDP, 2011).

Apheresis

A non-surgical procedure that draws stem cells from a donor's arm. The blood goes into a machine that extracts and collects the stem cells from the blood. The remaining blood is returned to the donor's other arm (NMDP, 2011).

Be The Match Registry or the Registry

The National Marrow Donor Program, which is the parent company to Be The Match Registry. Be The Match Registry is a nonprofit organization founded in 1987 by the

federal government; its main focus is to match donor-recipient bone marrow matches.

The Be The Match Registry maintains a worldwide database of potential bone marrow donors (NMDP, 2011).

Black

Black Americans of African descent.

Blood-Borne Cancer or Blood Cancer

Blood-borne cancers are cancers that originate in the bone marrow (American Society of Hematology, n.d.a).

Blood Forming Cells (sometimes called blood stem cells)

Cells found in the bone marrow and blood that can grow into a red blood cell, a white blood cell, or a platelet (NMDP, 2011).

Bone Marrow

The soft, fatty vascular tissue filling the cavities of bones, having a stroma of reticular fibers and cells (NMDP, 2011).

Bone Marrow Transplantation

Bone marrow transplant (BMT) is a special therapy for patients with certain cancers or other diseases. A bone marrow transplant involves taking cells normally found in the bone marrow (stem cells), filtering those cells, and giving them back either to the donor (patient) or to another person. The goal of BMT is to transfuse healthy bone marrow cells into a person after his or her own unhealthy bone marrow has been treated to kill the abnormal cells (Johns Hopkins Medicine, n.d.i, para. 2).

Brainstorming

Generating new possibilities and new alternative business models (Liedtka & Ogilvie, 2011).

Chronic Myeloid Leukemia

Also known as chronic myelogenous leukemia, chronic myeloid leukemia (CML) is a cancer that starts in the bone marrow. It grows slowly and eventually spreads to the blood and other areas of the body. In the event it begins to grow rapidly, it would then change from CML “chronic” to AML “acute” (Cancer Treatment Centers of America, n.d.c).

Culture

The shared values, norms, attitudes, and behaviors that guide decisions and actions (O'Reilly & Chatman, 1996).

Customer Co-Creation

Enrolling customers to participate in creating the solution that best meets their needs (Liedtka & Ogilvie, 2011).

Design Thinking

A systematic approach to problem solving (Liedtka & Ogilvie, 2011).

Engraftment

Engraftment Marrow/peripheral blood stem cells (PBSC) given to the patient during the transplant start to grow and make blood cells (NMDP, 2011).

Filgrastim

Also known as GCSF (granulocyte-colony stimulating factor) or by the trade name Neupogen®. It is given by injection to donors who have agreed to donate PBSC.

Filgrastim stimulates the bone marrow to make more blood stem cells and moves them from the marrow into the bloodstream so they can be collected by apheresis (NMDP, 2011).

HLA

See Human Leukocyte Antigen

Human Leukocyte Antigen (HLA)

Marker proteins on white blood cells that make each person's tissue unique. The HLA markers are important in matching patients and donors for a marrow or PBSC transplant (NMDP, 2011).

Ideate

To form an idea

Knowledge

Merely an awareness of the effects and outcomes of actions based on past experiences (Ackoff, 1972).

KMC

Knowledge, Motivation, and Culture theoretical framework utilized in this study.

Motivation

The work and fervency aimed at achieving a learning or performance goal (Hoffman, 2015).

Myeloid Dysplastic Syndromes (MDS)

Occurs when bone marrow does not produce sufficient red blood cells, white blood cells, and platelets or a combination of three (Cancer Treatment Centers of America, n.d.d).

National Marrow Donor Program (NMDP)

Dedicated to ensuring all patients who need a transplant receive access to this potentially life-saving treatment (NMDP, 2011).

Needs Assessment

“A systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources” (Witkin & Altschuld, 1995, p. 4).

Non-Hodgkin’s Lymphoma

Also referred to as non-Hodgkin lymphoma and occurs in the lymphatic system. This enables the cancer to spread throughout the body through the lymphatic system (Mayo Clinic, 2017).

Peripheral Blood Stem Cells (PBSC)

Peripheral blood circulates through the bloodstream in the body. Some blood stem cells are found in the peripheral blood (NMDP, 2011).

Peripheral Blood Stem Cell Donation

“One of two methods of collecting blood-forming cells for bone marrow transplants. The same blood-forming cells found in bone marrow are also found in the circulating (peripheral) blood (Be The Match, n.d.c, para. 1). PBSC donation is a nonsurgical procedure called apheresis (Be The Match, n.d.c, para. 2).

Post-match Attrition

When the potential donor decides not to donate bone marrow after being identified as a bone marrow match.

Pre-existing Condition

A medical condition a person has prior to joining the Registry or prior to donation.

Rapid Prototyping

The creation of visual (and sometimes experiential) manifestations of concepts. It is an iterative set of activities, done quickly, aimed at transforming the concepts generated in the *What if* stage into feasible, testable models (Liedtka & Ogilvie, 2011).

Registry

The Be The Match Registry is a confidential national database of potential volunteer marrow donors established and maintained by the National Marrow Donor or NMDP (2011).

Stem Cell Transplantation

See Bone Marrow Transplantation.

Stem Cells

Immature blood cells found in the bone marrow and blood (American Cancer Society, n.d.).

What is

The first phase of the Design Thinking process (Liedtka & Ogilvie, 2011), identifying the current reality of a problem or opportunity.

What if

The second phase of the Design Thinking process (Liedtka & Ogilvie, 2011), the generation of innovative ideas and solutions.

What wows

The third phase of the Design Thinking process (Liedtka & Ogilvie, 2011), the process of highlighting the best solutions while using the iterative process to improve upon the weaker solutions.

What works

The fourth phase of the Design Thinking process (Liedtka & Ogilvie, 2011), the accumulative result of the design thinking process resulting in an innovative solution or prototype.

White

Americans of European descent.

Chapter 2: Literature Review

The Registry is the largest bone marrow registry in the world with nearly 11 million unrelated potential donors (Confer & Robinett, 2008; Johansen et al., 2008; Kaster et al., 2014; Lown et al., 2014; Switzer, Bruce et al., 2013); however, Blacks are underrepresented on the Registry (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997) with fewer than 800,000 registrants (Lown et al., 2014).

The disparity of Blacks on the Registry leads to a Black bone marrow match rate of less than 30% (Glasgow & Bello, 2007). In contrast, Whites have a 68-70% match rate (Fingrut, 2015). In a study conducted by Laver et al. (2001), the researchers speculated that the solution to the 30% Black match rate is to increase Black registrants to approximately 800,000 from the 1999 level of just over 300,000. Blacks' match rate is still less than 30% (Laver et al., 2001) despite the fact that there are nearly 800,000 Black registrants today (Lown et al., 2014).

Blacks are also underutilized on the Registry (Onitilo et al., 2004). The literature review shows two key factors contributing to the reason Blacks are underutilized on the Registry ("Be the Match Tells," 2013; Fingrut, 2015; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013). One of the major factors contributing to Blacks being underutilized on the Registry is that Blacks have the most diverse and less common Human Leukocyte Antigen (HLA) types than any other ethnicity ("Be the Match Tells," 2013; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013). HLA is the genetic marker used to determine a donor-recipient match (Fingrut, 2015; Glasgow & Bello, 2007; Switzer, Bruce et al., 2013). The second major factor contributing to Blacks being underutilized on the Registry is the fact that Blacks are also underrepresented on the Registry (Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004). Bone marrow transplantation is

the last life-saving effort for those in need and without a bone marrow transplant, most would die (E. Rock, personal communication, June 9, 2017). The length of their survivorship without a bone marrow transplant is based on the type of cancer, stage of cancer, patient's age, and prior treatments (Gragert et al., 2014).

Joining and Staying on the Registry

To join the Registry is simple; a technician from the Registry swabs both inner cheeks of a potential registrant to collect HLA genetic material. The technician places the swabs in a sterile package, and the package is sent to the lab for processing (E. Rock, personal communication, June 9, 2017). To join years ago, a potential registrant had to undergo a blood draw to collect genetic material. Registrants must be between the ages of 18 and 44 years old to join; however, registrants can stay on the Registry until the age of 61 (Be The Match, n.d.j; NMDP, 2014a, 2014b).

In addition, the potential registrant must be in relatively good health. Certain pre-existing medical conditions could prohibit potential registrants from joining the Registry. According to the Be The Match, people with these conditions cannot donate because it could cause irreparable harm to the recipient's already compromised health, as well as the donor's (Be The Match, n.d.j). Pre-existing conditions that predominately eliminate Blacks from registering or donating bone marrow are HIV, hepatitis or risk for hepatitis, most forms of heart disease, previous cancer(s), chronic lung disease, diabetes requiring insulin or diabetes-related health issues, diseases that affect blood clotting or bleeding, recent back surgery or ongoing back problems, autoimmune and neurological disorders such as lupus, being an organ or marrow transplant recipient, and significant obesity (Be The Match, n.d.j; E. Rock, personal communication, June 9, 2017). These pre-existing conditions limit the Black potential registrant and donor pool.

According to the Centers for Disease Control and Prevention's (CDC) National Diabetes Statistics Report (2017), the number of Blacks being diagnosed with diabetes is steadily increasing each year. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK; 2017a) declares that approximately 30.3 million or 9.4% of the population in the United States has diabetes (para. 2). Blacks represent a disproportionate number of people diagnosed with diabetes in the United States (CDC, 2017; NIDDK, 2017a). Over 9% of the United States population has been diagnosed with diabetes (NIDDK, 2017a); however, 13.4% of Blacks are living with diabetes today (CDC, 2017). Another estimated 4.4% Blacks are living with diabetes undiagnosed (CDC, 2017). Additionally, an estimated 36.3% of Blacks are living with pre-diabetes (CDC, 2017).

High blood pressure is another ailment prevalent in the Black community (CDC, 2016) that also prevents Blacks from joining the Registry and participating in the bone marrow donation process (Be The Match, n.d.j). An estimated 75 million or 29% of American adults live with high blood pressure (CDC, 2016, para. 1). More Blacks have high blood pressure than any ethnic group in the United States, with 43% and 45.7% Black women and men (respectively) living with high blood pressure (CDC, 2016, para. 3).

Oftentimes, the aforementioned conditions can be brought on or exacerbated by obesity. More than 66% of adults are overweight in the United States, while 33% or 75 million of them are obese (NIDDK, 2017b; United States Department of Health and Human Services [HHS], 2017). The NIDDK (2017b) also asserts that 48.4% of Black adults are obese and an additional 12.4% are extremely obese (para. 12).

A pre-existing medical condition is one of the key factors contributing to post-match attrition rates (Fingrut, 2015; Lown et al., 2014). There are no studies specific to post-match

attrition rates due to pre-existing medical conditions in the Black community. On the other hand, some studies regarding post-match attrition rates due to pre-existing medical conditions in the general population exist. According to one study, 34.1% of the post-match attrition rates were attributed to pre-existing medical conditions with overweight being the highest cause (Lown et al., 2014). According to Lown et al. (2014), the pre-existing medical conditions of highest prevalence are obesity at 7.1%, pregnancy at 3.9%, and autoimmune diseases at 3.5%.

Matching Process

The Registry locates matches based on a database of potential donors' HLA typing (Bergstrom et al., 2009; Vasconcellos et al., 2011) and genetic heritage (Be the Match, n.d.f; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013).

According to Be The Match (n.d.g), HLA is a genetic protein marker that can be found on most cells in the human body, and is used to determine donor-recipient bone marrow matches. The closer the donor-recipient HLA match, the better the transplant outcome (Be The Match, n.d.d; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013).

According to the Be The Match (n.d.g), full siblings have a 25% chance of being a match; however, only 30% of matches come from family members (Be The Match, n.d.f; Bergstrom et al., 2009; Glasgow & Bello, 2007; Laver et al., 2001; NMDP, 2011). The remaining 70% of matches come from non-related donors (Be The Match, n.d.d; NMDP, 2011, 2014b, 2016).

The closer the HLA match, the higher the likelihood of a successful transplant (Be The Match, n.d.d; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013) and engraftment (Be The Match, n.d.e). Engraftment occurs when the donated cells begin to grow and create new healthy blood cells in the recipient (Be The Match, n.d.e). This is why recipients have a better chance of long-term recovery with a sibling match (Be the Match, n.d.e).

Since matches are based on HLA typing, 90% of matches are found within the recipients' ethnicity (E. Rock, personal communication, June 9, 2017). Blacks represent a small percentage of all registrants (Hutson, 2010), resulting in low match rates (Bergstrom et al., 2009; Glasgow & Bello, 2007; Laver et al., 2001; NMDP, 2014b).

How the Registry Works

One of Be The Match's critical tasks is to recruit new registrants to join the Registry as potential bone marrow donors. The Registry has coordinated over 50,000 donor-recipient bone marrow transplantations since 1987 (Switzer, Bruce et al., 2013) and has grown from just 10,000 registrants in 1987 (Be The Match, n.d.k) to more than 11 million today (Be The Match, n.d.j; NMDP, 2014b). Despite this growth, someone dies from a blood-borne cancer every 10 minutes equivalent to 144 deaths per day in the United States (Be The Match, n.d.a).

Stem cell recipient. The Registry searches for a bone marrow match immediately after a person has been diagnosed with a blood-borne cancer. The recipient endures several lifesaving efforts before a bone marrow transplant is done. This normally includes chemotherapy and radiation. If these lifesaving efforts do not do the job, the bone marrow donor is contacted. Prior to the transplant, the recipient's bone marrow cells are killed so they can accept the donor's healthy cells. The recipient's health is in a precarious position at this point. The recipient can take a turn for the worse and die prior to the transplant (NMDP, 2011).

Stem cell donor. The potential donor is contacted immediately if a bone marrow match is made. The Registry informs the potential donor that they are a match and are needed to donate bone marrow. The Registry shares basic information about the recipient, within the Health Insurance Portability and Accountability Act (HIPAA) guidelines, such as age and disease. The Registry confirms with the potential donor whether or not they are willing to complete the

donation if needed. If so, the donor then waits for the call to donate. The wait can take several months to a year. During this time, the recipient is exhausting other lifesaving means, such as chemotherapy and radiation. The donor is contacted after the recipient is ready for a transplant. The donor then completes a consent-to-donate form before the medical check-up and surgical process. The Registry schedules a telephone appointment with the donor to go over the donor's current and past medical history. The potential donor could be eliminated for numerous reasons, which was discussed earlier in this chapter. In the next step, if the donor's preliminary medical interview goes well, the donor is sent information regarding the actual procedure (E. Rock, personal communication, June 9, 2017; NMDP, 2011).

The donor undergoes a thorough medical exam, including having several tubes of blood taken to test for the presence of infectious diseases, blood pressure measured, urinalysis, electrocardiogram (EKG), pregnancy test, and chest x-ray (NMDP, 2011; The Cleveland Clinic Foundation, n.d.). The full medical exam takes approximately four hours, during which the physician conducts a lifestyle and medical history interview, usually taking about 1.5 hours. During the lifestyle and medical history interview, the doctor asks questions regarding safe sex practices, number of sexual partners in the past year, drug use (illegal, prescribed, over-the-counter, vitamins, and/or herbs), needle usage, family medical history, family members' cause of death two generations back, cancers in the family, menstrual history, past pregnancies, past surgeries, past overnight hospital stays, past medical check-ups, foreign travel within the past year, and symptomology questions that may allude to signs of a hidden medical problem (E. Rock, personal communication, June 9, 2017; NMDP, 2011).

Types of Donation Procedures

The Registry coordinates stem cell donations, also known as bone marrow donations. Currently there are two ways to extract stem cells (NMDP, 2011, 2014a, 2016). One is called a bone marrow transplant and the other is called PBSC donation (NMDP, 2011, 2014a, 2016). Both procedures extract stem cells from the donor. The bone marrow surgery extracts both immature and mature cells while the PBSC procedure is able to extract all mature cells (E. Rock, personal communication, June 9, 2017).

Today, the bone marrow surgical procedure is conducted 20% of the time and the PBSC non-surgical procedure is conducted 80% of the time (NMDP, 2016). Until recently, a bone marrow transplant was the only option available. Due to modern medicine, now there is also PBSC (Be the Match, n.d.h; NMDP, 2011). The doctor determines which route to take based on the recipient's medical needs. According to The Cleveland Clinic Foundation (n.d.), once extracted, the bone marrow is viable for transplant for up to 48 hours.

Bone marrow donation. According to NMDP (2016), the first surgical process for years had been to extract the bone marrow from the back of the pelvic bone. Other than the medical checkup, there is not any other preparatory work needed (E. Rock, personal communication, June 9, 2017). The procedure is conducted in a hospital setting (NMDP, 2011; The Cleveland Clinic Foundation, n.d). The donor is anesthetized and intubated for surgery (NMDP, 2011, 2014a, 2016; The Cleveland Clinic Foundation, n.d.). The donor is placed on their stomach for the procedure (NMDP, 2011), and the bone marrow is taken from the donor's pelvic bone (NMDP, 2011, 2016; The Cleveland Clinic Foundation, n.d.). The aspiration needles are inserted about one inch above the buttocks and one inch on both sides of the spinal cord (NMDP, 2011). Approximately one to two quarts of bone marrow is extracted, which is about 5% of an

average adult's total bone marrow (The Cleveland Clinic Foundation, n.d.). The donor stays in recovery at the hospital for several hours before receiving a prescription for pain before being released (NMDP, 2011; The Cleveland Clinic Foundation, n.d.). The recovery takes about a week to engage in normal activities; however, patients may experience lower back pain for approximately a month around the incision area. The donor will be able to return to their regular routine in approximately one week (NMDP, 2011, 2014a, 2016).

Peripheral blood stem cell donation. In 1999, PBSC was first conducted by the Registry for transplant (Ballen et al., 2008). PBSC transplants exceeded the bone marrow surgical extraction process by 2003 (Ballen et al., 2008). PBSC requires that the donor be given Filgrastim intravenously every day at the same time for five days (NMDP, 2011). Filgrastim increases the number of stem cells produced in the bone marrow (Be The Match, n.d.c; NMDP 2011, 2016). Filgrastim causes the extra stem cells to mature and enter into the blood stream (NMDP, 2011, 2016). The drug is injected by a nurse daily (NMDP, 2011, 2014, 2016); the first shot is given in a medical setting to monitor the patient for an adverse reaction (NMDP, 2011). The patient is monitored for approximately one hour (NMDP, 2011). The nurse can inject the Filgrastim for the remaining days at the donor's home or work location (NMDP, 2011). The fifth injection is given to the donor at the hospital on the day of the stem cell extraction (NMDP, 2011). The drug causes spasms in the diaphragm and muscle and bone aches (NMDP, 2011). Normally, the donor is prescribed medicine to abate the pain (NMDP, 2011).

The stem cells are extracted using a non-surgical process called apheresis (NMDP, 2011, 2016), a procedure whereby blood is continually drawn from a donor's arm and circulated through a machine that removes the stem cells or white blood cells while the rest of the blood is returned to the donor in the opposite arm (NMDP, 2011). On the day of the extraction, an

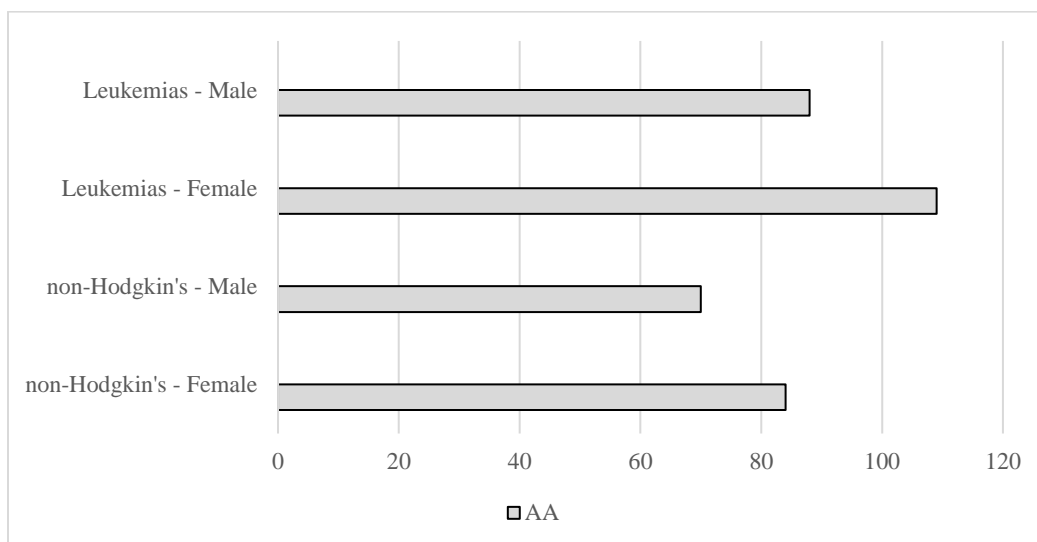
intravenous line that branches off into three or four lines is placed in one hand or arm (Be The Match, n.d.c; NMDP, 2011, 2016). The actual extraction takes about six to eight hours (NMDP, 2011). There is no residual pain immediately after; however, the donor may experience nausea and tiredness (NMDP, 2011, 2014a, 2016). Slight nausea and/or light-headedness is expected, as the donor's body takes approximately six weeks to reproduce the lost bone marrow and stem cells (NMDP, 2011). The donor's immune system is lowered during this time as well (NMDP, 2011).

Common Blood-Borne Cancers Treated with Bone Marrow Transplantation

In the United States, someone is diagnosed with a blood-borne cancer every three minutes and that number continues to rise (Be The Match, 2016). Typically, a person is treated with chemotherapy, radiation, and/or other remedies before a bone marrow transplant (NMDP, 2011). Bone marrow and PBSC transplants are used as the last life-saving effort for several blood-borne cancers (American Cancer Society, n.d.; Confer & Robinett, 2008; Johns Hopkins Medicine, n.d.c; Switzer, Dew, Butterworth et al., 1997). Not all blood-borne cancers and diseases are treated with a bone marrow transplant. The types of diseases treated with a bone marrow or PBSC transplant increase every day (Be The Match, n.d.b). The most common blood-borne cancers treated with a bone marrow transplant are Acute Myeloid leukemia (AML), Acute Lymphocytic Leukemia (ALL), Myeloid Dysplastic Syndromes, non-Hodgkin's Lymphoma, and Chronic Myeloid Leukemia (Confer & Robinett, 2008; Switzer, Dew, Butterworth et al., 1997). Leukemias are cancers that begin in the blood and bone marrow and progress quickly causing abnormal white blood cells to form, which prevents the growth of healthy red blood cells (American Society of Hematology, n.d.c). According to the American Cancer Society (n.d.) and the American Society of Hematology (n.d.d), lymphoma is a type of

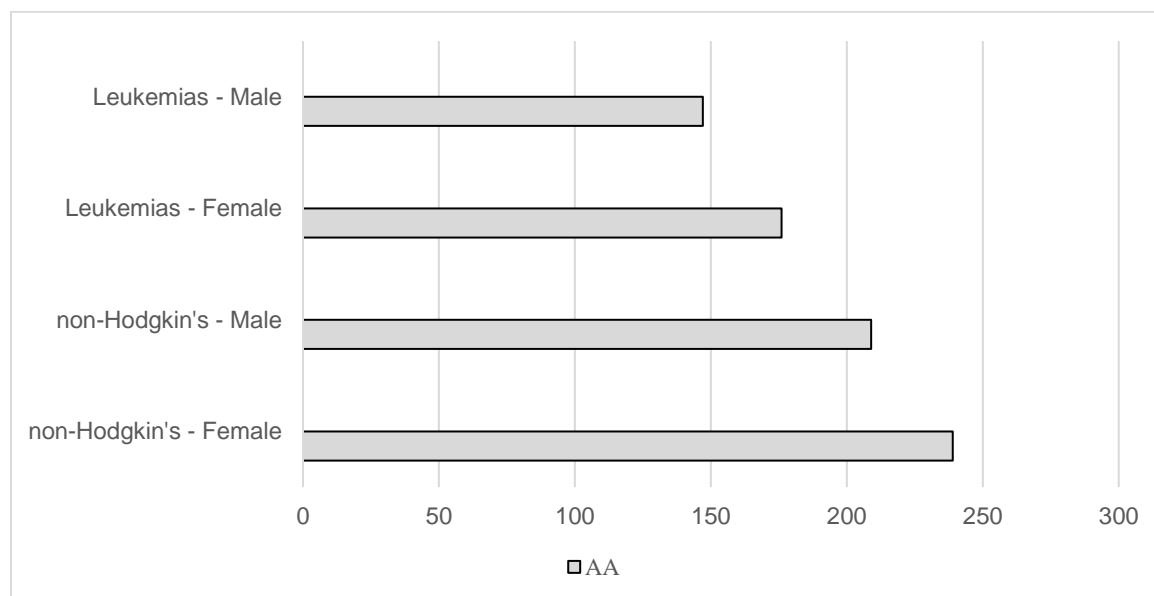
blood cancer that affects the lymphatic system, disrupting the immune system. Myeloma are cancers affecting white blood cells, also referred to as plasma cells, causing a weakened immune system (American Society of Hematology, n.d.e).

Blood-borne cancer statistics among Blacks. In the United States, approximately 174,250 people will be diagnosed with leukemia, lymphoma, or myeloma in 2018, accounting for 10% of all estimated cancer diagnosis (1,735,350) and 58,100 deaths in the U.S. (Leukemia and Lymphoma Society, n.d.). These cancers are projected to cause the deaths of 58,300 people, which equates to one death every nine minutes (Leukemia and Lymphoma Society, n.d.). According to the American Cancer Society (2016), Black females and males have a 1 in 84 and 1 in 70 (respectively) chance of being diagnosed with non-Hodgkin's Lymphoma and a death rate of 1 in 239 and 1 in 209, respectively. Black females and males have a 1 in 109 and 1 in 88 (respectively) of being diagnosed with a form of Leukemia and a death rate of 1 in 176 and 1 in 147, respectively (American Cancer Society, 2016). Overall, females fare better than males within their own ethnicity. For more details, see Figures 1 and 2. Figure 1 reflects the probability of diagnosis while Figure 2 demonstrates the probability of death.



Statistics compiled from American Cancer Society (2016)

Figure 1. Lifetime probability of diagnosis of non-Hodgkin's lymphoma and leukemias by sex in the United States, 2016-2018.



Statistics compiled from American Cancer Society (2016)

Figure 2. Lifetime probability of death of non-Hodgkin's lymphoma and leukemias by sex in the United States, 2016-2018.

Blacks do not fare as well as Whites when seeking a bone marrow transplant (Fingrut, 2015; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013; Yancey et al., 1997). A bone marrow transplant is usually the last life-saving effort available to a person with a blood-borne cancer after exhausting chemotherapy, radiation, and other experimental means (Johns Hopkins Medicine, n.d.c; E. Rock, personal communication, June 9, 2017). Less than 70% of Blacks in need of bone marrow ever find a match (Bergstrom et al., 2009; Glasgow & Bello, 2007; Laver et al., 2001). Blacks have lower donor-recipient bone marrow match rate due to the underrepresentation (Fingrut, 2015; Glasgow & Bello, 2007; Kaster et al., 2014; Laver et al., 2001) and underutilization (Glasgow & Bello, 2007; Kaster et al., 2014; Laver et al., 2001; Onitilo et al., 2004) as well as their diverse HLA genetic marker (Be The Match Tells the Black Community, 2013; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013).

Theoretical Framework

The Knowledge, Motivation, and Organization (KMO) performance improvement model was developed by Clark and Estes (2008) who are prominent pioneers in the field of performance improvement. The purpose of KMO is to improve the performance of organizations that lead to attaining organizational goals. Based on the KMO process model, performance improvement is obtained in six steps. The first step is to identify the organization's key goals. Next, each employee must identify their individual performance goals. The identified goals must be measured against the current status of goal attainment, and the difference between the two determines any performance gaps. The next step is to analyze the gaps to determine their causes. Step five is to identify knowledge/skill, motivation, and organizational process solutions and implement them. The last step is to assess the results, adjust the plan, and update goals. The

purpose of the aforementioned steps is to identify the gaps and develop solutions to fill them.

The applicable steps for this study are discussed later under Evolution of Theoretical Framework.

According to Clark and Estes, knowledge, motivation, and organizational support are all needed for organizations to improve performance and reach goals. To do this, organizations must evaluate the knowledge and motivation of employees and ascertain whether they have organizational support networks in place.

Evolution of theoretical framework. I felt it was critical to include *culture* in the framework based on the definition of culture. *Knowledge* and *motivation* elements of this framework support the purpose of this study and allowed me to identify and assess what specific *knowledge* constructs and *motivational* characteristics are needed for Blacks to overcome their knowledge and motivation limitations preventing them from joining and participating in the bone marrow donation process. My theoretical framework Knowledge, Motivation, and Culture (KMC) was adapted from the KMO performance improvement model for three reasons: (a) the impact *culture* has on an individual's decision-making and actions; (b) the review of the literature; and (c) this study assesses the needs of Blacks, not an organization. Each of the aforementioned reasons is explained in detail below.

The impact of culture on actions and decision-making. The *organization* element of KMO assesses the gaps between organizational processes and material resources (Clark & Estes, 2008). Clark and Estes assert that an organization's culture has an effect on process improvement solutions. Culture is the focal point of what drives an organization's actions (Clark & Estes, 2008) and determines the value of that action (Gilbar & Miola, 2014). To ascertain why Blacks take action or inaction and how they value their action towards joining the Registry and

participating in the bone marrow donation process, I decided that *culture* is an element critical to the framework of this study.

Culture also affects an individual's decision-making. According to Briley, Morris, and Simonson (2000), culture provides us with rules and guidance to make decisions. A comparative study assessed differences in the amount of influence culture has on patients' medical decisions in Western cultures versus non-Western cultures (Alden, Friend, Lee, & DeVries, 2015). The results of the study indicated that culture has greater influence in Western cultures when the medical decision has low risk to health, patients must assess possible side effects, or patients must consider long-term disease management. Gilbar and Miola (2014) assert that people tend to be influenced by culture when making health decisions, and culture has some influence over decisions in the Western world. Hence, I decided to add culture to the framework.

The impact review of the literature had on culture. I also decided to add culture to the theoretical framework based on the review of the literature. I came to realize that culture has a significant impact on this topic. The literature identified cultural characteristics as some of the key limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997; Switzer, Bruce et al., 2013). Thereby, culture is a critical element for this framework. It would be important to obtain a broader scope of these cultural characteristics and study how Blacks can circumvent these cultural limitations to join the Registry and participate in the bone marrow donation process. This premise makes it plausible that I substitute Clark and Estes' *organization* for culture.

The study of human subjects. The final reason I decided to add culture to the KMC framework is because this study focused on human subjects and not an organization. The focus

of this study was to identify and assess the needs of Blacks regarding joining the Registry and participating in the bone marrow donation process. This study sought to do that through participatory collaboration with African-American participants. I believe this research would yield depth by involving the subjects being studied. Participatory collaboration is the co-creation of research utilizing the researcher and participants also being studied (Jagosh et al., 2012). Jagosh et al. (2012) conducted a study on the benefits of participatory research by reviewing over 7,000 abstracts and 591 research papers during their literature review. The findings indicated seven benefits to participatory collaboration: it (a) enables the researcher to conduct and collect culturally applicable data, (b) improves recruitment efforts, (c) creates credibility with stakeholders, (d) provides the platform for functional negotiations, (e) provides the stage to collect appropriate data, and (f) offers a foundation to create change and unexpected opportunities for future research.

Knowledge. The literature informs us that knowledge is an important factor needed to develop solutions to problems and make informed decisions (Woolf et al., 2005). Clark and Estes (2008) assert that knowledge is one of three (KMO) critical factors needed for process improvement to occur. Knowledge in an organization is defined as having the capability to identify and solve problems and being flexible to a changing environment (Clark & Estes, 2008). Nonaka (1994) studied knowledge creation within organizations and states that knowledge is not simply a flow of information or communications. It is fluid in nature, which makes it challenging to measure, replicate, or deed to another; however, it could be managed to improve performance. Ackoff and Emery (1972) researched systems science as a way to engage a new way of thinking in order to solve societal problems. Ackoff and Emery (1972) state that knowledge is merely an awareness of the effects and outcomes of actions based on past

experiences. On the other hand, Anderson (2009) mentions two types of knowledge: declarative and procedural. Declarative knowledge is the understanding of *knowing what* and procedural knowledge is the understanding of *knowing how* and *knowing why* (Anderson, 2009).

My research sought to inform what knowledge needs Blacks have regarding joining the Registry and participating in the bone marrow donation process. According to Woof et al. (2005), knowledge is needed to make an informed decision. This study focused on knowledge based on four key areas regarding the Registry. The four key areas are: (a) the Registry and its purpose, (b) the bone marrow donor-recipient matching process, (c) the bone marrow donor-recipient donation process, and (d) the critical need for Blacks to join the Registry and participate in the bone marrow donation process.

Motivation. Motivation is the catalyst that moves us into action (Carrera et al., 2013; Clark & Estes, 2008). It is the inner drive that pushes us forward to obtain a goal and be successful (Clark & Estes, 2008; Pintrich & Schunk, 1996). Hoffman (2015) asserts that motivation is action led and sustained by a set goal, and motivation is the work and fervency aimed at achieving a learning or performance goal. Clark and Estes (2008) claim motivation consists of three critical elements: (a) selecting a goal, (b) consistently working towards a goal until it is accomplished, and (c) the amount of mental output required to obtain the goal.

Empirical research supports that motivation is required for performance improvement to be successful in an organization. Patricia and Leonina-Emilia (2013) conducted research on the effects human resources have on the motivations of employees. Their findings indicate that performance improvement is non-existent without motivation. Libby and Luft (1993) studied the impact skills, knowledge, motivation, and the environment have on performance. The results of their study demonstrated that motivation tends to be the catalyst that pushes a person to achieve

new skills and knowledge. Additionally, Washburn (2017) studied the utilization of gamification to incentivize and motivate employees, showing that employees require instant positive or negative feedback on their performance, which galvanizes their motivation to persist towards achieving the goal.

Five predominate motivational factors found during the literature review were applicable to this study (Batson, 1987; Batson, Duncan, Ackerman, Buckley, Birch, 1981; Cialdini et al., 1987; Glasgow & Bello, 2007; Kaster et al., 2014; Onitilo et al., 2004; Simmons, Schimmel, & Butterworth, 1993; Studts, Ruberg, McGuffin, & Roetzer, 2010; Switzer, Bruce et al., 2013; Switzer, Dew, Butterworth et al., 1997; Tanner et al., 1991; Toi & Batson, 1982). There are three positive motivational factors: (a) altruism (Cialdini et al., 1987; Simmons et al., 1993; Toi & Batson, 1982); (b) empathy (Batson et al., 1981; Carrera et al., 2012; Dovidio, Schroeder, & Judith; 1990; Switzer, Dew, Butterworth et al., 1997; Studts et al., 2010; Toi & Batson, 1982); (c) and empowerment (Switzer, Dew, Butterworth et al., 1997). The two negative motivational factors are: (a) fear of pain or health risk (Glasgow & Bello, 2007; Johansen et al., 2008; Kaster et al., 2014; Laver et al., 2001; Onitilo et al., 2004; Tanner et al., 1991) and (b) distrust of the medical community (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Bruce et al., 2013). The *motivation* element of KMC addresses motivational factors that affect Blacks' decision-making in regards to joining the Registry and participating in the bone marrow donation process.

Culture. Yates and de Oliveira (2016) state that culture encompasses the many ways a particular group lives and differentiates themselves from other groups. Culture provides us with rules and guidance for decision-making (Briley et al., 2000). According to Alexander (1990), culture is a resilient, self-governing phenomenon that can be singled out and identified

for assessment. O'Reilly and Chatman (1996) define culture as shared values, norms, attitudes, and behaviors that guide decisions and actions.

The review of literature indicates that culture consists of many parameters, which are dependent on the organization's priorities (Kilmann, Saxton, & Serpa, 1985). Some parameters are interrelated, while others are autonomous in nature (Alexander, 1990). Some priorities do not pollinate across departments within an organization, making it problematic for researchers to delineate the constructs of an organization's culture. According to Marcoulides and Heck (1993), culture consists of an organizational structure, individual and organizational values and beliefs, and climate. Whereas, Allaire and Firsirotu (1984), Kilmann et al. (1985), Owens (1987), and Schein (1990) assert that culture is a series of historically interconnected elements encompassing an organization's attitudes, beliefs, ideologies, values, expectations, and norms.

It is paramount that an organization's culture is taken into consideration before identifying and implementing a performance improvement model (Clark & Estes, 2008; Detert, Schroeder, & Mauriel, 2000; Valmohammadia & Roshanzamir, 2015). Altschuld (2010) asserts that a needs assessment cannot be conducted successfully without taking culture into consideration. It is one of the key determinants of long-term success or failure of a performance improvement model (Clark & Estes, 2008; Valmohammadia & Roshanzamir, 2015).

Valmohammadia and Roshanzamir (2015) studied the relationship between Total Quality Management (TQM), performance improvement model, and the organizational culture of 209 pharmaceutical companies. The results of their study demonstrate that a pharmaceutical organization implementing TQM without taking the organization's culture into account results in failure. Detert et al. (2000) conducted a study linking the effects culture has on performance improvement models. They found that organizations whose culture encompasses a short-term

outlook also have limited long-term success with performance improvement models (Detert et al., 2000).

KMC process improvement steps. This study utilized similar process improvement steps as the KMO model mentioned previously in this chapter. The KMC framework employed the following steps to access the needs related to Blacks joining the Registry and participating in the bone marrow donation process. Step 1 of the KMO model is to identify the goals of the organization, as is Step 1 of the KMC process. The purpose and goals of this study were identified and discussed in Chapter 1. Step 2 in the KMO model calls for the identification of individual performance goals. Step 2 of the KMC process involved the identification of the three inquiry questions, discussed in Chapter 1. Step 3 in the KMO model is to identify the performance gaps. Step 3 in the KMC model is also the identification of the performance gaps, done by comparing the need for more Blacks to join the Registry and participate in the bone marrow donation process with the current representation and utilization status. Step 3 is discussed in detail later this chapter. Step 4 of the KMO model is to analyze the gaps to determine the causes. The fourth step in the KMC model is to identify and analyze the limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process. I used the review of the literature, observations, observation surveys, and donor interviews to inform this study of the KMC limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process. The fifth step in the KMO model is to identify knowledge, motivation, and organization process solutions and implement them. Step 5 of the KMC model is conducting the needs assessment to ascertain Blacks' KMC needs that would circumvent their KMC gaps. This is when the data were collected. The last step of the KMO model is to assess the results, adjust the plan, and update goals. The last step of

the KMC was analyzing the data, reporting the findings, and making recommendations for future studies. Data analysis is discussed later in this chapter, and the findings are reported in Chapter 4 while recommendations for future studies are discussed in Chapter 5 of this study. See Table 2 for a listing of the steps.

Table 2

KMC Crosswalk

Steps	KMO Model	KMC Model	Discussion Setting
1	The identification of the goals of the organization	The identification of the purpose and goals of this study	Chapter 1
2	The identification of individual performance goals	The identification of the three inquiry questions	Chapter 1
3	The identification of performance gaps	The identification of the performance gaps	Chapter 2
4	The analysis of the gaps to determine the causes	The identification and analysis of the limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process	Chapter 2
5	The identification and implementation of knowledge, motivation, and organization solutions	The needs assessment will be conducted to ascertain Blacks' KMC needs that would circumvent their KMC limitations	Chapter 3
6	Assessing the results, revise the plan, and update goals	The data will be analyzed, findings reported, and recommendations will be made for future studies	Chapters 3 (analysis), 4 (findings reported), and 5 (recommendations for future research)

Strengths of the KMO process improvement model. Some strengths of the KMO process improvement model include that it analyzes the knowledge, skills, and motivations of people within an organization who are working towards common goals. It does not limit the assessment to task outcomes and the organization's position in the marketplace. It assesses the goals of the organization and compares them with the current status of goal attainment to identify gaps in the areas of knowledge/skills, motivation, and organization. This makes it easier to isolate the gaps, develop specific targeted solutions to fill the gaps, implement the solutions, monitor the progress, and make any necessary adjustments for further improvement. This framework is important to this study because I assessed the needs of Blacks to join the Registry and participate in the bone marrow donation process. The data will provide the Registry with the tools to improve their marketing, recruiting, and educational efforts and increasing Black registrants.

Additionally, many researchers have utilized and cited Clark and Estes' KMO model (2008). Fazio (2017) employed the KMO model to conduct a gap analysis on the underutilization of physicians reviewing and reporting opiate usage to the California controlled substance utilization review and evaluation system. Salinas (2013) conducted a gap analysis on leadership factors and student achievement employing the KMO model. In addition, Bugarin (2013) also researched English learners' achievement at a suburban high school using the KMO model.

Weaknesses of KMO process improvement model. The primary weakness of Clark and Estes' KMO performance improvement model (2008) is that it does not include culture within its framework. Clark and Estes acknowledge the effects culture has on the motivation of individuals, which is key to their framework; however, they do not study the effects of culture

singularly. They elaborate about the belief structures of *I* and *we* cultures (individualistic and collectivism, respectively) and how these cultures influence motivation. Additionally, Clark and Estes (2008) discussed the internal and external locus of control and how these belief constructs drive motivation. There is also a great body of knowledge on how culture influences decision-making (Briley et al., 2000; DuBay et al., 2014; Durand et al., 2002; Markus, 2016; Quick et al., 2016; Roark, 1999; Wittig, 2001; Yates & Oliveira, 2016). Since culture is so influential in the decision-making of individuals (DuBay et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999; Wittig, 2001), it should be a part of the performance improvement framework for this study. This premise is what led me to add culture to the framework, changing the performance improvement model to Knowledge, Motivation, and Culture (KMC). I define each of the KMC elements in the next section.

Conceptual Map

The conceptual map depicts the three inquiry questions this study was designed to answer utilizing the KMC framework. The map demonstrates the relationship KMC has on the four possible outcomes. Two are immediate outcomes: (a) Blacks do choose to join the Registry and (b) they choose not to join the Registry. The latent outcomes are not immediate and they may not occur if a person is not matched to a recipient. The latent outcomes are: (a) Blacks do participate in the bone marrow donation process and (b) they do not participate.

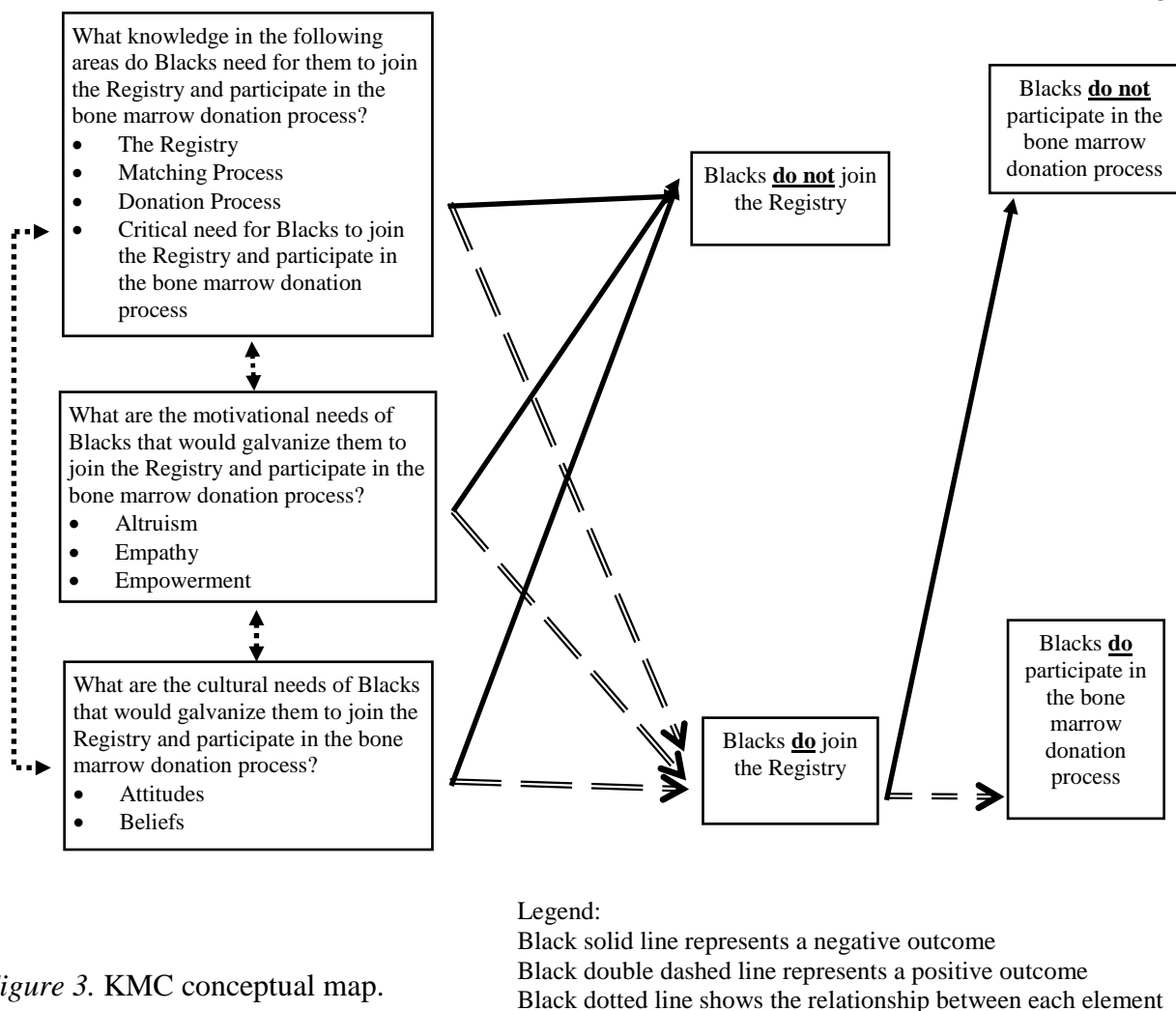


Figure 3. KMC conceptual map.

Theory of Action

My theory of action makes several assumptions: that the three key elements of the KMC framework have a relationship with one another and a causal relationship with the possible outcomes, that each KMC element has an effect on Blacks' decision to participate or not participate in the bone marrow donor process after a match has been made, and that KMC has one or more causal relationships with the possible outcomes. I identified three assumptions in my study relating to knowledge, motivational factors, and cultural characteristics. The first,

knowledge about the Registry, matching process, donation process, and the critical need to the Black community have a direct impact on whether or not Blacks do or do not register on the Registry and participate in the bone marrow donation process. The second assumption pertains to motivational factors. Motivational factors, such as altruism (Cialdini et al., 1987; Simmons et al., 1993; Toi & Batson, 1982), empathy (Gruhn, Rebucal, Labouvie-Vief, & Lumley, 2008), empowerment (Switzer, Dew, Butterworth et al., 1997), fear of pain or health risk (Laver et al., 2001), and distrust of the medical community (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Bruce et al., 2013) also have a direct effect on whether or not Blacks do or do not register on the Registry and participate in the bone marrow donation process. The third assumption pertains to culture. Cultural characteristics, such as attitudes and beliefs have a direct effect on whether or not Blacks join the Registry and participate in the bone marrow donation process.

Relationships between knowledge, motivation, and culture. The three key attributes of the KMC framework have a causal effect on one or more of the four possible outcomes. The KMC elements may act singularly to cause an impact on the outcomes. This means that knowledge, motivation, or cultural characteristics individually may encourage or discourage Blacks' decision-making regarding joining the Registry and participating in the bone marrow donation process. On the other hand, a combination of two or all three KMC elements may act together to impact the outcomes. This occurrence indicates that two or more of the KMC elements may work together to encourage or discourage Blacks' decision-making regarding joining the bone marrow Registry and participating in the bone marrow donation process. For example, a person may gain knowledge about the Registry through a friend in need of a bone marrow transplant. The potential registrant may become motivated to join the Registry based on

their friend's need. The registrant joined the Registry based on both knowledge and motivation. Also each element of KMC may not have an equal impact on Blacks' decision-making. One element of the KMC model may have a dominant influence over another in Blacks' decision-making.

Relationship of Knowledge to the Registry

A large body of research is focused on the limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process. Many researchers have concluded that the predominant reason Blacks are not on the Registry is due to a lack of knowledge (Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Yancey et al., 1997). A few decades ago, the only health decision people made was whether or not to visit the doctor and follow the direction of the physician (Woolf et al., 2005). Today, people seek knowledge to assist them in their decision-making regarding their healthcare needs and the treatment options available to them (Woolf et al., 2005). Yim, Kim, Kim, and Kwahk (2004) conducted research on the relationship knowledge-based decision-making has on business management problems. According to Yim et al. (2004), decision-making and knowledge are strongly interconnected. Knowledge has a positive impact on decision-making and is critical to organizational performance. Poor decision-making usually can be attributed to a lack of knowledge (Yim et al., 2004). A concerted effort must be made to identify the knowledge needed for Blacks to decide whether or not to join the Registry and participate in the bone marrow donation process. The results of this study will provide the Registry with data enabling them to develop a more successful and efficient marketing, recruitment, and educational outreach toward the Black community.

Underrepresentation due to a lack of knowledge. Underrepresentation means Blacks do not represent the same percentage on the Registry as they do in the U.S. population (Fingrut, 2015; Glasgow & Bello, 2007). A lack of knowledge is a contributing factor for why Blacks are underrepresented on the Registry (Kaster et al., 2014; Laver et al., 2001). Researchers have focused their studies on one or two key areas of knowledge (Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997; Yancey et al., 1997). No researcher has focused a study on all four key areas of knowledge. Some research findings show that many Blacks simply have never heard of the Registry (Johansen et al., 2008; Onitilo et al., 2004). This may account for the underrepresentation and underutilization of Blacks on the Registry. One study surveyed 589 Blacks regarding their knowledge and attitudes towards bone marrow donation. Over 48%, or 281, of respondents indicated they were not aware of the Registry (Laver et al., 2001). Other research demonstrates that Blacks are not on the Registry; however, they are aware that potential donors match with their own ethnicity (Laver et al., 2001; Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997; Yancey et al., 1997). Additionally, Laver's research shows that nearly 59.6%, or 348, of Blacks indicated they were aware that donor-recipient matches occur within the same ethnicity (Laver et al., 2001). According to a study conducted by Onitilo et al. (2004), 61.3% of the 408 Blacks surveyed were aware that donor-recipients best match within their own ethnicity while only 42.8% of the 421 Whites surveyed indicated such. Little research has been conducted focusing on the underrepresentation of Blacks on the Registry due to a lack of knowledge regarding the donation process; however, there are studies in this area of awareness pertaining to underutilization (Johansen et al., 2008; Laver et al., 2001). On the other hand, Blacks who understand the critical need to join the Registry have knowledge about the Registry. In one study, 90% of the 408 Blacks surveyed

(Laver et al., 2001) and 92% of the 539 surveyed (Onitilo et al., 2004) indicated they understand the critical need for Blacks to join the Registry.

Underutilization due to a lack of knowledge. Underutilization means the percentage of Blacks donating bone marrow does not represent the same percentage as their population in the United States (Glasgow & Bello, 2007; Kaster et al., 2014; Onitilo et al., 2004). A large body of literature is geared towards the underutilization of Blacks as bone marrow donors. According to a study conducted by Onitilo et al. (2004), Blacks lack a general overall awareness about the Registry, whereas other studies indicate that Blacks do not trust the matching process. Blacks believe Whites would have an unfair advantage to receive bone marrow from Blacks (Glasgow & Bello, 2007), which indicates a lack of awareness regarding the bone marrow matching process. Some Blacks do not move forward with the bone marrow donation process due to a lack of knowledge regarding the bone marrow donation process itself (Kaster et al., 2014). There is no research around the underutilization of Blacks on the Registry due to a lack of knowledge about the critical need for Blacks to donate bone marrow. Several studies indicate that a large percentage of Blacks would donate bone marrow if given a chance despite the fact that there is an insufficient number of Blacks donating bone marrow (Laver et al., 2001; Onitilo et al., 2004). The findings of one study demonstrated that 31.8% of the 408 Blacks surveyed would donate bone marrow (Onitilo et al., 2004). Another study indicated that 51% of the 589 Blacks surveyed would donate bone marrow (Laver et al., 2001). There is a commitment disconnect between those indicating they would donate and those actually taking action when called upon to donate bone marrow.

Effects knowledge about the Registry has on post-match attrition rates. A great body of research exists showing that a lack of knowledge has adverse effects on Blacks'

decision-making regarding joining the Registry and participating in the bone marrow donation process (Onitilo et al., 2004). Studies also show that Blacks that were already on the Registry have refused to participate in the donation process due to a lack of knowledge about the bone marrow donation process (Glasgow & Bello, 2007; Kaster et al., 2014; Switzer, Dew, Stukas et al., 1999; Yancey et al., 1997). Research needs to be conducted on those who refuse to donate after matching with a recipient as well as their original motives to join the Registry.

Effects knowledge has on organ donation. Several studies have been conducted to ascertain why Blacks are not registered organ donors. The predominate reason given for not registering as an organ donor is due to a lack of knowledge (Arriola et al., 2007; DuBay, Ivankova, Herby, Wynn et al., 2014; Minniefield et al., 2001; Morgan & Cannon, 2003; Moore, 2007). One study surveyed 87 Blacks to identify why they were not on the organ registry. The results indicated that 41.2% of the respondents cited a lack of knowledge or information for not registering (DuBay, Ivankova, Herby, Wynn et al., 2014). DuBay, Ivankova, Herby, Wynn et al.'s (2014) study did not indicate what type of information the respondents were seeking. Another study included 249 Blacks and 492 Whites to determine their attitudes toward organ donation. Only 38% of Blacks indicated they would not donate organs, whereas only 10% of Whites had indicated the same. Ironically, in this study, there was an 89% and 90% awareness rate among Blacks and Whites, respectively (Minniefield et al., 2001), but this study was not clear about whether respondents would donate organs for family members or non-related persons.

Relationship of Motivational Factors to the Registry

Motivational factors can be the catalyst to move us into action either in a positive or negative way (Clark & Estes, 2008); thus, motivational factors are important to this study. We

must understand what moves Blacks to react positively or negatively in regards to joining the Registry. What are the motivational needs required to circumvent their motivation limitations. Additionally, we need to ascertain what motivates Blacks to follow through with the bone marrow donation process. With this knowledge, the Registry is better able to market, recruit, and educate the Black community about the Registry and its purpose.

Altruistic behaviors. According to Cialdini et al. (1987), altruism is when a person is motivated to help another in order to minimize the other person's distress. There are several bodies of literature on altruistic behaviors (Cialdini et al., 1987; Simmons et al., 1993; Toi & Batson, 1982). Some research suggests that some altruistic behaviors may be misconstrued as egotistical behaviors, inferring that the underlining motives to help another is simply to ease one's own feelings of distress due to being aware of the need of another (Cialdini et al., 1987; Simmons et al., 1993; Toi & Batson, 1982). There are a limited number of studies on altruism specifically focused towards bone marrow donation. There is a need for research that specifically focuses on altruistic behaviors motivating Blacks to join the Registry and participate in the bone marrow donation process.

One study developed the concept of real-world altruism, focusing on the self-image of unrelated bone marrow donors. According to Simmons et al. (1993), real-world altruism entails a high level of sacrifice with potentially high rewards. Simmons et al. provided an example of a true real-world altruistic act as one that donates bone marrow to a stranger. The donor exhibits a high level of sacrifice by undergoing a surgical procedure exposing themselves to anesthesia and significant pain; however, saving the life of a stranger is the potential high reward (Simmons et al., 1993).

Another study surveyed 343 unrelated bone marrow donors to ascertain their motivations to donate (Switzer, Dew, Butterworth et al., 1997), focusing on six key factors that motivate people to donate bone marrow. Two of the factors consisted of altruistic behaviors: normative motives and past experience-based motives. Normative motives were described as donors that felt a social obligation or that it was the morally correct thing to do. Past experience-based motives were described as previous blood donors who felt bone marrow donation was the natural next step and why not help if they could. Twenty-six percent of the study respondents indicated they had normative motivations and an additional 8% indicated past experience-based motivations.

Empathetic behaviors. Empathy is having the capability to understand another person's thoughts, feelings, and experiences (Gruhn et al., 2008). Switzer, Dew, Butterworth et al. (1997) defines empathy as the capability of putting oneself in the shoes of the person in need. Blacks need to become aware of the critical need for bone marrow donors in their community. Over 90% of unrelated donor-recipient bone marrow matches occur within the same ethnicity (E. Rock, personal communication, June 9, 2017). Thus, it is important for Blacks to empathize with the plight of other Blacks in need of bone marrow transplantation.

A great body of literature focuses on the barriers preventing Blacks from joining the Registry and participating in the bone marrow donation process; however, only a limited number of studies focus on the motivational factors leading Blacks to join the Registry and participate in the bone marrow donation process. One of the motivational factors most studied is empathy. Studts et al. (2010) conducted a study on a person's decision to join the Registry based on rational versus emotional appeals. The group exposed to emotional appeals had a higher propensity to agree to register versus the group exposed to rational appeals. Eighty-five percent

of the individuals in the emotional appeals group agreed to register on the Registry, which alludes to the fact that empathy generates a higher call to action (Studts et al., 2010). No studies show the longevity emotional appeals have on an individual. Another study (Switzer, Dew, Butterworth et al., 1997) surveyed 343 unrelated bone marrow donors to ascertain their motivations to donate. One of the six motivational factors studied was empathy. Of the 343 respondents, 18% indicated they had empathy-related motives to donate bone marrow (Switzer, Dew, Butterworth et al., 1997).

Intra-related motivational factors – Empathy and altruism. Some researchers believe that empathy alone is not a call to action. One researcher believes it is a combination of empathy and personal distress that influences behavior (Carrera et al., 2013). Whereas Batson et al. (1981) developed the empathy-altruism model based on the premise that empathy and personal distress act alone. Empathy is an emotion focusing on others' needs and personal distress is an emotion focusing on oneself, eliciting egotistical behaviors (Batson et al., 1981; Carrera et al., 2013; Toi & Batson, 1982). The empathy-altruism model states that witnessing a person in need evokes either personal distress or empathy (Batson et al., 1987; Dovidio et al., 1990). Reacting only to personal stress is equivalent to egotistical behavior; however, reacting to either or both personal distress and empathy elicits altruistic motivations only if the intent is based solely on the other person's welfare (Batson, 1987; Batson et al., 1981). Furthermore, Batson (1987) stated that empathy leads to altruistic motivation; and he tested this framework by studying a person's decision to help another person in an environment with an ease to escape versus high difficulty to escape (Batson et al., 1981). Altruistic motivations occur when a person helps another in need while in an environment that allows easy escape (Batson et al., 1981; Cialdini et al., 1987).

Empowerment. Limited research has been conducted focusing on empowerment as a motivational factor that encourages Blacks to join the Registry and participate in the bone marrow donation process. Switzer, Dew, Butterworth et al. (1997) ascertained the motivational factors that inspired bone marrow donors to donate. They surveyed 343 unrelated bone marrow donors. Two of the six motivational factors researched had empowerment motives: (a) exchange-related motive and (b) idealized helping motive. Exchange-related motive was defined as a donors' awareness of their own costs and benefits of donating and feeling fortunate to donate. Idealized helping motive was described as a donor making an automatic decision to donate without any serious consideration. Of the 343 respondents, 45% indicated they had exchange-related motives and 37% indicated idealized helping motives (Switzer, Dew, Butterworth et al., 1997).

Fear of pain and fear of developing a health condition. Little research has been conducted on the effects of Blacks' underrepresentation on the Registry due to a fear of pain or disruption of health as a limitation to registration; however, a large body of research has been conducted on the underutilization of Blacks on the Registry due to fear. It is healthy and natural for a potential donor to have a certain amount of fear of pain and concern for maintaining the integrity of one's own health (Tanner et al., 1991). These concerns become a problem to the mission of the Registry when they are not addressed. Potential registrants and donors are forced to make a decision based on fear, which leads to low registration rates, donor registration attrition, and post-match attrition. Kaster et al. (2014) discovered in her research that a lack of knowledge was the main contributing factor to a potential donor's fear of the donation process.

One study surveyed 589 African-Americans regarding their willingness to donate bone marrow; and one of the most common barriers cited in that study indicated that fear prevented

them from donating (Laver et al., 2001). Another study surveyed 408 Blacks and 421 Whites regarding their intentions to donate bone marrow. The outcomes of that study indicated that both races shared a common fear of pain; however, 37.4% of Blacks indicated they had a fear of pain in comparison to only 23% of Whites (Onitilo et al., 2004). Additionally, Blacks feared they would contract an infection or disease as a result of donating bone marrow (Glasgow & Bello, 2007; Johansen et al., 2008; Onitilo et al., 2004).

Distrust of the medical community. Distrust of the medical community is defined as a lack of trust of one or more of the following: doctors, hospitals, and racial equity regarding medical treatment (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Bruce et al., 2013). The Black community has had a long-lived distrust of the medical community that has been entrenched in history since American slavery. Blacks have been the subject of medical atrocities utilizing them as medical guinea pigs and test subjects. Many bodies of literature identify the Tuskegee Syphilis Study as the main reason Blacks distrust the medical community (American Medical Association, 2000; Gamble, 1997; Harrell, Crutcher, & Wilson, 2017; Katz et al., 2008; Siminoff & Arnold, 1999). Distrusting the medical community is one of the predominant factors that has dominated studies focused on determining the limitations preventing Blacks from joining the Registry and participating in the bone marrow donation process (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Bruce et al., 2013).

Effects motivation has on post-match attrition rates. A great body of research has been conducted about the effects motivation has on Blacks' decision-making regarding their decision to participate in the bone marrow donation process. Several studies show that some motivational factors have negative effects on Blacks' decision to participate in the bone marrow donation process. Two key motivational factors dissuade Blacks from participating in the bone

marrow donation process. First is fear (Glasgow & Bello, 2007; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Tanner et al., 1991) and second is distrust (Glasgow & Bello, 2007; Onitilo et al., 2004; Switzer, Bruce et al., 2013; Yancey et al., 1997). The most common types of fear reported are the fear of pain (Laver et al., 2001; Onitilo et al., 2004) and the fear of developing an adverse health condition (Glasgow & Bello, 2007; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Tanner et al., 1991).

A few studies indicate that Blacks have a general fear of the bone marrow donation process (Johansen et al., 2008; Kaster et al., 2014; Laver et al., 2001; Onitilo et al., 2004). Some studies cite the fear of bodily harm or the disruption of health status (Glasgow & Bello, 2007; Yancey et al., 1997), while others indicate that Blacks have a fear of pain in regards to participating in the bone marrow donation process itself (Johansen et al., 2008; Yancey et al., 1997). Glasgow and Bello (2007) surveyed 220 Blacks to ascertain their attitudes towards bone marrow donation. The results of their study indicated that 23% of Blacks feared they would contract an infection, HIV, or hepatitis as a result of donating bone marrow (Glasgow & Bello, 2007).

On the other hand, distrust is also a leading factor why Blacks choose not to participate in the bone marrow donation process. Yancey et al. (1997) conducted an exhaustive study to include more than 1,000 brief interviews and 220 surveys with Blacks to ascertain their barriers to follow through with the bone marrow donation process. The results of their study indicated a three-pronged attitude towards medical distrust. The three attitudes are distrust of the medical establishment based upon the history of exploitation of communities of color by researchers. The second is the lack of faith in the medical system to effectively treat health problems. Third is the concern about the misuse of the bone donated marrow, often expressed as a preference for

assurance that donated marrow will be given exclusively to Black patients (Yancey et al., 1997). A study conducted by Switzer, Bruce et al. (2013) also indicated that distrust of the medical community or misuse of the donated marrow as a barrier for Blacks to participate in the bone marrow donation process.

Effects motivation has on organ donation. Several studies have been conducted to ascertain why Blacks do and do not register as organ donors (DuBay, Ivankova, Herby, Wynn et al., 2014; DuBay, Ivankova, Herby, Schoenberger et al., 2017; Durand et al., 2002; Minniefield et al., 2001; Roark, 1999). Another area of study is why Blacks do and do not participate in the organ donor process. Most studies focus on post-life donations. There is limited research on non-related live donations in the Black community. The predominant negative motivational factors that serve as a barrier to Blacks joining the organ registry and participating in the organ donation process mirror the same motivational factors explaining why Blacks do not join the Registry and participate in the bone marrow donation process. The two predominant negative motivational factors are fear and distrust. The positive motivational factors that serve as a catalyst to Blacks joining the organ registry and participating in the organ donation process are altruistic, empathetic, and empowerment (DuBay, Ivankova, Herby, Wynn et al., 2014; DuBay, Ivankova, Herby, Schoenberger et al., 2017; Roark, 1999).

DuBay, Ivankova, Herby, Wynn et al. (2014) conducted a study to ascertain the common barriers preventing Blacks from joining the organ registry. They surveyed 22 Black organ registrants and 65 non-registered participants, and the research results indicated that 12.4% did not donate due to a fear of pain caused from the surgical removal of the organ (DuBay, Ivankova, Herby, Wynn et al., 2014). On the other hand, 16.5% indicated a distrust of the medical community, feeling the medical community would not give the necessary care to

preserve donors' lives (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Minniefield et al., 2001; Roark, 1999). In another study, 249 Blacks were surveyed to determine their attitudes towards organ donation. Of the 249 surveyed, 46% indicated a lack of trust for doctors (Minniefield et al., 2001).

In contrast, some Blacks do donate organs. More research needs to be conducted around the positive motivational factors that lead Blacks to take action and donate organs. One study conducted by Roark (1999) indicated that a sense of empowerment motivated Blacks to donate organs. Blacks believe saving a life could be a good result of donating the organs of a deceased loved one (Roark, 1999). Other studies conducted by DuBay, Ivankova, Herby, Wynn et al. (2014) and DuBay, Ivankova, Herby, Schoenberger et al. (2017) show altruistic, empathetic, and empowerment motivational factors lead Blacks to donate organs. In one study 87 Blacks participated in a focus group to determine the motivational factors that encouraged Blacks to donate organs. The results of this study indicated that 51.6% demonstrated altruistic motives; 20% demonstrated empowerment motives; and 18.3% demonstrated empathetic motives (DuBay, Ivankova, Herby, Wynn et al., 2014).

Importance of Culture in Decision-Making

A great body of research exists around culture. Likewise, there are many definitions of culture. Yates and Oliveira (2016) define culture as the many ways a particular group of people lives their lives. Culture is also defined as a complex network of ideas, interactions, and institutions that guide our behaviors and actions (Markus, 2016). If culture influences the behaviors and actions of individuals, then it stands to reason that culture also influences decision making. Thus, culture is important to this study focused on Blacks' decision-making regarding joining the Registry and participating in the bone marrow donation process.

Although cultures share a collective commonality of belief and attitude constructs, the majority of cultures within the United States are individualistic in nature (Clark & Estes, 2008). In an individualistic culture, each person takes pride in their freedom to make their own decisions and choices (Briley et al., 2000; Clark & Estes, 2008; Markus, 2016; Yates & Oliveira, 2016). In a collectivist culture, individuals seek guidance and advice from others before making decisions. By contrast, in an individualistic culture, individuals have autonomy on decision-making; however, their decisions are influenced by cultural norms, beliefs, and attitudes in all areas of an individual's life (Markus, 2016). There are also sub-cultures affiliated with a person's religious beliefs. Oftentimes, these sub-cultures within religious constructs rely upon the church for guidance on decision-making (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999; Wittig, 2001).

How cultural attitudes affect decision-making. There is limited research on the effects cultural attitudes have on Black decision-making regarding joining the Registry and participating in the bone marrow donation process. The research available demonstrates that cultural attitudes do affect Blacks' decisions in regards to joining the Registry and participating in the bone marrow donation process. One research study surveyed 206 Blacks and 302 Whites to determine their bone marrow donation decisions based on race and ethnicity. The results of that study showed that Blacks and Whites shared the same level of ambivalent attitude towards bone marrow donation (Switzer, Bruce et al., 2013). The research results of Yates and Oliveira (2016) indicated that Blacks have the following cultural attitude barriers towards bone marrow donation. Blacks did not want to participate in the donation process due to perceived bone marrow allocation bias based on race and socioeconomic status. Blacks believed Whites would take precedence over Blacks in need of bone marrow. Also, Blacks perceived cancer as a White

person's disease (Yates & Oliveira, 2016). A comparative study surveyed 408 Blacks and 421 Whites in South Carolina to determine willingness to donate. The results showed that 31.8% of Blacks and 34% of Whites indicated they were willing to donate, of which only 11% and 18.3%, Blacks and Whites respectively, were disinterested in signing up on the bone marrow Registry (Onitilo et al., 2004). Additionally, 11.9% of Blacks and 18% of Whites indicated they did not want to become a bone marrow donor simply because it was not convenient (Onitilo et al., 2004).

How belief constructs affect decision-making. There is limited research on the effects that religious beliefs have on bone marrow donation; however, a great body of research exists on the effects religious beliefs have on organ donation overall. The research shows that some religious faiths and personal belief constructs do not believe in bone marrow donations. Additionally, some people rely on their church to assist them with making decisions regarding organ donation (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999; Wittig, 2001). Two studies focused on Blacks' barriers to participate in the bone marrow donation process. Two of the barriers cited were Blacks' superstitious and religious beliefs (Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997); however, neither study indicated the basis of the superstitious beliefs or identified which religions prohibit donation.

Effect culture has on post-match attrition rates. No research exists on the effects cultural attitudes and beliefs have on post-match attrition rates. Instead, research has been geared towards the cultural characteristics discouraging Blacks from joining the Registry (Glasgow & Bello, 2007). Research has also been conducted on cultural characteristics preventing Blacks from donating bone marrow (Onitilo et al., 2004; Switzer, Dew, Butterworth

et al., 1997). There is room to research those who have joined the Registry and later taken themselves off the Registry due to newly adopted cultural attitudes and religious beliefs. Additionally, for the purposes of this study, research is needed in the area of cultural attitudes and beliefs regarding post-match attrition.

Effect culture has on organ donation. Many studies have been conducted on the effects culture has on organ donations. All of the cultural characteristics found during this literature review impacted organ donation negatively. There are four most prevalent cultural characteristics cited as barriers to organ donation: (a) religious beliefs (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999; Wittig, 2001); (b) mutilation (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Roark, 1999); (c) superstitions; and (d) attitudes of disgust (Quick et al., 2016; Wittig, 2001). Religious beliefs were cited the most as a barrier to organ donation (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999; Wittig, 2001). Several studies indicated that many believe their bodies must remain whole in order to gain access into heaven (DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Quick et al., 2016; Roark, 1999). While other studies have found that some religious ideologies believe those in need of an organ transplant are being punished for not living righteously (DuBay, Ivankova, Herby, Wynn et al., 2014; Wittig, 2001). Some survey participants stated that “God intends for the wicked to suffer” (Wittig, 2001), “you reap what you sow” (Wittig, 2001), and “I believe that it is God’s will that those with organ-related diseases are sick so doctors should not intervene” (DuBay, Ivankova, Herby, Wynn et al., 2014).

Others believe their bodies would be mutilated while harvesting their organs for donation and the mutilation from organ donation would prevent them from having an open-casket funeral

(DuBay, Ivankova, Herby, Wynn et al., 2014; Durand et al., 2002; Roark, 1999). One study surveyed 22 registered organ donors and 65 non-registered organ donors to ascertain the barriers preventing Blacks from donating organs. The results of this study stated that 10.6% of the participants believed they would be unable to have an open-casket funeral (DuBay, Ivankova, Herby, Wynn et al., 2014), while another study cited mutilation of the body as a barrier to donation (Durand et al., 2002).

One study conducted by Quick et al. (2016) surveyed 200 Blacks, 200 Whites, and 200 Hispanics to determine the barriers to organ donor registration based on race. One of the barriers cited for Blacks was superstitious beliefs, indicating Blacks were more superstitious than Whites. Also Blacks' superstitious beliefs were equal to those of Hispanics. Black males were more superstitious than Black females. The superstitious believed that being on the organ donor registration would cause them to die sooner. Another barrier cited in this study was the attitude of disgust. More Blacks than both Whites and Hispanics expressed disgust about the idea of organ donation. Again, more Black men expressed disgust than Black females.

Conclusion

The purpose of this chapter was to provide an overview of my study topic, which is to understand the needs related to Blacks registering on the Registry and participating in the donation process. This will assist the Registry with the development of a more targeted marketing, recruitment, and educational effort in the Black community. I introduced and analyzed KMC, my theoretical framework. I built upon current theories by discussing the positive and negative effects knowledge, motivation, and culture have on Blacks' decision-making in regards to joining the Registry and participating in the bone marrow donation process. Also, I assessed the underrepresentation and underutilization of Blacks on the Registry and their

participation in the bone marrow donation process. Then I reviewed the effects knowledge, motivation, and culture have on post-match attrition rates among Black bone marrow registrants. Additionally, I examined the overall participation of organ donations within the Black community. Lastly, I examined the gaps in the literature. The next chapter details the methodology utilized for conducting this study.

Chapter 3: Research Design and Methods

The previous chapter highlighted the limitations preventing African-Americans from joining the Registry (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997) and participating in the bone marrow donation process (“Be the Match Tells,” 2013; Fingrut, 2015; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013). Themes emerged while researching Blacks’ limitations to joining the Registry and participating in the bone marrow donation process during the literature review. These emerging themes fell into three categories: knowledge, motivation, and culture (KMC) and manifested into the theoretical framework used in this study, KMC, which was adapted from Clark and Estes’ (2008) knowledge, motivation, and organization (KMO) framework. In this chapter, I first list and elucidate my research questions. I then expound on why qualitative methods worked best for this study. I provide an overview of the data collection, followed by clarifying the data analysis process and ethical considerations. I conclude by reviewing the limitations of the study.

Purpose and Inquiry Questions

The purpose of this study was to increase the number of Blacks on the Registry by decreasing the critical knowledge, motivational, and cultural gaps preventing Blacks from joining the Registry and participating in the bone marrow donation process. The results of this inquiry would provide the Registry and other bone marrow recruitment organizations with data to assist with the development of a more targeted marketing, recruitment, and educational plan towards the Black community. This study is important because more Blacks need to join the Registry and participate in the bone marrow donation process to increase Black donor-recipient bone marrow match and donor rates. To accomplish this feat, this study answered inquiry

questions to ascertain Blacks' knowledge, motivation, and culture needs in regards to joining the Registry and participating in the bone marrow donation process.

1. What knowledge do Blacks need about the Registry, the matching process, the donation process, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process?
2. What are the motivational needs of Blacks that would galvanize them to join the Registry and participate in the bone marrow donation process?
3. What are the cultural needs of Blacks that would allow them to overcome adverse cultural attitudes and beliefs towards joining the Registry and participating in the bone marrow donation process?

Inquiry Approach

I had utilized a project-based approach employing qualitative methods to inform this study on the needs of Blacks from the perspective of the participant. According to Merriam and Tisdell (2016), "qualitative researchers are interested in understanding the meaning people have constructed; that is, how people make sense of their world and the experiences they have in the world" (p. 15). The purpose of this inquiry was to obtain an understanding of Black participants' KMC needs to join the Registry and participate in the bone marrow donation process. I sought to understand the needs of Blacks through the lens of Black participants. Creswell (2013) indicated that qualitative research begins with the assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem. This study was conducted with an interpretive viewpoint that each study participant shared some of the same experiences; however, they had

different interpretations of those experiences. Hence, the results of this research yielded multiple realities. According to Merriam and Tisdell (2016):

Interpretive research, which is the most common type of qualitative research, assumes that reality is socially constructed; that is, there is no single, observable reality rather, multiple realities, interpretations, of a single event. Researchers do not "find" knowledge; they construct it. (p. 9)

Using this premise, I understand that each participant did not share the same needs to fill their KMC gaps because each participant had their own reality formed by their own individual experiences and interpretations. I share participants' multiple realities in Chapter 4.

As shown in the previous chapter, multiple studies are focused on the limitations preventing African-Americans from joining the Registry (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997) and participating in the bone marrow donor process (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997). There is a significant gap in the research on what is needed for Blacks to circumvent these limitations. This study built upon the aforementioned previous studies to address the needs of Blacks that would increase the number of Blacks on the Registry by decreasing their KMC gaps thereby enabling them to aid those in their community.

Qualitative methods were the best fit for this study because it allowed me to gain first-hand knowledge about the participants' needs from the perspectives of the participants. This study is uniquely positioned to abstract the KMC needs from the perspectives of both current and non-registrants, as well as obtain an individualized needs perspective from five to six registrants that have undergone the bone marrow donation process. A qualitative study afforded me the opportunity to delve deeply into the experiences, thoughts, and insights of participants, extracting data about what knowledge, motivation, cultural limitations they had prior to joining the Registry and participating in the bone marrow donation process, unlike in a quantitative

study whose main focus is to extract data for the purposes of interpreting it with numbers.

Qualitative methods allowed me to explicate how the bone marrow donors personally overcame their limitations and filled their KMC gaps.

Needs assessment rationale. As mentioned in Chapter 1, a needs assessment “is a systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources” (Witkin & Altschuld, 1995, p. 4). According to Witkin and Altschuld (1995), a needs assessment focuses on the outcome and not the methods employed to achieve it; it allowed me to determine the gaps between the current status and the intended goal, which also coincided with the third step of the KMC model. The focus of this study was to obtain an understanding of the KMC needs of the Black participants, which would allow them to overcome their KMC limitations preventing them from joining the Registry and participating in the bone marrow donation process.

A needs assessment gives me the platform to collect data aimed at addressing the KMC needs of the Black participants. The data were collected by actively engaging participants with a hands-on process. I was aware participants would identify multiple needs for each KMC element because each participant views their world through a different lens representing multiple realities. According to Creswell (2007), the methodological assumption is inductive, surfacing, and formed by the data collection and analysis experience of the researcher; however, the findings were based on the singular realities/needs of the participants. This needs assessment was conducted using Liedtka and Ogilvie’s Design Thinking Model.

Design thinking. According to Liedtka and Ogilvie (2011), design thinking is a methodical approach to identifying and solving problems using the iterative process to develop a better answer or solution. This study used Liedtka and Ogilvie’s Design Thinking Model, which

focuses on answering four distinct questions: (a) *what is*, (b) *what if*, (c) *what wows*, and (d) *what works*. It also employs four project management aids: (a) design brief, (b) design criteria, (c) napkin pitch, and (d) the learning guide.

The design brief gives direction to the designer (Liedtka & Ogilvie, 2011). According to Brown (2009), it informs the designer of the project's milestones, goals, and objectives. It is the starting point for all design thinking projects (Brown, 2009; Liedtka & Ogilvie, 2011) and can be used to keep the design team focused on the problem (Liedtka & Ogilvie, 2011).

The first question is *what is?*, representing the first phase of design thinking. According to Liedtka and Ogilvie (2011), designers employ three tools during the *what is* phase: journey mapping, value chain analysis, and mind mapping. The tools assist with the identification of the current situation or reality, the here and the now (Liedtka & Ogilvie, 2011). Journey mapping assesses the participants' current state, which is limited to current experiences and realities (Liedtka & Ogilvie, 2011). Value chain analysis values the worth of creating a new idea (Liedtka & Ogilvie, 2011). The last tool utilized during the *what is* phase is mind mapping, which assists design thinkers (designers) with generating insights and exploring the problem (Liedtka & Ogilvie, 2011).

The second project management aid is the design criteria (Liedtka & Ogilvie, 2011), conducted between the *what is* and *what if* phases. The design criteria is a tool that forecasts the project's ideal outcome and describes the outcome in abstract terms because the outcome is unknown and driven inductively. It is also used to measure progress.

The second question asks *what if?*, wherein new ideas and concept development are created (Liedtka & Ogilvie, 2011). The *what if* stage is when the needs assessment will be conducted. The purpose of the *what if* stage is to collect data that will ultimately be used to fill

the critical gaps of this study, also used to transform the reality of *what is* through visualization, brainstorming, and concept development exercises. Designers/participants visualize best-case scenarios that would solve the problem being studied. Their visualizations are shared through the inductive brainstorming process. Participants actively engage in separating their brainstorming responses into emerging themes and categories, which help formulate concepts and possible solutions.

The third project management aid is the napkin pitch (Liedtka & Ogilvie, 2011), conducted after concept development in the *what if* phase. The napkin pitch is brief, consisting of no more than one page. It provides a summary of the concepts derived from the *what if* phase, the target market, their needs, concept value, benefits, and a competitive analysis. It allows the designers to work on key concepts simultaneously.

The third question is *what wows* (Liedtka & Ogilvie, 2011) and is when assumption testing and rapid prototyping occur. The prototype or solution is developed during this stage. The participants streamline their concepts into a manageable size based on logic and viability. It could be accomplished by condensing the number of categories.

The fourth project management aid is the learning guide (Liedtka & Ogilvie, 2011), which occurs in the *what works* phase before the formal customer co-creation process. It is a living document that should be reviewed for revisions before launching the prototype. The function of the learning guide is to reiterate the purpose of the project and the guidelines for testing the assumptions.

The final question asks *what works?* During this final phase is where customer co-creation and learning launch occur. Customers work hands-on with the development of the solution(s) to the problem. The learning launch is where the prototype is taken into the field for

implementation. The overarching tools critical to the design thinking process and traverses across *what is*, *what if*, *what wows*, and *what works* are visualization and empathy. Visualization is the ability to imagine the possibilities and bring them to fruition (Liedtka & Ogilvie, 2011).

According to the Liedtka (2011), empathy is the ability to develop an in-depth understanding of another person, the ability to walk in someone else's shoes. Brown (2009) equates empathy with borrowing the life of another. Empathy is a profound emotional tie to customers and the ability to understand and relate to their needs (Dunne & Martin, 2006; Kumar, 2013). Empathy is essential to the success of any design thinking (Brown, 2009; Kumar, 2013; Liedtka & Ogilvie, 2011), and separates design thinking from scholastic reasoning (Brown, 2009).

Justification for design thinking. Liedtka and Ogilvie's (2011) design thinking model fit best with this study. It gave me the ability to collect and assess data based on the current status of the problem, envision a future state, develop prototypes based on data and assessments of the future state, and co-create a final prototype with participants (Liedtka & Ogilvie, 2011). Their design thinking model also gave me the platform that allowed participants to take a hands-on approach to addressing their own needs. As the researcher, I drove the process by facilitating the needs assessment while the participants provided and molded the data based on their world-views into solutions, through the iterative process that culminated into a prototype. The prototype development and the collection and analysis of data derived from the prototype are discussed later in this chapter.

Design thinking in this study. To commence the project, I completed the design brief. Most of the first phase of Liedtka and Ogilvie's (2011) design thinking model, *what is*, was identified in four ways: (a) the literature review, (b) observation, (c) post-observation survey, and

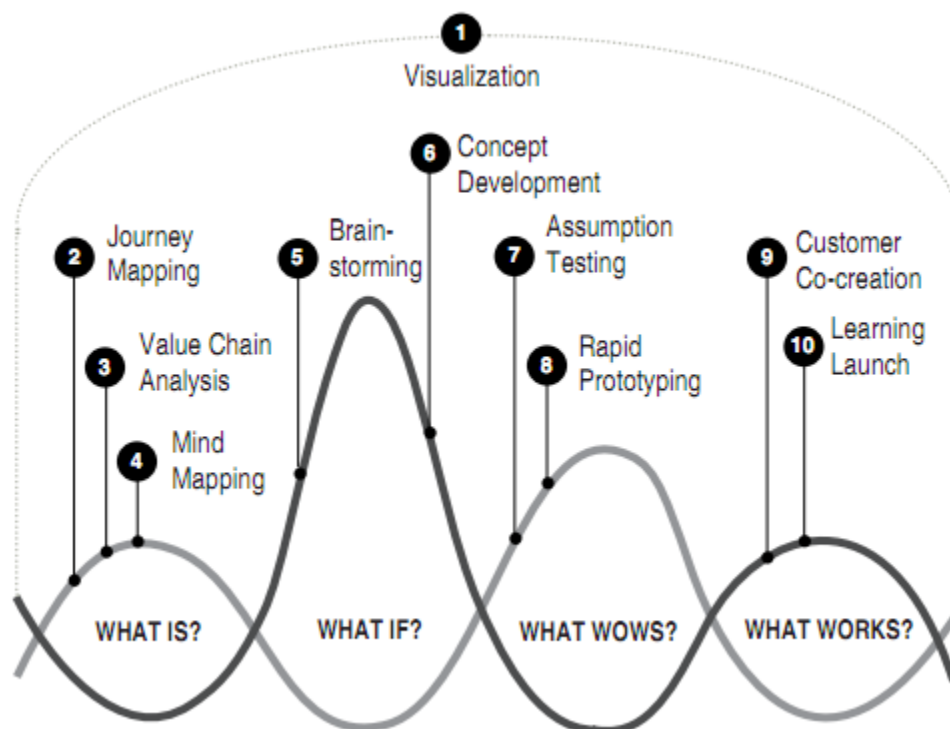
(d) the donor interviews. Although the literature review is not traditionally used for journey mapping, value chain, and mind mapping, I chose to use it due to the wealth of literature informing this study of the current reality of Blacks regarding their limitations to joining the Registry and participate in the bone marrow donation process, the critical need in the Black community, and the establishment of the KMC framework through the exploration of the problem. To strengthen the *what is* processes, the literature review was supplemented with a bone marrow drive observation and post-observation survey. I discuss the observation and post-observation survey in more detail in data collection and data analysis. The donor interviews identified the limitations they faced when they joined the Registry and after becoming a bone marrow match.

This study built upon previous studies throughout the *what if* phase during the donor interviews. *What if* is addressed during Focus Groups 1 and 2, as well as during the donor interviews. Participants formulated best-case scenarios that would address their needs and allow them to circumvent their limitations to join the Registry and participate in the bone marrow process by utilizing a divergent iterative brainstorming process. Then later the ideas/data were categorized into themes employing a convergent process. Donor interviewees informed the study by reflecting on their past experiences that allowed them to overcome their limitations to join the Registry and participate in the bone marrow donation process, which contributed to the concept development. After the ideas/data had been categorized, the two prototype development groups completed the napkin pitch.

What wows also occurs during the donor interviews and the two prototype development groups, where assumption testing and rapid prototyping occur. According to Liedtka and Ogilvie (2011), assumption testing is synonymous to proving a hypothesis. Assumption testing

occurs when possible solutions are identified and tested utilizing thought testing. Thought testing utilizes reason and thought to visualize the solution or prototype in action (Liedtka & Ogilvie, 2011). The participants in the prototype development groups employed visualization and thought testing to conduct assumption testing, which converged the ideas/data. They were tasked with completing the learning guide while in small groups. The learning guides were merged together as one before the commencement of rapid prototyping, and each prototype development group presented their final prototypes. Also, during the *what works* phase, donor interviews were used to triangulate the data collected during prototype development groups.

The *what works* phase also occurred in prototype development groups one and two during the customer/participant co-creation phase when the project culminated into a prototype. The prototype field test group and pre- and post-test surveys were conducted to assess the viability of the prototype from the perspective of the customer. Additionally, the prototype will provide the Registry and other bone marrow recruitment organizations with the data to assist them with the development of a more targeted marketing, recruitment, educational plan aimed at increasing the number of Blacks on the Registry, as well as with increasing the utilization of Blacks in the bone marrow donation process. The Liedtka and Ogilvie's (2011) design thinking model is depicted in Figure 4.



Reprinted from Liedtka & Ogilvie (2011)

Figure 4. Design thinking process relationship with KMC model.

Inquiry Context

The setting for this study is the Registry, a nonprofit organization that began in 1987. The Registry maintains a database of potential volunteer bone marrow donors for recipients with a blood-borne cancer (Be The Match, n.d.i). The main focus of the Registry is to match a recipient with a potential bone marrow donor. Currently, nearly 11 million potential unrelated donors are on the Registry (Be The Match, n.d.i). Blacks are underrepresented on the Registry (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997) with fewer than 800,000 registrants (Lown et al., 2014). Due to so few Blacks being on the Registry, they are also underutilized on

the Registry (“Be the Match Tells,” 2013; Fingrut, 2015; Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Switzer, Bruce et al., 2013).

I chose this setting based on my experience with the Registry, which I joined in 1994 through a bone marrow drive. I became a bone marrow match for the first time in 2000 and donated bone marrow, undergoing the surgical process in 2001 for a 46-year-old Black gentleman with myelodysplastic syndrome. Three weeks after transplantation, he passed away. During this time, I became passionate about creating awareness in the Black community about the Registry and the critical need for Blacks to join the Registry and participate in the bone marrow donation process. I began to volunteer for the Registry giving presentations to predominantly Black audiences, writing op-ed pieces for magazines and newspapers geared towards the Black community, working at bone marrow drives, and answering questions for Blacks recently informed that they were also a bone marrow match. Later, in January 2015, I was informed that I was a match again to a 43-year old Black female with Non-Hodgkin’s Lymphoma. I underwent the bone marrow extraction process, PBSC, in December of 2015. Based on reports from the Registry, my second recipient’s cancer is in remission and her body show no signs of rejecting my bone marrow. More recently in April 2018, I had participated in the Registry’s Strategic Planning Meeting in Minneapolis, Minnesota.

Sequence of Data Collection

First, I had obtained approval for the dissertation proposal. Then I had obtained approval from the University of the Pacific’s and the Be The Match bone marrow Registry’s Institutional Review Boards (IRB). I completed the design brief in February 2018, and in March 2018, I conducted an observation of a bone marrow drive. I observed the Registry and its volunteers solicit nine Blacks join the Registry. Also, I solicited some of those being observed to complete

a post-observation survey, which occurred immediately after the observation. Four participants completed the post-observation survey, then I facilitated five donor interviews and the design criteria in March 2018. Next, I facilitated the prototype development group surveys and prototype development groups one and two in April 2018, followed by the completion of the napkin pitch. I completed the learning guide after the prototype development groups in April 2018. The prototype field test, to include the pre- and post-prototype surveys, was launched on April 26, 2018 in a Black class at a community college in Northern California.

Table 3

Sequential Data Collection Methods

Step	Method	Participants	Number of Participants	Medium	Approximate Time	Design Thinking Phase
1.	Design brief	• Myself	N/A	N/A	1 hour	<i>What is</i>
2.	Observation	• Blacks • 18-61 years of age • Not gender specific • Non-registrants	9	Bone marrow drive	3-4 hours	<i>What is</i>
3.	Post-observation survey	• Blacks • 18-61 years of age • Not gender specific • Non-registrants	4	Bone marrow drive	5-10 minutes	<i>What is</i>
4.	Demographic survey – donor interviewees	• Blacks • 18-61 years of age • Not gender specific • Bone marrow donor	5	• On site • Telephone	5-10 minutes	<i>What is What if What wows</i>
5.	Donor Interviews	• Blacks • 18-61 years of age • Not gender specific • Bone marrow donor	5	• On site • Telephone • Skype	1-1.5 hours	<i>What is What if What wows</i>
6.	Design criteria	• Myself	N/A	N/A	1 hour	<i>What is/What if</i>

Table 3 (Continued)

Step	Method	Participants	Number of Participants	Medium	Approximate Time	Design Thinking Phase
7.	Demographic Survey (for prototype development groups one and two participants)	<ul style="list-style-type: none"> • Blacks • 18-61 years of age • Not gender specific • Registrants and non-registrants 	11	On site	5-10 minutes	<i>What if</i>
8.	Prototype development group one	<ul style="list-style-type: none"> • Blacks • 18-61 years of age • Not gender specific • Registrants and non-registrants 	5	On site	2 hours	<i>What if</i> <i>What wows</i>
9.	Prototype development group two	<ul style="list-style-type: none"> • Blacks • 18-61 years of age • Not gender specific • Registrants and non-registrants 	6	On site	2 hours	<i>What if</i> <i>What wows</i>
10.	Napkin Pitch	<ul style="list-style-type: none"> • Prototype development group one and two participants 	6-12	On site	During focus group	<i>What if</i> <i>What wows</i>
11.	Learning Guide	<ul style="list-style-type: none"> • Prototype development group one and two 	6-12	On site	During prototype development group	<i>What wows</i> <i>What works</i>
12.	Pre-prototype field test survey	<ul style="list-style-type: none"> • Prototype group Participants • Blacks • 18-61 years of age • Not gender specific • Registrants and non-registrants 	7	On site	During prototype development group	<i>What works</i>
13.	Prototype field test group	<ul style="list-style-type: none"> • Blacks • 18-61 years of age • Not gender specific • Non-registrants 	7	One site	1 hour 20 minutes	<i>What works</i>
14.	Post-prototype survey	<ul style="list-style-type: none"> • Prototype participants 	7	One site	10 minutes	<i>What works</i>

Participants

Actively engaged participants are important in any study. According to Merriam and Tisdell (2016), the researcher needs to focus on ascertaining participants' experiences and views throughout the study. This study utilized participants for the purposes of conducting surveys, Prototype development groups, and interviews. Participants were actively engaged in conducting the needs assessments and seeking solutions. The aforementioned interrelated data collection tools were utilized to extract participants' viewpoints, experiences, and needs as they related to joining the Registry and participating in the bone marrow donation.

Observation participants. I observed a bone marrow drive in the Sacramento, California area organized by the Registry, the purpose of which was to gain empathy and develop an understanding for the customer. I observed nine Blacks of any gender between the ages of 18 and 61. I understand that people may travel in groups; thus to give proper attention to each observation, I did not observe groups with more than two people.

The bone marrow drives are usually held in conjunction with a blood drive. The Registry tries to solicit the attendees of the blood drive to join the Registry. This benefited my observation because it allowed me to observe people who were not coming to the event specifically for the bone marrow drive. It gave me the opportunity to observe those who did not have an expectation of being solicited by the Registry and to obtain true insights into those being observed. More details about the observation are discussed in data collection section.

Post-observation survey participants. After each observation, I solicited (see Appendix A) the observed to complete a brief post-observation survey. I obtained a signed consent form from those who agreed to complete the survey and offered a post-observation survey introduction. The purpose of the post-observation survey was to enable me to develop empathy

and understanding for those being observed. I received four completed surveys. More details about the post-observation survey are discussed in the data collection and data analysis section.

Interviewees. Participants used for the interviews self-identified as Black. The only geographic requirement was that participants must live in the United States. Participants did not have to live in the Sacramento region because interviews were conducted telephonically. Also, there were no specific gender requirements and participants needed to be between the ages of 18 and 61. It was paramount that all interviewees had donated bone marrow at least once to a non-related recipient because the purpose of the interviews was to ascertain the participants' KMC needs to join the Registry and their needs after becoming a match. It was also important that the interviewees had donated bone marrow to a person not related to themselves because related donors would have a different view as to their KMC needs. A related donor may simply be motivated to make the decision to donate by the fact that a loved one or family member is in need. I solicited participants from friends and community organizations (see Appendices B & C).

Prototype development groups one and two. Prototype development groups one and two consisted of five and six participants, respectively. The participants of prototype development groups were utilized to develop the data through an iterative brainstorming process, concept development, and the completion of the napkin pitch. The participants needed for this study self-identified as Black. There were no specific gender requirements and participants needed to be between the ages of 18 and 61. I was specific about this age group because this is the age limitation to join the Registry. It made sense for the participants of the study to be within the allowable age range to join the Registry and participate in the bone marrow donation process since one of the bases of this study was on discovering what was needed for Blacks to

circumvent the limitations preventing them from joining the Registry and participating in the bone marrow donation process. Also, for the sake of convenience, the participants lived and or work in the Sacramento and North Bay Area. It was not required for participants to be on the Registry, a bone marrow donor, or even be aware of the Registry.

Due to the specific participant requirements for this study, I utilized purposeful sampling to include snowball, criterion, and convenience techniques. I used the snowball technique to solicit referrals from other participants and friends (Creswell, 2007). I also solicited participants from community groups, the University of the Pacific, friends, and other relevant groups (see Appendices D & E). For the sake of convenience and to save time, all participants that met the specific aforementioned criterion were allowed into the study.

Videos. Three short videos about the Registry were shown to participants prior to the commencement of prototype development groups one and two (see Appendix F). The videos took approximately 11 minutes and explained what the Registry is, its primary purpose, the matching and donation process, and the critical need. The videos provided the participants with a frame of reference equipping them to understand the prototype development group's exercises.

Prototype field test group. The participants for the prototype field test group were solicited from a Black studies course at a community college in Northern California (see Appendix G). Seven participants between the ages of 18 and 61 self-identified as Black and had no gender-specific requirements. None of the participants had ever been on the Registry or had ever donated bone marrow. This was important because it allowed this study to accurately determine the KMC needs of the participants prior to being exposed to the prototype or joining the Registry, as well as ascertaining the KMC needs after exposure to the prototype. The

professor of the class shared an agenda for the field test (see Appendix H) with the class (called a symposium) so they would know what to expect.

Data Collection Tools

Data for this study were obtained utilizing interrelated qualitative collection methods, such as observations, post-observation surveys, prototype development group surveys, pre-interview surveys, interviews, and prototype field test group surveys (see Appendix I for the observation checklist). As outlined above, a total of two prototype development groups (1 and 2) consisting of five and six participants, respectively, were used. The prototype development groups were identical with the same interview questions and directives for the ideation process. The function of the prototype development groups, relating to data collection, was three-fold: (a) to ascertain the Black participants' KMC needs to join the Registry and participate in the bone marrow donation process, (b) to collect data using an iterative brainstorming process, and (c) to analyze the data. The reason for having two identical prototype development groups was to ensure an adequate amount of data for analysis and the development of the final prototype. Journal annotations were completed immediately after each prototype development group and interview. The interviews also served to validate findings and triangulate the data collected from prototype development groups one and two. The prototype development groups were also utilized to analyze the data to create the final prototype. All of the aforementioned data collection sources are subsequently discussed.

Design brief. I completed the design brief, which represented the commencement of this study (see Appendix J). The design brief provided the designer with a road map throughout the design thinking process (Liedtka & Ogilvie, 2011) and gave focus to the design process for this study. It provided the design team with 11 key data points: (a) project description, (b) intent

scope, (c) exploration questions, (d) target users, (e) research plan, (f) expected outcomes, (g) success metrics, (h) project planning, (i) milestones, (j) goals, and (k) objectives.

Observations. The purpose of the observations was for me to gain empathy and develop an understanding of the customer. To do this, I observed nine Blacks, any gender, between the ages of 18 and 61 while attending a blood/bone marrow drive in the Sacramento, California area. I used a checklist as a guide to observe the interactions of the Registry staff and the potential registrants (see Appendix I). My goal was to collect data in five key areas: (a) how the Registry engaged potential registrants, (b) what type of information is being disseminated to the potential registrants, (c) what type of questions were being asked, (d) how the answers were addressed, and (e) what the outcomes were. I took copious notes while conducting observations. I used the data to develop a user's journey map (Kumar, 2013). In addition, I made a journal annotation immediately to assist me with the data analysis process later.

The bone marrow drives are usually held in conjunction with a blood drive. The Registry tries to solicit the attendees of the blood drive to join the Registry, which benefited my observation because it allowed me to observe people who did not come to the event for the Registry. It gave me the opportunity to observe those who did not have an expectation of being solicited by the Registry and allowed me to obtain authentic insights of those being observed.

Post-observation surveys. The post-observation surveys served as a follow-up to the observations. The purpose of the post-observation survey was to explore the decision-making of the observed regarding the Registry. I read an introduction to the observation participants explaining the purpose and design of the study as well as possible risks and rights of the participants (see Appendix K) and participants signed a consent form (see Appendix L). The post-observation survey consisted of 11 questions, informing this study on what KMC needs

were not addressed during the Registry's solicitation (see Appendix M). It also told us what, if anything, was needed for the participants to join the Registry and participate in the bone marrow donation process.

Demographic surveys. A short survey was administered to prototype development groups one and two and the donor interviewees. According to Witkin and Altschuld (1995), surveys are most effective when the researcher is seeking information about respondents' "personal experience, background, expertise, knowledge, or for facts themselves and others about which they have direct knowledge" (pp. 130-131).

The purpose of the demographic surveys was to get to know the participants and their relationship with the Registry. The surveys provided context to the data collection in prototype development groups one and two and the interviews. The surveys collected data in eight areas: (a) demographic information, (b) awareness of the Registry, (c) whether they were on the Registry, (d) awareness of the matching process, (e) awareness of the donation process, (f) awareness of the critical need for Blacks to join the Registry and participate in the bone marrow donation process, (g) if they had ever donated bone marrow, and (h) if they knew of anyone who was ever in need of a bone marrow transplant (see Appendix N). The information sought from the interviewees was different from that of the prototype development groups because the interviewees were all previous bone marrow donors. The participants signed consent forms prior to the survey administration (see Appendix O). The purpose of the pre-interview demographic survey was to collect data in seven key areas: (a) demographic, (b) when they joined the Registry, (c) did they join during a blood or bone marrow drive, (d) did anyone they know join with them, (e) how many times were they a bone marrow donor, (f) when were they first notified they were a bone marrow match, and (g) which bone marrow extraction procedures did they

undergo (see Appendix P). The surveys were conducted telephonically prior to the commencement of the interviews and after the participants agreed to consent.

Interviews. There are several advantages to conducting an interview with open-ended questions. Interviews with open-ended questions give participants wide latitude in which to share their views and experiences, thus providing valuable data (Witkin & Altschuld, 1995). Interviews provide the opportunity to adapt the interview questions based on the participants' answers to previous questions (Witkin & Altschuld, 1995), which "allows the researcher to respond to the situation at hand, to the emerging world view of the respondent, and to new ideas on the topic" (Merriam & Tisdell, 2016, p. 111). Interviews also gave me the advantage of observing the participants' body language.

Prior to the interviews, I read the interview introduction to the interviewees (see Appendix Q) and each participant completed a consent form (see Appendix O). I conducted five interviews telephonically with previous bone marrow donor, and each interview was audio-recorded for the purposes of transcription. The interviews were conducted utilizing an interview protocol approved by the IRB (see Appendix R). The protocol consisted of semi-structured open-ended questions aimed at ascertaining data in four key areas. The first and second key areas focused on collecting data about the participants' KMC needs when they joined the Registry and after being informed that they were a bone marrow match. Third, it was ascertained how they were able to overcome their KMC needs. Lastly, their thoughts and feelings about joining the Registry and after being informed they were a bone marrow match were elicited. The goal of these questions was to gather data about their KMC needs when they joined the Registry and after being informed that they were a bone marrow match as well as how they were able to overcome them. The interviews were transcribed by a transcription service immediately after

each interview. After each transcription, I analyzed the data, coded the data, and categorized the data into emerging themes. After each interview, I created a journal annotation to assist me later during the data analysis phase. The interviews provide data supporting the *what is*, *what if*, *what wows*, and *what works* phases.

Design criteria. The design criteria was completed immediately after the *what is* phase just prior to entering the *what if* phase (Liedtka & Ogilvie, 2011). This means that the design criteria was completed prior to the commencement of prototype development groups one and two (see Appendix S). The data utilized for the completion of this project management aid came from the data collected during the *what is* phase. The design criteria furnished me with the measuring stick by which the ideal solution was evaluated.

Prototype development groups. Prototype development group one of five people was held in a meeting room at a church in the North Bay Area. The second one comprising six people was held in a meeting room at the University of the Pacific. Each participant completed a consent form prior to the commencement of the study (see Appendix T). I read the prototype development group introduction to the participants (see Appendix U). The participants completed a prototype development group demographic survey prior to beginning the iterative process (see Appendix N). Each prototype development group shared the same prototype development group interview protocol with the donor interviewees focused on acquiring the KMC needs that limit the Black participants from joining the Registry and participating in the bone marrow donation process (see Appendix R).

Each prototype development group was broken into smaller groups of no more than four to complete the brainstorming ideation process. Groups were developed randomly by having participants draw numbers for their assigned group. To ensure that all the participants were

aligned, I read the definitions of knowledge, motivation, and culture as they are defined in Chapter 1 of this study prior to their respective interview questions (see Appendix V).

Ideation is a process that uses a divergent approach to develop a large number of ideas condensed into categories or themes (Brown, 2009; Osterwalder & Pigneur, 2010). The inductive data collection process of brainstorming ideation leads to the building of concepts based on emerging themes, and later to a prototype/action plan (Merriam & Tisdell, 2016). In this study, the brainstorming ideation process was driven by semi-structured open-ended questions (see Appendix W). The ideation process entailed a sequence of 5-minute and 3-minute interval brainstorming exercises prompted by each question. Each prototype development group team member participated in each exercise, and there were two iterations of each KMC question. Thus, there were six questions each for prototype development groups one and two. The iterative brainstorming process was conducted on self-stick wall pads affixed to large tabletops and other large blank surfaces. Participants plotted their ideas to the self-stick wall pads using sticky notes (see Appendix X). I provided the prototype development groups with ample supplies to conduct the exercises. The supply list included: pens, markers, sticky notes, self-stick wall pads, and stickers.

Then prototype development group participants analyzed the wealth of data collected during the data collection process employing assumption testing, rapid prototyping, and converging the data into a prototype to be tested in the field. More detail about the assumption testing, rapid prototyping, and field testing a prototype is discussed later in this chapter in the data analysis section. Lastly, I completed journal annotations immediately after each prototype development group also to assist with data analysis.

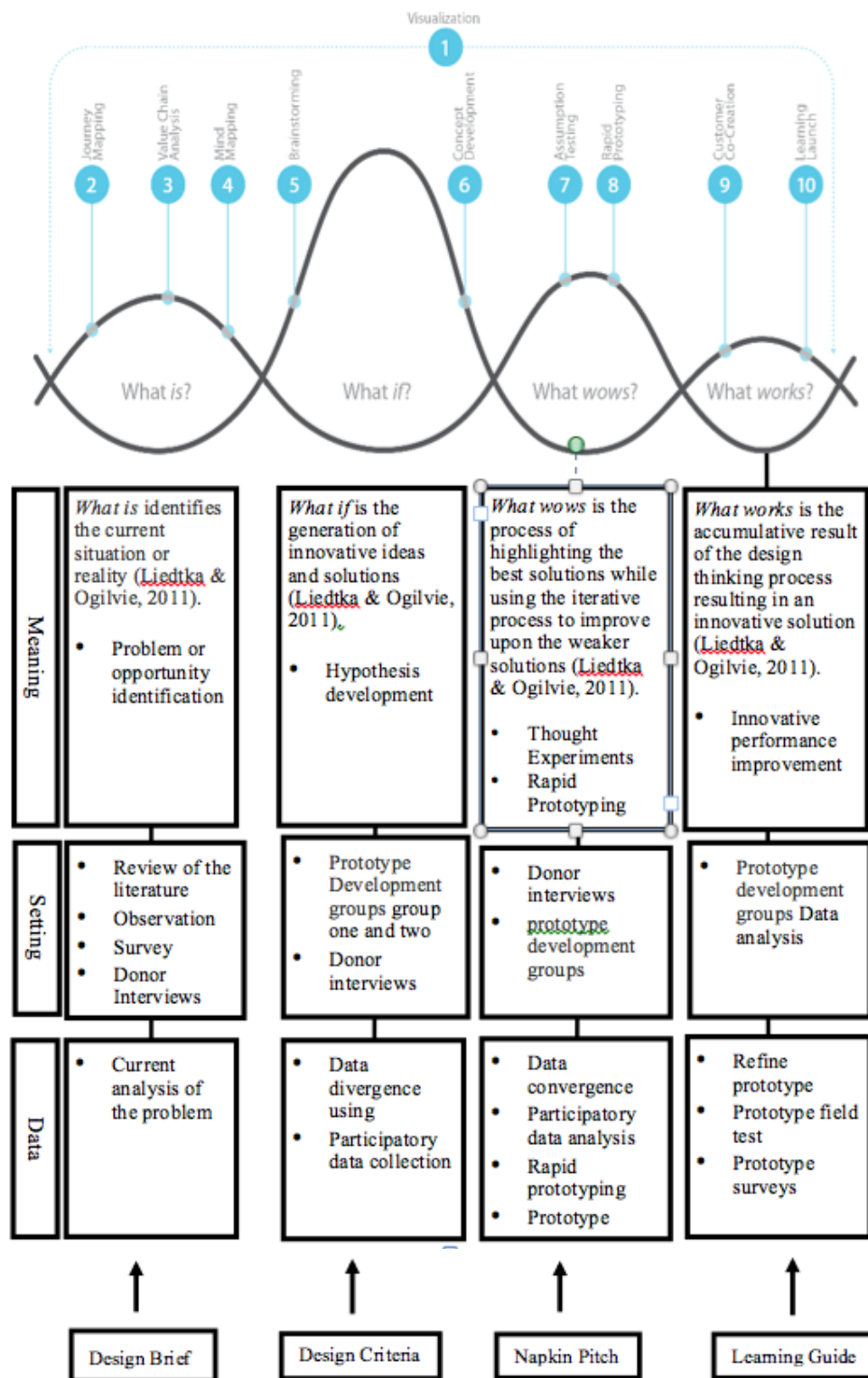
Napkin pitch. The napkin pitch is a project management aid that provides designers with a succinct view of the key components of the concepts developed during the *what if* phase (Liedtka & Ogilvie, 2011; see Appendix Y). It is completed immediately after the concept development during the *what if* phase but before entering the *what wows* phase. The napkin pitch was the first project management aid completed using a collaborative effort. The participants of prototype development groups one and two completed the napkin pitch. Each group within the prototype development groups had completed one napkin pitch based on the data collected through concept development. This yielded two napkin pitches from each prototype development group to move forward to assumption testing in the *what wows* phase. Each prototype subgroup merged their napkin pitches into one representing the whole prototype development groups.

The learning guide. The learning guide is a project management guide that reiterates the project's strategic plan and provides the boundaries for assumption testing (Liedtka & Ogilvie, 2011). The learning guide was completed between the *what wows* and *what works* phase (see Appendix Z) and was completed utilizing a collaborative effort by the participants from the prototype development groups. The learning guide served to delineate the purpose of the new concept, the assumptions that needed to be evaluated, and financial and other resources needed.

Prototype field test group. The prototype field test group and the learning launch are the last phases of the design thinking process and the culminating result of the iterative divergence and convergence of data collection processes (Brown, 2009; Kumar, 2013; Liedtka & Ogilvie, 2011; Plattner, Meinel, & Leifer, 2012). Prototyping is the development of a physical concept from an intangible one (Brown, 2009; Kumar, 2013). Ideas and concepts are converted into something meaningful and beneficial (Kolko, 2015). Prototyping helps designers to

recognize flaws in the design process and the platform to rapidly make refinements based on the needs of the customer (Brown, 2009). It also enabled the participants to recognize the strengths of the prototype.

First, the prototype field test group completed a consent form (see Appendix AA) before I read the introduction (Appendix BB) and requested that the participants complete the pre-prototype survey (see Appendix CC). The pre-prototype survey informed this study about the participants' current knowledge, motivation, and cultural needs prior to being exposed to the prototype. The purpose of the prototype field test group was to test the final prototype aimed at addressing the knowledge, motivation, and cultural needs of the Black participants related to joining the Registry and participating in the bone marrow donation process. A post-prototype survey was administered to the field test group after the prototype (see Appendix DD). The purpose of the post-prototype survey was to assess the participants' knowledge, motivation, and cultural needs after being exposed to the prototype.



Adapted from Liedtka and Ogilvie (2011)

Figure 5. The relationship between the design thinking model and the KMC model.

Data Analysis

I utilized several interconnected data collection methods to address the problem statement including an observation, surveys, prototype development groups, interviews, and a prototype field test. This garnered a voluminous amount of data to be analyzed. According to Merriam and Tisdell (2016), data analysis entails the assessing, clarifying, coding, assimilating, and developing of meaning. Employing a qualitative project-based dissertation method uniquely positioned me to utilize the prototype development group participants to assist in the data analysis process.

Participatory data analysis. There is a wealth of research on utilizing participatory research; however, there are minimum studies on or that employ participatory data analysis. Nind conducted many studies utilizing participatory research, which is the process by which those being researched are included throughout the entire research process including the decision-making from the research design, methods, findings, and the dissemination of the findings. This approach allowed the participants to actively engage in the process of the research. Bergold and Thomas (2012) assert that participatory research participants must be those being studied. It is utilized most when studying marginalized people (Nind, 2011). On the other hand, participatory analysis occurs when the participants in the research actively partake in the data analysis process (Nind, 2011) and not necessarily the entire research.

There are some advantages and disadvantages to utilizing participatory research and participatory data analysis. One of the advantages is that it gives voice to those without one (Bergold & Thomas, 2012; Nind, 2011). It can be a flexible endeavor giving latitude for both structured and unstructured processes (Nind, 2011; Seale, Nind, Tilley, & Chapman, 2015). It is authentic because the point of view is from the participants being studied (Seale et al., 2015).

Participatory research and participatory data analysis also come with disadvantages. According to Bergold and Thomas (2012), one of the disadvantages of participatory research and participatory data analysis is that it does not have history. It also has issues regarding ethics and participation when using participants from vulnerable populations (Bergold & Thomas, 2012).

Project management aids analyses. The purpose of the design brief, design criteria, napkin pitch, and learning guide project management aids was to serve as a tool guide for the design team to reflect on set standards (Liedtka & Ogilvie, 2011). The design brief supported the design team by keeping them focused on the project's milestones, goals, and objectives. The design criteria served as a reminder of an ideal solution to the current reality. The napkin pitch was a resource that allowed the design team to reflect on their customer base and their needs. Lastly, the learning guide focused on preparing the design team to test in the field.

Observation analysis. Before beginning the analysis process, I reviewed my journal annotations written soon after the observations. Then I reviewed my notes taken during the observations. I coded the data into emerging themes inductively following the data. I reexamined the survey, coding the data deductively and seeking themes that supported the KMC framework.

Post-observation survey analysis. I reviewed each of the completed surveys for accuracy and completion immediately after the participants turned in the surveys. Later, I coded the data into emerging themes. First, I coded the data inductively, allowing myself to follow the data. Then I reviewed the surveys a second time, coding the data deductively and seeking KMC themes.

Interviews. After transcription, I reviewed the transcripts for accuracy and made any necessary corrections. Then I coded the data, which were reduced into categories utilizing

deductive coding followed by categorizing using inductive emerging themes. I plotted each of the coded answers within each KMC category for both underrepresentation and underutilization into a spreadsheet for further analysis, completed for all five donor interviews. The plotting allowed me to compare and contrast the answers given by each donor interviewee. Figure 6 depicts the interview coding process.

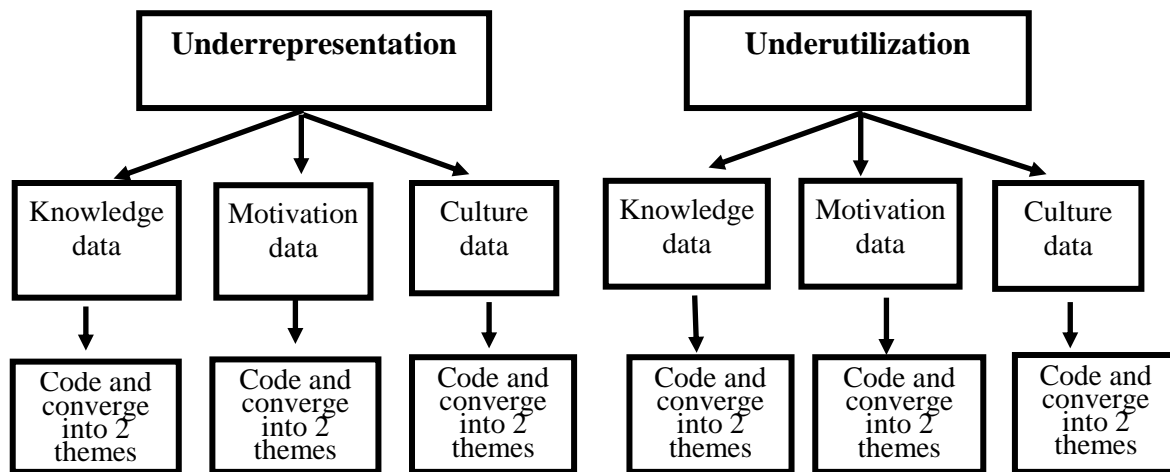


Figure 6. The interview data coding and analysis process of the donor interviews.

Prototype development group analysis. The participants participated in the data analysis during prototype development groups one and two. According to Witkin and Altschuld (1995):

Data analysis and interpretation in needs assessments are often not clear-cut. It should be remembered that the reason for analysis and aggregation of data is to provide a sound basis for determining priorities of need and criteria for future action. Therefore, the analysis should reveal differences and magnitude of needs that are of practical value, not just of statistical significance. (p. 57)

The prototype development groups were divided into smaller groups of no more than four to complete the exercises. I instructed the participants to draw numbers to develop the subgroups. An effort was made to include non-donors and previous donors in each group to create diversity of views and experiences within each group.

Participants began the data analysis when they coded and categorized the data they had developed during the iterative brainstorming exercises. This occurred when the participants were tasked to categorize their responses into emerging themes and to name each of the categories, all of which constitutes data analysis. According to Creswell 2013, “coding involves aggregating the text or visual data to small categories of information” (p. 184). Creswell (2013) further asserts that not all data will be utilized.

The prototype development group participants ranked the categories in order of importance utilizing the paired-weighting procedure, which is a preferred method for group exercises (Witkin & Altschuld, 1995). The paired-weighted procedure is the process of ranking by comparing one category of data to another (Witkin & Altschuld, 1995). The prototype development groups narrowed each category down to two for each underrepresentation, knowledge, motivation, and culture theme, as well as underutilization, motivation, and culture theme. Figure 7 depicts the analysis process for the prototype development groups.

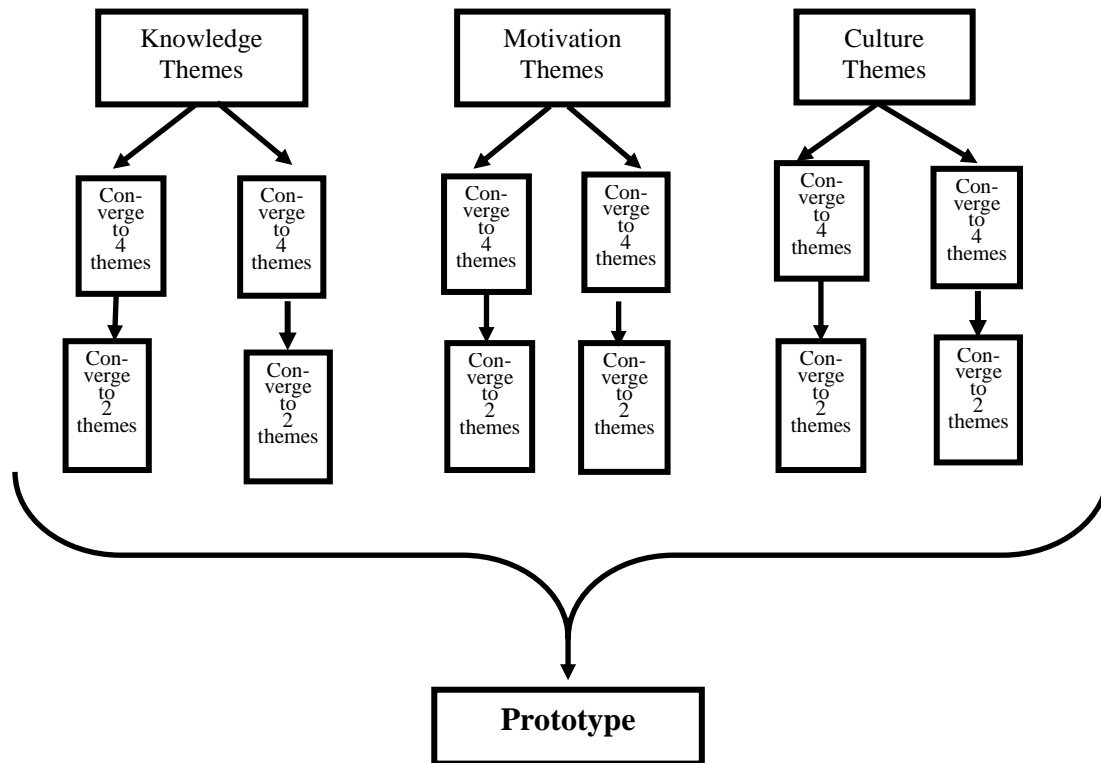


Figure 7. The prototype development group analysis process.

Each prototype development subgroup was tasked with conducting rapid prototyping to create visible renditions of concepts. The premise of creative design and innovation is to allow the process to unfold inductively without a pre-conceived idea of the outcome (Brown, 2009; Liedtka & Ogilvie, 2011). This process enabled the prototype development groups to test the viability of concepts. To complete the task, I provided the participants with the supplies necessary to conduct the exercises including: pens, markers, sticky notes, construction paper, scissors, tape, self-stick wall pads, pipe cleaners, glue, and other items to facilitate a creative rapid prototyping process.

Each prototype development subgroup presented their final prototype to the entire prototype development group. More assumption testing was done with the prototype development subgroups before the final presentations. Each prototype development group member voted to select the final prototype to be field tested. This process was repeated with each prototype development group yielding one viable prototype per prototype development group. I selected the final prototype from the two remaining prototypes. The final prototype consisted of a pre-prototype field survey, an introduction, three videos, a panel discussion consisting of Black bone marrow donors, a question and answer session with the panelists, and a post-prototype field survey. The final prototype is discussed in more detail in Chapter 4.

Prototype field test. The prototype field test provided this study with a wealth of data. The data collection from the prototype field test was derived from the pre- and post-prototype field test surveys (see Appendices D & T), as well as the questions the participants had asked of the panelists. I began coding the data of the pre- and post-prototype field test by plotting their coordinating questions and answers alongside one another, allowing me to quickly assess the narrowing of the KMC gaps before and after exposure to the prototype. I coded the answers to each of the questions deductively within the parameters of the KMC inquiry questions. Then I coded the data again, letting the themes emerge from the data. Regarding the questions asked of the panelists, I grouped all the questions that were similar into categories. Then I plotted the answers to each of those questions on a spreadsheet before I coded each of the answers. Just like with the surveys, I coded the answers deductively according to the KMC parameters before enlisting inductive coding.

Ethics

Before commencing the prototype development groups and interviews, each participant was required to read and sign a consent form, which I had also signed. The consent form asked for permission to collect data, for the purposes of this study, from the surveys and prototype development group exercises. The consent form included the requirements set forth by Creswell (2013). According to Creswell (2013), consent forms require the following to be included:

The right of participants to voluntarily withdraw from this study at any time; the central purpose of the study and the procedures to be used in data collection; the protection of the confidentiality of the respondents; the known risks associated with participation in the study; the expected benefits to accrue to the participants in the study; and the signature of the participant as well as the researcher. (p. 153)

I worked within the guidelines of AERA (aera.net) and my dissertation chair throughout all areas of this study. The appropriate approvals and consent were obtained prior to engagement to ensure participants' rights and the rights of those participating in the videos. Any ethical concerns were reported through the proper channels. Additionally, I took all precautionary measures to ensure unbiased instruments, coding, interpreting, and reporting.

Quality

This research employed a constructivist approach. The purpose of this study was to ascertain the KMC needs of the Black participants regarding joining the Registry and participating in the bone marrow donation process. I understood that the KMC needs may have been different for each participant, yielding multiple outcomes (Hong, Morris, Chiu, & Benet-Martinez, 2000; Jacobson, 1998; Rovai, 2004). Thus, the outcomes of this study cannot be generalized throughout the Black community (Jacobson, 1998).

The constructivist stance is based on an individual's truth (Hong et al., 2000; Jacobson, 1998; Rovai, 2004), which could be drawn from multiple variables. These variables could

include the (a) participant's current knowledge, (b) participant's experiences, and (c) the participant's interpretations and meanings associated with these experiences (Jacobson, 1998). I understood that these variables could not be controlled.

The premise of the constructivist approach is that an individual's knowledge cannot be separated from the person (Jacobson, 1998; Rovai, 2004). Knowledge was dependent on each individual, which could be affected by a person's values, experiences, and interpretations of those experiences (Jacobson, 1998; Rovai, 2004). The participants of this inquiry may have varied knowledge regarding the Registry, the matching process, the donation process, and the critical need within the Black community. It did not necessarily mean that all Blacks would join the Registry and participate in the bone marrow donation process once knowledge had been acquired because the value and interpretation of this knowledge may prove to be meaningless to some (Jacobson, 1998). Additionally, it does not mean that the constructs of the participants' knowledge would take the forefront of their mind at any point during or throughout their participation (Hong et al., 2000).

Human experience also highlights the foundation of constructivism (Jacobson, 1998). A person's interpretations and meanings are derived from their experiences, and knowledge is dependent on the human experience. The constructivist approach supports that the knowledge, voice, and experiences derived from the researcher also influences the research. The methods and data collection processes were chosen based on my experience and association with the research topic.

The constructivist approach does not come without limitations. One of the limitations is that I may not interpret the participants' reality accurately (Jacobson, 1998; Rovai, 2004). On the other hand, the participants may not have shared their truths. The constructivist understands

that a homogeneous approach may yield outcomes from multiple reference points (Jacobson, 1998; Rovai, 2004). Thus, all the participants could have been given the same stimulus; however, their responses would have come from varied contexts. For example, participants viewed three short videos about the Registry, the matching and donation processes, and the critical need in the Black community. These videos left each participant with their own interpretations and understandings of the video.

Triangulation

This study utilized multiple interconnected data sources during the data collection. I employed an observation, post-observation survey, prototype development group survey, two identical prototype development groups, donor interviews, pre- and post-prototype field test survey, and prototype test group. I utilized multiple sources of data collection to validate emerging themes through triangulation. The donor interviews were used to triangulate the findings from the observation, post-observation surveys, pre-prototype development group surveys, prototype development groups one and two, pre- and post-prototype field test survey, and the prototype field test.

Limitations of the Project

There are several limitations to this study. One limitation, particularly for the prototype development groups, is that participants may not have a good understanding of the Registry, the matching process, donation process, or the critical need for Blacks to join the Registry and participate in the bone marrow donation process. To minimize this limitation, I showed the participants three short videos about the Registry, the matching and donation process, and the critical need to give context to the study. The second limitation to this study is conducting telephone interviews. Telephone interviews did not allow me to visualize nonverbal

communication. It also limited my ability to build rapport with the participant. On the other hand, there is an advantage to a telephonic interview. The participants may have felt more comfortable with sharing intimate details when they were not in the presence of the interviewer. In contrast, a face-to-face interview could have had its own complications as well. The participants may have felt intimidated by me or the interview questions, which could have lead the participant to be untruthful or vague. The nature of an interview sets up an unequal power dynamic between the interviewer and the interviewee. The interviewer is the one controlling the interview (Creswell, 2013). To minimize these limitations, each interviewee was given the choice of being interviewed face-to-face or telephonically.

Threats to quality. There are a couple of threats to the validity of this study. Participants may have been reluctant to tell the truth or may have withheld critical information. Participants may have felt compelled to answer questions based on what they thought I wanted to hear. Additionally, some prototype development group members may have succumbed to group think or group coercion.

Positionality. I am passionate about this study. It is difficult for me to understand that outside of a medical condition preventing Blacks from joining the Registry and participating in the bone marrow donation process that an informed person would choose to not join the Registry. Initially, the study topic was the limitations preventing Blacks from join Registry, which was more connected to my bias. The current topic surrounding the needs of Blacks to circumvent KMC limitations to joining the Registry and participating in the bone marrow donation process is not linked to my bias. At least, I had chosen not to engage participants in this study regarding whether or not they would or would not choose to join the Registry. Thus, I was able to minimize bias regarding positionality.

Conclusion

In this study, I utilized multiple interrelated data collection methods to obtain a broader view of Black's KMC needs from the perspective of both registrants and non-registrants, as well as from previous bone marrow donors. I actively engaged participants in the development of data collection to make sense of the participants' world and their interpretations of their realities. This was done utilizing various design thinking tools, such as brainstorming, concept development, assumption testing, rapid prototyping, and participant co-creation. The data were analyzed, categorized, and condensed into a final prototype using participatory data analysis. In Chapter 4, I review the findings from the data analysis.

Chapter 4: Findings/Results

In the previous chapter, the knowledge, motivation, and culture (KMC) theoretical framework was discussed. I expounded on how the theoretical framework would be utilized to guide the study through the process of answering the research questions. In this chapter, I provide an overview of the data collected, which falls into four categories. The first is observations, which encompass observation solicitations and post-observation surveys. The second is interviews, which includes a pre-interview survey and five donor interviews. Next is the prototype, which includes a prototype development group survey and two prototype development groups. Last is the prototype test consisting of a pre-prototype field test survey, prototype field test group, and a post-prototype field test group survey. I highlight the data that answer the research questions aimed at narrowing the KMC gap representing the needs of Blacks to join the Registry and participate in the bone marrow donation process. Table 4 depicts the data collection processes, settings, and their purposes.

Table 4

Data Collection Processes

Process	Setting	Participants	Purpose
Observation Solicitations	A community college in Northern California	Nine Black students attending a community college in Northern California between the ages of 18 and 61	To observe the Registry's staff and volunteers solicit Blacks to join
Post-observation Surveys	A community college in Northern California	Four Black students attending a community college in Northern California between the ages of 18 and 61	Ascertain the participants' KMC needs
Pre-interview survey	Telephone conference	Five Black bone marrow donors living in the United States between the ages of 18 and 61	Informs this study on when the participants joined the Registry, became a match, and donated to a non-relative
Five donor interviews	Telephone conference	Five Black bone marrow donors living in the United States between the ages of 18 and 61	<ul style="list-style-type: none"> • Answers the research questions • Participants' KMC needs prior to joining the Registry and prior to participating in the bone marrow donation process • How the participants overcame their KMC needs
Prototype Development Group Survey	Northern California	11 Blacks living or working in Northern California between the ages of 18 and 61	To obtain demographic data and KMC needs
Prototype Development Groups	Northern California	11 Blacks living or working in Northern California between the ages of 18 and 61	To develop a prototype that would narrow the KMC needs gap of the prototype test group participants, enabling them to join the Registry and participate in the bone marrow donation process
Pre-prototype Field Test Survey	An African American class at a community college in Northern California	Blacks between the ages of 18 and 61 that were enrolled in a Black course at a community college in Northern California	Ascertain the participants' current KMC needs prior to exposure to the prototype
Prototype Field Test Group	An African American class at a community college in Northern California	Blacks between the ages of 18 and 61 that were enrolled in a Black course at a community college in Northern California	The Final Prototype: Introduction, three videos about the Registry, panel discussion, and questions and answers with the panelists
Post-prototype Field Test Survey	An African American class at a community college in Northern California	Blacks between the ages of 18 and 61 that were enrolled in a Black course at a community college in Northern California	Assess the participants' KMC needs after exposure to the prototype

Observations

During this study, nine observations were made at a blood and bone marrow drive held at a community college campus in Northern California. The purpose of the observations was to watch the Registry's staff and volunteers solicit Blacks to join the Registry and participate in the bone marrow donation process. The goal was to collect data in five key areas: (a) how the Registry engages potential registrants, (b) what type of information was disseminated to the potential registrants, (c) what type of questions were being asked by the observed, (d) how the questions were addressed, and (e) what the outcomes were.

Observation subjects. The observation subjects consisted of nine Blacks that appeared to be between the ages of 18 and 61. They were all students, staff, or visitors on the community college campus at the time of the solicitation. The function of the observation subjects was to inform this study on the experiences of the solicited from their perspective. This was accomplished through the nine observations and four observation surveys.

How the Registry engages potential registrants. The observation subjects were approached in three different ways: (a) soliciting observation subjects walking by the booth, (b) soliciting observation subjects who originally approached the booth to donate blood, and (c) a Registry representative walked around the campus soliciting observation subjects. Five of the observation subjects were solicited as they walked by the booth, while two observation subjects had approached the booth to donate blood. A Registry representative walked around campus seeking potential registrants, which is how the remaining two observation subjects were solicited. Table 5 depicts how the Registry engaged with the observation participants.

Table 5

Types of Registry Solicitation Engagement

How the Registry engages potential registrants	Observation subjects	Gender	Response
A representative asked an observation subject, as he/she walks by the booth, if they had ever heard of the Registry	Alex	Female	None of the observation subjects had ever heard of the Registry
	Blair	Female	
	Cassidy	Male	
	Jamie	Male	
	Kennedy	Male	
Observation subject approached the booth to sign up to donate blood. A representative sign them up to donate blood. While they are waiting their turn to donate blood a Registry representative asks them if they had ever heard of the Registry.	Addison	Female	None of the observation subjects had ever heard of the Registry
	Kendall	Female	
A Registry representative walked around the campus soliciting potential registrants.	Chris	Male	None of the observation subjects had ever heard of the Registry
	Drew	Male	

Information disseminated to potential registrants. The Registry representative began the solicitation by asking each observation subject whether they had ever heard of the Registry. This question was the catalyst leading to the actual solicitation. The Registry representative allowed the questions and answers of the observation subjects to guide the dialogue. All the observation subjects indicated they had not ever heard of the Registry. Seven of the observation subjects allowed the dialogue to continue, while two simply said no they had not heard of the Registry and continued on their way. Seven were informed about two or more of the following (a) who is the Registry and its purpose, (b) why bone marrow is needed, (c) a general brochure

about the Registry was given to observation subjects who had asked questions, (d) a brochure about the donation process, and (e) a binder that had a list of medical conditions that would prohibit a person from joining the Registry and participating in the bone marrow donation process. The Registry representative spent less than one minute with the two observation subjects who chose not to engage in dialogue after stating they had never heard of the Registry. Approximately two to three minutes was spent with six of the observation subjects and about five minutes with the remaining one.

Type of questions asked. Several questions were asked during the Registry solicitation. First, the Registry representative asked whether the observation subjects had ever heard of the Registry. If yes, the Registry representative asked if the observation subjects were between the ages of 18 and 61. The representative quickly informed the observation subjects about the purpose of the Registry after the subject indicated they met the age requirement.

Knowledge. After the qualifying question, the dialogue became more focused and targeted towards the questions and concerns of the observation subjects. The observation subjects asked a wide variety of questions. Blair, Chris, and Kennedy asked health and procedural questions. Blair asked, “Why is bone marrow needed?” Blair and Kennedy inquired about how the bone marrow is extracted. Blair was also concerned about whether diabetes would prohibit her from joining the Registry and participating in the bone marrow process.

Motivation. Some of the questions and concerns uncovered the motivations of the observation subjects. Blair inquired about the financial costs to the donor. In contrast, Chris and Kennedy were concerned about the impact costs would have on themselves. They asked whether the bone marrow donation process would be painful. On the other hand, Jamie wanted to know who would receive his bone marrow donation.

How questions were addressed. The Registry representative addressed some of the observation subjects' questions and concerns verbally and others with literature. All observation subjects, with the exception of Alex and Drew, were offered a general brochure that had basic information about the Registry and its website address for observation subjects to obtain additional information. In conjunction with a verbal response, some observation subjects were given brochures focused on the observation subjects' questions and concerns. Blair, Chris, and Kennedy were given a brochure about bone marrow donation, which addressed their questions regarding extraction processes, pain, and recovery time.

Outcomes. None of the observation subjects joined the Registry. Alex and Drew simply walked away after being asked if they had ever heard of the Registry. Kennedy and Jamie decided not to join, indicating they needed more time to think about it. Cassidy wanted to know if he did decide to join, whether he could change his mind later. The Registry representative told Cassidy he should only join the Registry if he were willing to follow through with the donation process. Cassidy was encouraged to carefully think it through before joining. Blair was willing to join; however, after referencing the medical binder regarding her diabetes, elected not to join at that time. Table 6 depicts the information shared with each observation subject and the amount of time spent with each.

Table 6

Observation Data

Observation Subjects	Information Shared	Questions asked by Observation Subjects	How were Questions Addressed	Time Spent	Outcomes
Addison	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> No questions 	N/A	2-3 minutes	Did not join
Alex	<ul style="list-style-type: none"> Nothing 	<ul style="list-style-type: none"> No questions 	N/A	Less than one minute	Did not join
Blair	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> How much would it cost me to donate? Why is bone marrow needed? How do they get the bone marrow out? Could I join if I have diabetes? 	Verbally, general & donation brochures, & medical binder	5 minutes	Did not join due to medical issue
Cassidy	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> Could I change my mind? 	Verbally	2-3 minutes	Did not join
Chris	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> Does it hurt? 	Verbally, general & donation brochures	2-3 minutes	Did not join
Drew	<ul style="list-style-type: none"> Nothing 	<ul style="list-style-type: none"> No questions 	N/A	N/A	Did not join
Jamie	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> Do you know who it is going to? 	Verbally & general brochure	2-3 minutes	Did not join
Kendall	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> No questions 	N/A	2-3 minutes	Did not join
Kennedy	<ul style="list-style-type: none"> Who is the Registry Why is bone marrow needed 	<ul style="list-style-type: none"> How do they get the bone marrow out? Does it hurt? 	Verbally, general & donation brochures	2-3 minutes	Did not join

Post-Observation surveys. The purpose of the post-observation survey was to ascertain the participants' KMC needs that led to their decision to join or not join the Registry and participate in the bone marrow donation process. Seven of the nine observation subjects were asked to complete a post-observation survey. Alex and Drew were not invited to do so because they had abruptly ended the solicitation. Blair, Chris, Jamie, and Kennedy agreed to participate in the post-observation survey process. They were asked 11 questions developed to obtain their KMC needs that were critical to their decision to join or not to join the Registry.

Knowledge. The participants were asked a set of questions to obtain their knowledge of the Registry. One of the results of the survey found that none of the participants was aware of the Registry prior to the bone marrow drive; however, they indicated they had learned about the Registry as a result of the solicitation. Blair and Jamie also learned during the solicitation about the critical need to join due to the underrepresentation and underutilization of Blacks on the Registry. Also, Chris and Kennedy learned there were two bone marrow extraction processes: one surgical and the other non-surgical.

Motivation and culture. The remaining survey questions pertained to the motivation and culture framework elements. It is important to know what motivated each participant to attend the blood and bone marrow drive and what things they had taken into consideration to aid them in their decision to join the Registry. Blair was the only participant who had approached the booth unsolicited inquiring about the bone marrow drive despite the fact she had stated earlier she knew nothing about the Registry prior to the bone marrow drive. She was motivated by a sense of empowerment and had taken the critical need for Blacks to join the Registry and participate in the bone marrow donation process into consideration. While Chris and Kennedy were solicited, they had taken one thing into consideration: the ability to save lives. Although

the possibility of saving lives gave them a sense of empowerment, Chris and Kennedy still decided not to join the Registry.

To successfully recruit Blacks to join the Registry, it is critical to understand what would motivate them to join. The observation subjects shared some things that would motivate them to join. Chris, Jamie, and Kennedy stated that the possibility of “saving lives” would motivate them to join the Registry, while Blair had referenced the low participation in the Black community as a motivation for her to join. Beyond just joining the Registry, all four observation subjects indicated they would feel empowered helping someone in need. Jamie stated that he would want someone to do the same for him. If they were ever called upon to donate bone marrow to a non-relative, they all felt they would receive support from others. Chris, Jamie, and Kennedy believed they would receive support from their friends and family, whereas Blair indicated she would only receive support from family. Despite all of this, none of the participants joined the Registry on the date of the bone marrow drive. Chris, Jamie, and Kennedy indicated they did not understand the matching and donation processes. In contrast, Blair stated that she would sign-up online.

Interviews

The interview data collection section encompassed a pre-interview demographic survey, as well as five donor interviews. The participants consisted of five Blacks between the ages of 18 and 61 who were previous bone marrow donors. All five participants completed the pre-interview demographic survey and the donor interview. They had all donated to a non-related recipient and resided throughout the United States.

To protect their privacy, I gave each pre-interview survey and interview participant gender-neutral pseudonyms: (a) Bailey, (b) Jesse, (c) Jordan, (d) Kelly, and (e) Sam. The

purpose of their participation in this study was to ascertain their KMC needs when they joined the Registry and participated in the bone marrow donation process. Additionally, the data serve to inform this study on how they were able to overcome their KMC needs.

Pre-Interview demographic survey. One of the sources of data collected during this study was a pre-interview survey, which consisted of 12 questions. This survey asked pre-qualifying questions to ensure the participants met the study's age and ethnic requirements. The purpose of this survey was to inform the participants' level of awareness about the Registry. The survey also gathered the date the participants joined the Registry, when they became a bone marrow match, the date they donated, and the extraction process they underwent.

Joining the Registry. The interviewees were motivated to join the Registry for various reasons. Her mother's volunteerism while Bailey was young served as a catalyst for Bailey. Bailey joined the Registry in Houston, Texas on March 3, 1999 at a bone marrow drive at the university she had attended. Jesse had joined the Registry after organizing and attending a church event aimed at creating awareness about the Registry and recruitment. At the time, Jessie served as the president of the men's fellowship club at his church in the Midwest. As president, one of the tasks was for him to create events around issues regarding health. Jesse had originally made arrangements for the American Heart Association to present; however, they backed out at the last minute, and the Red Cross had referred him to the Registry. Jesse had not heard of the Registry prior to him contacting them. Jesse joined the Registry during the bone marrow drive he organized in March 2003. Fifty other members of his church joined that day as well. On the other hand, Jordan joined the Registry after stumbling upon a blood drive. He did not have the 45 minutes to one hour needed to donate blood, so he decided to leave. This is when Jordan was solicited by a representative of the Registry who indicated it would only take five minutes to

join, so Jordan decided to join the Registry. “So, I did.” Jordan had never heard of the Registry prior to joining. In contrast, Kelly joined the Registry in Stockton, California in 2001 after watching a news broadcast about a young Black boy in need of a bone marrow transplant. Sam joined the Registry during his senior year of high school where he had attended a blood drive hosted by his high school. The Registry had been in attendance as well, recruiting for new registrants. Sam was 18 years old at the time, which is the minimum age requirement to join the Registry. Sam recalled not knowing anything about the Registry or its processes and joined the Registry that day on February 1, 1996.

Bone marrow donation. All the participants had indicated they had donated bone marrow one time to a non-relative. Bailey had been on the Registry for 13 years before she was first notified; she became a bone marrow match in 2012. Jesse was first notified of being a bone marrow match in April 2003, which occurred only three weeks after joining the Registry. Similarly, Jordan first received news of being a bone marrow match in May 1990, also three weeks after joining the Registry. The Registry conducted its first transplant three years before Jordan’s donation. Kelly was first notified in April 2002 that she was a bone marrow match to a recipient in need, one year after she had joined the Registry. Last, Sam was informed on April 5, 2015, which occurred 20 years after joining the Registry. Jesse and Jordan waited the shortest amount of time between joining the Registry and becoming a match.

The interviewees’ donations took place two months to one year after becoming a bone marrow match. Bailey donated bone marrow surgically on July 9, 2013, and her donation occurred one year after becoming a bone marrow match. Jesse donated surgically in early June 2003. His donation occurred two months after becoming a bone marrow match. Whereas, Jordan donated surgically in 1990, a few months after becoming a bone marrow match. Kelly

donated surgically in 2002, a few months after becoming a match. More recently, Sam donated non-surgically on April 5, 2016, one year after becoming a bone marrow match. Sam is the only participant who donated via PBSC, or non-surgically. Table 7 depicts when each interviewee joined the Registry, became a bone marrow match, and donated bone marrow.

Table 7

Donor Interviewees

Name	Gender	Joined Registry	Date became a bone marrow match	Date of Donation	Donation Process
Blair	Female	3/3/1999	7/2012*	7/9/2013	Surgical extraction
Kelly	Female	2001*	2002*	2002*	Surgical extraction
Jesse	Male	3/2003*	4/2003*	6/2003*	Surgical extraction
Jordan	Male	1990*	1990*	1990*	Surgical extraction
Sam	Male	2/1/96	4/12/2015	4/5/2016	Non-surgical extraction or PBSC

*The exact date is unknown.

Donor interviews. The donor interviews were an important source of data collection during this study. The purpose of the donor interviews was threefold. First, the donor interviews

assisted this study with answering the research questions. Second, the donor interviews provided this study with a foundation of the participants' KMC needs when joining the Registry and participating in the bone marrow donation process. Most importantly, the donor interviews informed this study about how the participants were able to overcome their KMC needs and continue with the bone marrow donation process. Five interviews were conducted for this study. The interviewees were Blacks between the ages of 18 and 61 living in the United States. They were currently on the Registry and had all participated in the bone marrow donation process for a non-related recipient.

Knowledge: Underrepresentation. This study explored the knowledge needed by the interviewees in order for them to join the Registry. These questions were focused on the time period between joining the Registry and before being identified as a bone marrow match. All the interviewees were not aware of the Registry prior to them joining. The interviewees shared that they had learned about the Registry during the solicitation to join. On the other hand, all but Jesse had learned about the matching process after becoming a match. In contrast, Sam had learned about the matching process during the solicitation process to join the Registry.

The interviewees' knowledge of the donation process prior to joining the Registry. Four interviewees stated they knew nothing about the donation process prior to joining. Bailey, Kelly, Jordan, and Sam all stated they had not learned about the donation process until after they were informed they were a match. The registry representative had thoroughly explained the process to them during that call. In contrast, Jesse was informed about the donation process during the bone marrow drive he had organized at his church. That means Jesse was not informed about the matching process; however, he was informed about the donation process during the bone marrow drive.

In contrast, the interviewees had learned about the critical need for Blacks to join the Registry through several avenues. Bailey stated she learned about the critical need for Blacks to join the Registry when she was contacted by the Registry representative to inform her that she was a bone marrow match. During that conversation, Bailey was also informed about the importance for her to follow through with the bone marrow donation process. On the other hand, Kelly had learned about the critical need for Blacks to join from the news broadcast that had implored her to join the Registry in an attempt to find a match for a young Black child with a blood-borne cancer. Jesse had learned about the critical need for Blacks to join the Registry through two sources. First, he had learned from the Registry during the bone marrow drive at his church. The second source of information was from Jesse taking initiative and conducting his own research online. In contrast, Jordan and Sam had not learned about the critical need for Blacks to join the Registry and participate in the bone marrow donation process until this study. Sam had assumed, “Well, if I’m doing it, then everybody’s doing it.”

Knowledge: Information. The next set of data discusses the information the interviewees wish they had known prior to joining the Registry. Sam stated that he wished he had been told about the time that it takes being on the Registry before you are ever a match. “‘Cause it’s not a next day thing. It’s not a next year thing. Sometimes, the whole lifetime waiting.” Sam stated that not having this information prior to joining the Registry had no effect on his decision to join. On the other hand, Bailey and Sam had concerns about the information regarding the matching process. Bailey stated she was given too much information. She explained that it was “sometimes too detailed.” Bailey wished the information could have been simplified because the terminology became too complicated, which made her tune out and not

listen. In contrast, Sam wished he had been told that he would not have any communication with the person to whom he was donating.

Motivation: Underrepresentation. The next set of data pertains to motivation as it relates to the underrepresentation of Blacks on the Registry. The data cover the thoughts and things the interviewees had taken into consideration before deciding to join the Registry. Jesse considered the critical need for Blacks to join the Registry. He also felt obligated to join since he was the president of the men's fellowship group at his church and he had organized the blood drive. On the other hand, Sam took his health into consideration. He wanted to know how this would affect his health and whether he would regenerate the donated bone marrow.

Next, the interviewees shared what actually motivated them to join. Bailey, Jordan, and Sam were motivated to join the Registry based on the need for people in general to join; however, Jesse was motivated to join the Registry based specifically on the need for Blacks to join and participate in the bone marrow donation process. Kelly was motivated to join based on an emotional appeal on a news broadcast reporting about a Black child in need of a bone marrow transplant. All the interviewees expressed feeling good, excited, happy, and proud to join the Registry. Bailey stated that joining the Registry made her feel as if she had already saved a life.

Knowledge: Underutilization. The purpose of this section is to identify the knowledge Black donor participants needed in order to join the Registry. This discussion is based on the time period between the time when the interviewees were first notified that they were a bone marrow match through the bone marrow donation. The interviewees described their feelings and thoughts when they were first notified they were a bone marrow match. All the participants expressed feelings of excitement and nervousness. Jesse recalled being in a prayer circle with a group of people from all over the country in front of the Supreme Court in Washington, DC.

They were praying about affirmative action being implemented in the college admissions process and were about to begin marching in front of the Supreme Court when his phone rang. It was the Registry. He was informed that he was a bone marrow match to a two-year-old Black child. Jesse donated bone marrow two months after becoming a match.

After becoming a match, questions and concerns arose. For Bailey, Kelly, and Sam, their feelings of elation quickly dissipated after being told they were a match. Their feelings were replaced with questions and concerns. Bailey remembers asking if anyone had died from donating bone marrow. She said it was not so much of a concern, but a curiosity. Whereas Kelly wanted to know what it meant and what all it involved. Sam wanted to know if he would feel pain and discomfort from the donation process. He finally concluded, “I am going to walk out the same way that I walked in. I can do this.” Also, Kelly wanted to know whether she was related to the recipient since she was a perfect match.

They also had questions and concerns regarding the donation process. After Bailey was informed that she was a match, Bailey wondered whether they would keep her awake during the donation process or would she be under anesthesia. She confided that if she would have been awake during the donation process, she would have changed her mind. Jesse and Kelly had questions regarding the risk factors and how they would affect their health in the short- and long-terms.

Motivation: Underutilization. The next set of data pertains to motivation as it relates to the underutilization of Blacks participating in the bone marrow donation process. The purpose of this section is to identify what motivated the Black donors to donate bone marrow, whether they were supported, and if they had to overcome any obstacles. This section focuses on the

time period between the time when the interviewees were first notified they were a bone marrow match through the bone marrow donation.

Moving forward. The interviewees informed this study why they had decided to move forward with the bone marrow donation process. Bailey, Kelly, Jesse, and Jordan stated they were motivated to move forward based on the need alone. Bailey stated she was motivated to move forward just by the thought that her recipient was in need. She felt empowered knowing she could possibly extend this person's life. Bailey had imagined her recipient fighting for her life and "all this person has gone through, with chemo and radiation. All that she has subjected her body too and she still wants to live on." Bailey went on to say that her recipient was 52 years old at the time of the donation. "She could have easily just thrown in the towel. Even at 52, she said to herself, I've got a lot of living to do." On the other hand, Bailey had considered the time away from work and stated that she felt very anxious about having to tell her job that she needed to take some days off. She was unsure how her job would react to it. Bailey had "months of personal time leave built up, but I still felt a little bit of anxiety about approaching my job." Bailey went on to say that she feared losing her job if she took the time off.

Like Bailey, Kelly and Jesse were motivated to move forward with the donation process based on the need of their recipient. Jesse was focused on the life of a two-year-old. I had remembered during a previous conversation he had shared with me that he had a one-year-old child. This prompted me to ask whether he had taken his child into consideration before deciding to donate bone marrow. Jesse said he did take his child into consideration. He stated, "I would want someone to do it for my one-year-old." In contrast, Sam was focused on his own health and wanted to know how much time he would need to recuperate and the short- and long-

term effects of the donation. Sam was most concerned about malingered pain as a result of the procedure.

After exploring how others thought of the interviewees' decision to donate, it was important to gauge how the interviewees felt about donating to a person in need. Bailey remembered feeling like a superhero. "I felt like I had done something that few people in life get to do." Bailey explained that donating bone marrow made her a better person. She felt the need to get in shape and work on her own health because she did not know if she would be called to donate again. It also inspired Bailey to become an advocate for the Registry. Kelly, Jesse, Jordan, and Sam indicated that donating to someone in need made them feel proud of what they had done.

Support. Interviewees shared who they had first told about being a match and the impact of their support or lack of support. Bailey first shared her news of being a bone marrow match with her spouse and mother. Bailey's mother was a little apprehensive about the prospect of her undergoing surgery. The mother soon gave her full support after Bailey had informed her mother about the purpose of the Registry. Bailey's mother showed her support by bragging to family and friends about the wonderful act Bailey was about to do for a person in need. This made Bailey feel very proud of her decision to donate. Jordan also first shared his news with family. His twin was proud of him when he told him the news.

Lack of support. It is just as important to consider the impact on the interviewees when people demonstrate a lack of support. Bailey was quick to state that her father did not support her decision to donate bone marrow and was completely against it. Bailey's father told her that she was "going to die." He made references to the Tuskegee Institute experiment, Henrietta Lacks, and others. He told Bailey they were going to harvest her organs and sell them on the

black market. Bailey explained, “He is from an era and time that’s a little different than now. He rarely goes to the doctor himself. He’s got a phobia of the medical community.” Bailey shared that she would have liked to have had her father’s support.

Jordan also experienced some negativity towards his decision to donate bone marrow. A couple of Jordan’s friends told him he should not go through with the process. Jordan was disappointed by their lack of support. He stated this experience let him know who his true friends are.

Similarly, Sam also had friends that tried to talk him out of the donation process. They questioned whether he had made a sound decision and assured him they would not judge him if he changed his mind. Sam stated he was able to deflect the negativity because “nobody was going to talk me out of it.” Sam went on to say that he knew he would be okay because he had “the backing of the doctors that were a part of the process.”

Culture: Underutilization. The next set of data was collected to obtain the cultural beliefs and attitudes that may support or prevent Blacks from joining the Registry. The focus is during the time period between becoming a match and donating bone marrow. The interviewees shared what their church thought of their decision to donate and how it affected their decision to donate. Jesse was happy to inform his church, considering many church members witnessed him join the Registry. He said the church members were thrilled. “Here we are 15 years later, and they still remembered the day we joined the Registry. They are still thrilled about all of it.” The church welcomed Jordan’s decision to donate bone marrow as well. They were excited for him. They showed their support by praying for him, as well as for the recipient. He knew he had made the right decision.

Would you do it again? The interviewees shared whether they would be willing to donate bone marrow again to a non-relative and they all stated they would do it again. Bailey said, “Saving a life gives you a feeling that you cannot explain to someone who had never done it before. If I couldn’t do anything else for this person, I have done my part.” Bailey stated that many people do not ever hear from their recipient; however, that was not her case. Bailey remembered meeting her recipient, which motivated her to donate again if called.

The act of saving a life also inspired Jesse. He had joined the Registry in March 2003, and he became a match just three weeks later to a Black two-year-old male child. The donation occurred in early June just three months after the bone marrow match. By December 2003, Jesse had started a non-profit organization geared towards creating awareness in the Black community and underrepresented groups within the Detroit, Michigan area.

On the other hand, the act of saving a life was bittersweet for Jordan. He had joined the Registry on a whim in 1990, and he also became a match just three weeks after joining the Registry. Jordan’s recipient was able to survive his leukemia diagnosis after receiving Jordan’s donated bone marrow. Ten years after Jordan had donated bone marrow for a non-related recipient, his identical twin brother, Victor, was diagnosed with leukemia. Victor was unable to find a bone marrow match. Jordan was a natural match being an identical twin; however, Jordan was not a viable donor due to his diabetes, which he had gotten years after his bone marrow donation in 1990. Victor died two days before their 50th birthday in August 2017.

Prototype Development

The prototype development section consists of a pre-prototype development group survey and two prototype development groups. The purpose of prototype development is to create a possible solution to the problem of the underrepresentation and underutilization of Blacks on the

Registry. All the participants of the prototype development groups completed a pre-prototype development group survey. The participants in the prototype development section consisted of African-Americans between the ages of 18 and 61 who lived or worked in the Sacramento or North Bay areas.

Pre-Prototype development group surveys. Pre-prototype development group surveys were another source of data utilized during this study. The purpose of the pre-prototype development group surveys was to collect demographic information about the participants, as well as ascertain their KMC needs. There were two prototype development groups, each consisting of different participants: five participants in the first prototype development group and six in the second. Each of the participants completed a pre-prototype development group survey, which consisted of 10 questions.

Survey results. One of the purposes of this survey was to ascertain when the participants first heard of the Registry to determine the awareness level of the participants prior to this study. The time frame of when the prototype development group participants first heard of the Registry varied widely from early 2001 to March 2018 during the recruitment process for this study. Six of the participants indicated they were aware of the bone marrow matching process. Similarly, seven participants indicated they were aware of the bone marrow donation process. In contrast, only three stated they were aware that 90% of bone marrow matches occurred within the same ethnicity.

Despite the fact that over half the prototype development group participants were aware of the Registry, only three had indicated they were on it. Also, three participants knew someone who was on the Registry at the time of the study. Of the three participants on the Registry, one participant indicated they were a match to someone who was a non-relative. On the other hand,

two had stated they had known of someone who had needed a bone marrow transplant in the past. Four participants indicated they knew someone who had donated in the past.

Prototype development groups. A total of two prototype development groups each consisted of different participants: one prototype group consisted of five participants and the other six. Each prototype development group utilized participatory research and collaboration consisting of members of the community being studied. The purpose of these groups was to develop a prototype as a possible solution to narrow Blacks' KMC needs preventing them from joining the Registry and participating and the bone marrow donation process.

To create the prototype, the prototype development group utilized design thinking. The design thinking process consisted of iterative brainstorming exercises, the completion of project management aids, the diverging of data into common themes, and rapid prototyping and prototype testing. Each prototype development group presented their prototype(s) and then they all voted for the final prototype. The final prototype was tested in the field, which is discussed later in this chapter and in Chapter 5. The results of the iterative brainstorming process after the data were coded into themes as shown in Figure 8, the collection data after having been coded into themes and ranked in order of hierarchy.



Figure 8. Results of the prototype development group's (group two) iterative brainstorming.

The final prototype. The final prototype emerged from the prototype development groups, consisting of a pre-prototype field test survey, an introduction, three videos, a panel discussion consisting of Black bone marrow donors, a question and answer session with the panelists, and a post-prototype field survey. The purpose of the pre-prototype field survey was to measure the participants' current awareness of the Registry before being exposed to the prototype, its processes, and the critical need for Blacks to join the Registry and participate in the

bone marrow registry process, as well as the participants' KMC needs. The introduction provided an overview of the purpose of the study and how it will be used in the future, the purpose and history of the Registry and its processes, and the agenda and timeline of the prototype field test. Videos were used to introduce the participants to the bone marrow Registry and its processes, as well as to the critical need for Blacks to join the Registry and participate in the bone marrow donation process. The panel discussion and questions and answers served to inform the participants about the panelists' experience as bone marrow donors. The post-prototype field survey serves as a measuring tool, indicating the effectiveness of the prototype at narrowing the KMC gaps of the prototype field test participants. Figure 9 illustrates the prototype the prototype development groups decided to be the best and final prototype that would narrow Blacks' KMC needs gaps. The prototype was field tested.

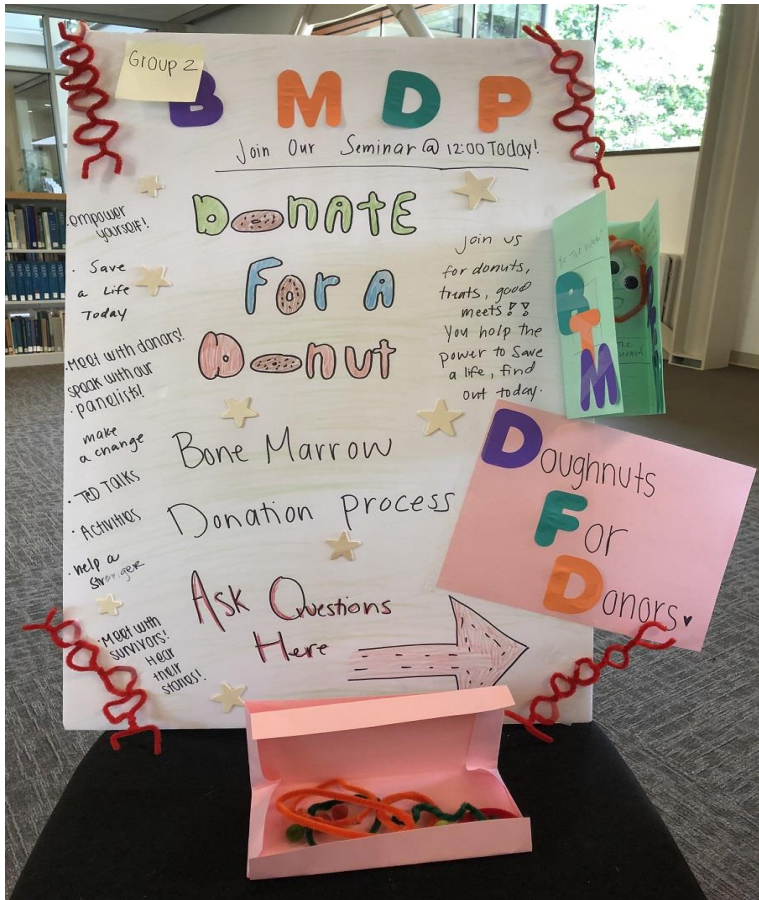


Figure 9. The final prototype.

Prototype Testing

The prototype test determined the effectiveness of the prototype at narrowing the KMC gaps of the prototype field test group participants. The prototype field test included a pre-prototype field test survey, the prototype field test, and a post-prototype field test survey, which utilized the same participants. The pre-prototype field test survey identified the Black participants' current KMC needs, while the prototype served to address and narrow the

participants' KMC needs gap. Last, the post-prototype field test survey measured whether the prototype narrowed the KMC gaps and highlights the participants' remaining KMC needs. The results of the pre-and post-prototype field test surveys were also utilized to improve the prototype.

The prototype test took place in a Black studies course at a community college in Northern California during the course's normal 80-minute class time. Seven students between the ages of 18 and 61 self-identified as Black and participated in the prototype test. They all completed the pre- and post-prototype field test surveys and the prototype field test.

Pre-Prototype field test survey. The pre-prototype field test survey of 12 questions was administered after the prototype field test introductions. The purpose of the prototype field test survey was threefold. It was used to inform this study about the participants' current knowledge, motivation, and cultural needs prior to being exposed to the prototype. It aimed to measure the participants' current level of awareness to the Registry and its processes. Additionally, it was utilized as the basis to compare against the post-prototype field test survey results, which informed this study on the effectiveness of the prototype. Below are the results of the pre-prototype field test survey.

Pre-prototype field test survey results: Knowledge. The first set of questions on the pre-prototype test survey was directed towards the participants' knowledge about the Registry and its processes. Nearly all the participants had reported a lack of awareness about the Registry. Six participants indicated they knew nothing about the Registry. Of the six, one stated they knew "nothing other than what the name implies." Another participant indicated they had never heard of the Registry until their professor told them about the upcoming prototype presentation. The

one remaining participant indicated they knew “very little” about the Registry, which they had attributed to the little information given to them by their professor.

Similarly, the many participants did not know about the Registry’s matching process. Again, six participants stated they knew nothing about the donation process, while the remaining participant stated the little they did know about the matching process was attributed to the little information given to them by their professor. The participants’ responses were exactly the same regarding their knowledge of the matching process.

Additionally, the participants indicated they needed more information about the Registry and its processes in order to join. Five participants simply indicated they needed “a lot of information.” Another participant had specific information needs, like “is it similar to being an organ donor,” “is the procedure harmful,” and “what happens after.” While the remaining participant wanted to know the long-term and short-term effects and how to become a member. Also, the participants had informational needs regarding the bone marrow donation process. Two participants wanted questions answered by those who had donated bone marrow before. One participant wanted to know how much of your bone marrow is extracted during harvesting.

The participants also shared their level of awareness regarding the critical need for Blacks to join the Registry and participate and the bone marrow donation process. Three participants admitted they did not know anything about the need for Blacks to join the Registry. In contrast, three participants acknowledged an awareness of the need for Blacks to join the Registry. One participant stated they knew “A lot about the need for Black to become donors.”

Pre-prototype field test survey results: Motivation. This section discusses the motivations of Blacks who were willing to join the Registry for a non-relative. One participant shared they needed more knowledge and a better understanding about the need for bone marrow

before they could be motivated to join for a non-relative. In contrast, three other participants referenced personal gain as a motivation. One stated that “money” would motivate them to join the Registry. Another participant indicated that nothing would motivate them to join the Registry. Similar to the motivations to join, two participants indicated they could be financially motivated. They replied “money” and “financial stability” would motivate them to donate bone marrow to a non-relative. Four participants indicated they would be motivated to help based solely on need.

Pre-prototype field test survey results: Culture. This section discusses how the participants’ cultural attitudes and beliefs would affect their decision to join the Registry and participate in the bone marrow donation process for a non-relative. Five participants indicated their beliefs would not interfere with their decision to join the Registry. On the other hand, only three participants indicated their beliefs would not affect their decision to donate bone marrow. In contrast, one participant responded, “If it interferes with my values and morals, I won’t donate;” however, they did not indicate what values and morals could be in conflict. Two participants indicated they needed additional information, while the remaining participant shared that it “depends on who exactly it’s going to.”

Prototype field test. The participants were present for the entire prototype field test. The prototype field test began with the participants completing a consent form and the pre-prototype field test survey. Then the introduction and three videos about the Registry and its processes were shown to the participants. Next was the panel discussion by three Blacks who were previous bone marrow donors for non-related recipients. Two of the panelists had also participated in the donor interviews: Bailey and Sam. Bailey and Sam Skyped in from Houston,

Texas and Los Angeles, California for the panel discussion and question-and-answer session. While the third panelist, Avery, was present in the classroom during the prototype field test.

Fifteen minutes were allocated for the participants to ask the panelists questions. The participants had asked the panelists thought-provoking questions, like: (a) the financial costs to the donor, (b) who pays for the surgery, (c) the recovery process, (d) the type of bone marrow extraction process they underwent, (e) had they experienced cancer in their family before, (f) what did they know about their recipient, (g) how do you join, and (h) had they met their recipient. Bailey, the only panelist who had met her recipient, shared her story about meeting her recipient with the participants.

After the question-and-answer session, the participants completed the post-prototype field test survey. After the conclusion of the post-prototype field survey, a representative from the Registry introduced herself and allowed the students to ask additional questions, after which two of the students asked if they could join the Registry. The two students joined the Registry that day. One of the new registrants was Black and the other was Hispanic, which is another underrepresented and underutilized population on the Registry.

Post-prototype field test survey. A post-prototype field test survey was administered after the participants were exposed to the prototype. The purpose of the post-prototype field test survey was to assess the participants' knowledge, motivation, and culture needs after participating in the prototype field test and to measure whether or not the prototype narrowed the KMC needs gap and, if so, how much. The post-prototype survey was also utilized to test the viability of the prototype and to identify and make improvements of the prototype, all of which are discussed in more detail in Chapter 5.

Results: knowledge obtained. After being exposed to the prototype, the participants shared what they had learned about the Registry. Each participant indicated they had learned something resulting from their exposure to the prototype. One participant learned about the critical need for Blacks to join the Registry. They had “learned that African-Americans are so diverse that 22 million people are needed to join” in order to obtain a 75% match rate. Two participants indicated they had learned about the purpose of the Registry. One participant believed they had learned everything they needed to know about the Registry and its processes.

After being exposed to the prototype, the participants shared what they had learned about the matching process. Two participants’ responses were geared towards the critical need for Blacks to join the Registry to increase Black bone marrow matches. They had also learned that it was important for Blacks to follow through with the bone marrow donation process. One participant indicated they had learned about the bone marrow matching process from the testimonials of the panelists. On the other hand, one participant learned about the matching process from the videos shown during the prototype test. They learned how an individual’s unique genetic markers are used to match recipients with donors, while one participant realized locating a match could take a long time.

After being exposed to the prototype, the participants shared what they learned about the donation process. One participant directed their response towards the health factor. They had learned the bone marrow donation process involves minimal risks. On the other hand, two participants focused on the donation process itself. They had learned about the surgical and non-surgical donation processes, while another participant learned about the bone marrow donation process through the experiences shared by the panelists. Two participants reflected on the time aspect of bone marrow donation. They had learned that it could take weeks or years before a

person is called to donate. The remaining participant directed their focus on the critical need by stating, “When you choose to donate, don’t back out. The recipient could die.” On the other hand, after being exposed to the prototype test, six of the participants understood the critical need for Blacks to join the Registry. One participant stated, “It is a huge need for Blacks to join.”

After the participants shared what they learned, they informed this study about the additional information needed for them to join the Registry. Three participants indicated they did not need additional information. One of them responded, “I am pretty sold.” In contrast, other participants needed additional information regarding health and recovery. They needed information about the risks, costs, and recovery time. The remaining participant was interested in obtaining more information about whether or not they could drop out at any time. Table 8 depicts the results of the knowledge portion of the pre- and post-prototype field test, illustrating Blacks’ knowledge gaps before and after exposure to the final prototype.

Table 8

Knowledge: Pre- and Post-Prototype Field Test Survey Results

Pre-prototype		Post-prototype	
Knowledge		Knowledge	
Questions	Answers	Questions	Answers
What do you know about the Registry?	Nothing – 6 <ul style="list-style-type: none"> • “Nothing other than what the name implies” • “Nothing I have never heard about this until my professor told us about this presentation” • Very little – 1 	What did you learn about the Registry?	<ul style="list-style-type: none"> • I learned that Blacks are so diverse that 22 million people need to join • You can register at any point • You can save someone’s life • The procedures of joining the bone Registry • It could save a life... It seems like it’s a physical and emotional journey • Once you’re registered you don’t get called as soon as possible but you will get a call
What do you know about the matching process?	Nothing – 5 Very little - 2	What did you learn about the bone marrow matching process?	<ul style="list-style-type: none"> • Once you get a match the bone marrow transplant is the last result. • Not always will you find a match... Volunteering can save a life • The testimonials of the panelists • Everything • HLA process and how they get blood to identify the unique marker in an individual’s blood • I learned that the matching process can take a long time
What do you know about the donation process?	Nothing – 6 Very little – 1	What did you learn about the bone marrow donation process?	<ul style="list-style-type: none"> • I learned there is not that many risks • It could take up to months/years before you get a call to donate • Its both non-invasive and invasive • I learned that bone marrow donation can be painful or painless • The testimonials of the panelists • It can take time ... Seems scary • Don’t back out the recipient could die

Table 8 (continued)

Pre-prototype		Post-prototype	
Knowledge		Knowledge	
Questions	Answers	Questions	Answers
What information do you need before you decide to join for a non-family member?	<ul style="list-style-type: none"> • All information to help me understand and feel like it's worth it to me - 5 • Is it similar to being an organ donor? Is the procedure harmful? What happens after? • How much? Why is it necessary? How is it beneficial to me and my family? Long- and short-term effects? How do I become a member? 	What information do you still need before you decide to join the Registry?	<ul style="list-style-type: none"> • No information • The risks ... Becoming more informed • I'm pretty sold • How long will it take for me to donate ... can I drop out • Not that much information • More information on cost ... And recovery time • Nothing. I'd be okay with helping
What information do you need before you decide to donate bone marrow for a non-family member?	<ul style="list-style-type: none"> • Do I have to take a blood test? • Their information to feel like I sort of know them • All information and some names of people that have donated • All of the information • Why do they need it? Can it backfire? • How much do I have to donate? How often? To where? 	What information do you still need before you decide to donate bone marrow for a non-family member?	<ul style="list-style-type: none"> • Nothing - 7
What do you know about the need for Blacks to join the Registry	<ul style="list-style-type: none"> • Nothing – 3 • Only that there is one – 1 • It seems to be high – 1 • I know a lot about the need for Black donors – 1 • How does it work? – 1 	What did you learn about the need for Blacks to join the Registry?	<ul style="list-style-type: none"> • There is a need for more Blacks • It is important to help the community • A lot • It is a huge need for Blacks to join • There is a small percentage of Black matches due to the widely diverse black population • That it is really hard for Blacks to find a match • No answer

Results: Motivation. In this section, the participants informed this study on what would motivate them to join the Registry. Four participants replied they were motivated to join the Registry outside of a family member being in need. All but one participant was motivated to join the Registry after being exposed to the prototype test. In contrast, one participant stated that nothing would motivate them to join the Registry outside of a family member being in need.

On the other hand, the participants informed this study on what would motivate them to donate bone marrow to a non-relative. Although four participants stated they were willing to join the Registry, only three indicated they were willing to donate to a non-relative. They felt empowered to have the opportunity to save a life. One participant indicated their motivation to donate was dependent on their own health status. In contrast, two participants stated they would be motivated if there was financial gain. Table 9 depicts the results of the motivation portion of the pre- and post-prototype field test, illustrating Blacks' motivation gaps before and after exposure to the final prototype.

Table 9

Motivation: Pre- and Post-Prototype Field Test Survey Results

Pre-prototype		Post-prototype	
Motivation		Motivation	
Questions	Answers	Questions	Answers
What would motivate you to join the Registry outside of a family member in need?	<ul style="list-style-type: none"> • Learning how it can help others • Hopefully, save a life • If it seems like something worth it to me • Money • Didn't answer • Some type of benefits • Nothing 	What would motivate you to join the registry outside of a family member in need?	<ul style="list-style-type: none"> • If it's worth it to me, I'm all for it. • Already motivated • Hopefully to save a life • Nothing • Feeling as though I'm healthy enough to do so ... I know I can/will help someone ... being 100% sure that I'm ready to donate... More research • I am motivated • No answer
What would motivate you to donate bone marrow to a non-family member?	<ul style="list-style-type: none"> • Money • Financial stability • Just the idea that someone other than myself is in need • If it is worth it to me • Hopefully, save a life • The need to help another • Just the idea that someone other than myself is in need 	What would motivate you to donate bone marrow to a non-family member?	<ul style="list-style-type: none"> • The need to help • Feeling healthy enough • Money • Save a life • Already motivated • If it's worth it, I'm for it • No answer

Results: Cultural beliefs. After being exposed to the prototype, the participants shared how their beliefs would affect their decision to join the Registry. Five participants indicated their beliefs would not affect their decision to join the Registry. In addition, the participants informed this study how their beliefs would affect their decision to donate bone marrow to a non-relative. The answers to this question nearly mirrored the previous responses. Five participants

indicated their beliefs would not affect their decision to donate bone marrow to a non-relative.

Table 10 depicts the results of the culture portion of the pre- and post-prototype field test, illustrating Blacks' culture gaps before and after exposure to the final prototype.

Table 10

Culture: Pre- and Post-Prototype Field Test Survey Results

Pre-prototype		Post-prototype	
Culture		Culture	
Questions	Answers	Questions	Answers
How would your beliefs affect your decision to join the Registry?	<ul style="list-style-type: none"> • My beliefs would not affect me - 2 • No beliefs • Depends on who exactly it is going to • Not sure. I don't know what the bone marrow is • If it is against something I stand for such as my values or morals I won't participate • My beliefs could or could not affect my decision 	How would your beliefs affect your decision to join the registry?	<ul style="list-style-type: none"> • No, they wouldn't • They don't affect my decision • I have no problem • Not sure • Nothing • It won't • No answer
How would your beliefs affect your decision to donate bone marrow?	<ul style="list-style-type: none"> • If it interferes with my values and morals, I won't donate • Not sure, I don't know what bone marrow is • My beliefs would not affect me. - 2 • I have no problems • Depends on who exactly it is going to • I am not sure until I get information on the subject. 	How would your beliefs affect your decision to donate bone marrow?	<ul style="list-style-type: none"> • It won't • Nothing • Not sure • I have no problem • They don't • No they wouldn't • No answer

Conclusion

In this chapter, I explained how the Registry solicited Blacks to join, the questions the observed asked, how the questions were addressed, the modality of information shared with the observed, and the outcomes. Next, the findings of the post-observation surveys identified the participants' KMC needs that were shared and explained. Then the KMC needs of the interviewees and how they overcame them to move forward with the bone marrow donation process were reviewed. The functionality of the prototype development group and their development processes was explained. I shared how the final prototype was developed and selected, as well as the final prototype tested in the field. The KMC needs of the prototype field test group prior to being exposed to the prototype were measured and compared to the findings of the post-prototype field test group survey, which demonstrated the narrowing of the participants' KMC needs gaps. In Chapter 5, I discuss the limitations of the study, data analysis, data connections to broader literature, policy and practice implications, recommendations, and discussions.

Chapter 5: Discussion

In the previous chapter, the findings from each data collection source were discussed. I highlighted the data collected that addresses this study's inquiry questions. In this chapter, I share the limitations of this study and how they impacted the results. Then I provide an overview of the data analysis to include collection sources, participant selection, and the coding system implemented. Additionally, I explore the data connections to the KMC framework and the broader literature. Then I explore the implications for policy and practice. Next, I offer recommendations based on the limitations of the study and the findings. Last, I provide a conclusion to the study.

Limitations of the Study

One of the limitations of this study lies in the observations and observation survey data collection. During this study, nine observations were conducted to observe the Registry staff and volunteers solicit Blacks to join the Registry and participate in the bone marrow donation process. Of the nine observed people, four volunteered to complete the observation survey. The sampling of this data collection was small. One may speculate that the reason for a small sample could be attributed to the fact that the observations were conducted at one bone marrow drive. In addition, the weather conditions consisted of heavy rains with driving winds, which could have contributed to the low turnout. Also, the low Black participation could also be attributed to this particular community college having a low Black enrollment rate. Hence, the ability to apply the results to a broader population sample is limited.

Another limitation of this study is assigned to the prototype field test. Due to time constraints of the Ed.D. program, it was impossible to conduct multiple iterations of the prototype field test to include modifying the prototype after each iterative prototype field test.

This would have required analyzing and coding the data after each prototype field test, as well as reconvening the prototype development group that had developed the original prototype to conduct rapid prototyping implementing the new data. In addition, a new set of prototype field test participants would have been needed, as well as the scheduling and facilitation of another prototype field test for each iteration.

The final limitation of this study was the time limitation of the prototype field test. The prototype test took place in a Black studies course at a community college in Northern California during the course's normal 80-minute class time. During this time, some time had to be allocated to those students who had forgotten to bring their completed consent forms to class, as well as the pre-prototype field test survey, the facilitation of the introduction, the viewing of three videos totaling 11 minutes, a panel discussion, questions and answers with the panel, and the completion of the post-prototype field test survey. The panel discussion and the questions and answers were rushed to allow the participants time to complete the post-prototype field test survey so they would not be late for their next class. I recommend 1 hour 45 minutes to 2 hours for the prototype field test.

Discussion

The KMC theoretical framework was adopted because each element specifically applies to the research questions. The KMC framework is the vehicle guiding this study, allowing the identification and access of specific knowledge constructs and motivational characteristics needed for Blacks to join the Registry and participate in the bone marrow donation process. Also, the framework examines the influence cultural attitudes and beliefs have on decision-making.

The data were collected from multiple data sources to demonstrate the KMC needs of Blacks towards joining the Registry and participating in the bone marrow donation process. The data collected from the observations, observation surveys, prototype development groups, and the prototype field test group allowed this study to explore the KMC needs firsthand from the perspective of those being studied. The interviews allowed this study to glance into the KMC needs of the participants when they were deciding to join the Registry and after becoming a bone marrow match and were faced with the decision to move forward with the bone marrow donation process. The interviews also allowed this study to ascertain how the participants were able to overcome their KMC needs and move forward.

Knowledge. Knowledge is the first element in the KMC theoretical framework that guided this study. According to Ackoff and Emery (1972), knowledge is merely an awareness of the effects and outcomes of actions based on experiences, whereas a deeper sense of awareness comes from declarative and procedural knowledge. Declarative knowledge is knowing the *what* (Anderson, 2009). For example, what is the Registry? Procedural knowledge is discussed later in this section.

This study sought to inform what knowledge needs Blacks had regarding joining the Registry and participating in the bone marrow donation process. This study focused on knowledge in four key areas: (a) the Registry and its purpose; (b) the matching process; (c) the donation process; and (d) the critical need for Blacks to join the Registry and participate in the bone marrow donation process. According to Woof et al. (2005), knowledge is critical to make an informed decision.

Knowledge: The Registry. Knowledge about the Registry is critical for someone to make an informed decision to join. Many participants in this study were unaware of the Registry prior

to their observation solicitation, their solicitation to participate in the prototype development groups, or the prototype field test group. All the observation participants and interviewees indicated they did not know anything about the Registry prior to being solicited to join. Many of the prototype development group participants had not heard of the Registry until their recruitment to participate in this study or at the actual prototype development group meeting. Some research findings show that many Blacks simply have never heard of the Registry (Johansen et al., 2008; Onitilo et al., 2004) and that the predominant reason Blacks are not on the Registry is due to a lack of knowledge (Johansen et al., 2008; Laver et al., 2001; Onitilo et al., 2004; Yancey et al., 1997). On the other hand, the donor interviewees indicated the possibility of saving a life enabled them to join the Registry despite their lack of awareness.

Knowledge: Registry processes. Procedural knowledge is knowing the *how* and the *why* (Anderson, 2009). In this study, the *how* is the matching and donation process and the *why* is the critical need for Blacks to join the Registry and participate in the bone marrow donation process. In this study, more participants indicated they had an awareness about the matching process than those who were aware of the Registry. This informs this study that participants were unaware of the Registry but somehow had an awareness about the matching process. Many studies demonstrate that Blacks are not on the Registry; however, they are aware that potential donors match with their own ethnicity (Laver et al., 2001; Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997; Yancey et al., 1997).

All the interviewees had joined the Registry at blood and bone marrow drives. All but one was not aware of the Registry, its processes, or the critical need prior to joining the Registry. According to Yim et al. (2004), decision-making and knowledge are strongly interconnected, and

knowledge has a positive impact on decision-making. The interviewees were able to circumvent their KMC needs and join the Registry based on the possibility of saving lives.

In contrast, Jesse was equipped with the knowledge of the Registry and its processes when he joined the Registry. Jesse had organized a bone marrow drive at his church. The drive was structured as an educational event aimed at educating church members about the registry and its processes. This format allowed the Registry to develop a relationship with the members, gaining their trust, and narrowing their KMC gaps. As a result, over 50 church members joined the Registry that day.

On the other hand, all the interviewees indicated a need to understand the Registry and its processes before they were motivated to move forward with the donation process. They were all able to fulfill their KMC needs either through consultation with a Registry representative or through their own research. Some Blacks do not move forward with the bone marrow donation process due to a lack of knowledge (Kaster et al., 2014), demonstrating that the participants were able to join the Registry despite their knowledge needs; however, they needed to narrow their knowledge needs gaps in order to move forward with the donation process.

Likewise, several participants from the prototype development groups also indicated they did not know about the donation process. In this case, more participants were aware of the donation process than those who knew about the Registry. This could mean that the participants had more of a procedural knowledge (the *how* and the *why*) but lacked declarative knowledge (the *what*). According to Kaster et al. (2014), Blacks are underutilized in the bone marrow donation process due to a lack of knowledge about the donation process.

In contrast, knowledge of the critical need for Blacks to join the registry and participate in the donation process was not as important to the participants and did not impact their decision-

making. All the donor interviewees indicated they were unaware of the critical need for Blacks to join the Registry and participate in the bone marrow donation process. In addition, several of the participants in the prototype development groups and the prototype field test group were unaware as well. No studies are related to the impact awareness of the critical need for Blacks to join the Registry and participate in the bone marrow donation process has on decision-making.

Motivation. Motivation is the second element in the KMC theoretical framework that guided this study. Motivation is the catalyst that moves us into action either in a positive or negative way (Clark & Estes, 2008). This study focused on three motivational factors: (a) altruistic, (b) empathy, and (c) empowerment. According to Cialdini et al. (1987), altruism is when a person is motivated to help another in order to minimize the other person's distress, whereas empathy is having the capability to understand another person's thoughts and experiences (Gruhn et al., 2008) or the capability of putting oneself in the shoes of the person in need (Switzer, Dew, Butterworth et al. 1997). According to Switzer, Dew, Butterworth et al. (1997), empowerment motives are defined as donors' awareness of their own costs and benefits of donating and feeling fortunate to donate or a donor making an automatic decision to donate without any serious consideration.

The predominant motivating factors participants indicated would incentivize them to join the Registry and participate in the bone marrow donation process were based on the possibility of saving lives and understanding the low participation of Blacks on the Registry. According to Studts et al. (2010), those subjected to empathetic emotional appeals would have a higher propensity to join the Registry. As stated earlier, a lack of awareness about the critical need did not impact participants' decision-making regarding whether they would join the Registry;

however, it did serve as a motivating factor to the interviewees. The critical need immobilized them to join the Registry and move forward with the donation process.

On the other hand, according to Batson et al. (1987) and Dovidio et al. (1990), empathy is not a call to action on its own. It must be accompanied with altruistic behaviors leading a person to help another just to alleviate their personal distress. In contrast, the motivating factors that would preclude participants in this study from joining the Registry and participating in the bone marrow donation process are a lack of information about the Registry and its processes and concerns that the donation process would be harmful to their health. A lack of knowledge is the predominant factor as to why Blacks are underrepresented on the Registry (Kaster et al., 2014; Laver et al., 2001) and it is also the predominant reason potential donors fear the donation process (Kaster et al., 2014).

Culture. Culture is the third element of the KMC theoretical framework that guided this study. Culture is defined as a complex network of ideas, actions, and institutions that guide our behaviors and actions (Markus, 2016). This study focused on two cultural factors: attitudes and beliefs. Neither positive nor negative cultural attitudes or beliefs manifested themselves in the observations, prototype development groups, or the prototype field test group; however, they did arise in the donor interviews. Two predominant cultural attributes arose during the donor interviews. One was the positive influence family members had on donors' decision to donate bone marrow, as demonstrated through encouragement and support. The second cultural attribute that arose was demonstrated by Bailey's father after she had become a bone marrow match. Bailey's father exhibited a distrust of the medical community. According to a study conducted by Yates and Oliverira (2016), Blacks do not participate in the donation process due to a distrust of the medical community and a perceived bone marrow allocation bias based on

race and socioeconomic status. Another barrier cited in a different study indicated that Blacks have a propensity to not donate bone marrow due to superstitious attitudes and religious beliefs (Onitilo et al., 2004; Switzer, Dew, Butterworth et al., 1997).

Other outcomes. No new Black registrants resulted from the bone marrow drive observed during this study. Nine Blacks at a bone marrow drive were observed during this study. In contrast, the prototype test utilizing seven Blacks yielded one Black and one Hispanic registrant, representing over 14% or 1:7 success rate, whereas the bone marrow Registry yielded 0%.

Policy and Practice Implications

Increasing black representation and underutilization on the Registry had been consistently inconsistent. The Registry and its affiliates across the United States had developed and implemented their own policies towards the recruitment of Blacks. Not until recently, in April 2018, did the Registry develop a strategic planning committee aimed at developing solutions to increasing the representation and utilization of Blacks on the Registry. Thus far, this committee has only met one time with no set plan of action as to its future purpose or goals of the committee, as well as how often it would meet.

The Registry. Currently, the Registry, its partners, and other recruitment organizations are utilizing a one-size-fits-all recruitment strategy. The assumption is that the recruitment strategy that has been successful in one population will also be successful in another. The Registry's enrollment numbers show this is not true. Currently, 11 million potential unrelated donors are on the Registry (Be The Match, n.d.i), while Blacks are underrepresented on the Registry (Fingrut, 2015; Laver et al., 2001; Yancey et al., 1997) with fewer than 800,000 registrants (Lown et al., 2014).

According to Jagosh et al. (2012), the best way to create a successful solution to a problem is to utilize those being studied. This is also referred to as participatory collaboration or co-creation research, which utilizes the researcher and participants who are being studied. Two benefits of participatory collaboration are that it enables the researcher to conduct and collect culturally applicable data and it improves recruitment efforts (Jagosh et al., 2012). This is why I chose participatory collaboration involving Blacks throughout this study to solve the problem of Blacks being underrepresented and underutilized on the bone marrow Registry.

The Registry, its partners, and other recruitment organizations are not successfully recruiting enough Blacks on the Registry that are representative of their population in the United States. Currently, the model is to increase outreach and spending while utilizing the same marketing tactics. This would increase Black registrants; however, the ratio between the time utilized and the financial outlay measured against new Black registrants would not change or would only show marginal improvement, meaning the economies of scale or the cost per new registrant would remain the same. Instead, more effort needs to be made in forming relationships in the Black community, as demonstrated at Jesse's donor drive hosted at his church. The Registry, its partners, and other recruitment organizations need to incorporate Blacks in the development of the recruitment and educational effort. One possible solution is the prototype developed in this study by the prototype development groups.

Angels in Disguise. Angels in Disguise (AID) is a nonprofit organization, 501(c)3, formed by Indria Gillespie in the state of California. The mission of AID is two-fold. Its first mission is to create awareness about the Registry in the Black, Hispanic, and Native American communities. Its second mission is to conduct additional research to provide insight into these communities that would aid in the recruitment process.

AID plans to develop and institute educational, marketing, and recruitment policies resulting from research that are specific to the needs and demographics of the Black, Hispanic, and Native American communities. To accomplish such development, AID will conduct five test markets each of the prototype in the top five cities with the highest Black, Hispanic, and Native American populations. The prototype would be modified based on the test market results before the prototype is implemented nationwide in each community. In addition, AID will continue to support the efforts of the Registry and its mission to increase the representation and utilization of Blacks on the Registry, which would include conducting collaborative research with the Registry, as well as forming synergistic partnerships aimed at education and recruitment in the aforementioned communities. Lastly, AID will participate in collaborative research with other leading researchers in this field. This research will be limited towards the education and recruitment in the aforementioned communities, as well as training and professional development of staff of the Registry. The purpose of this research would also serve to inform AID and its collaborators on topics, such as post-match attrition rates and the short- and long-term effects of emotional appeals.

Recommendations

The data collection from the prototype development groups culminated into a prototype. The prototype groups developed a prototype using a design-thinking iterative brainstorming process. The prototype was tested in the field. The purpose of the prototype test was to identify the participants' current KMC needs through the prototype field test survey, expose them to the prototype, and measure their KMC needs after being exposed to the prototype using a post-prototype survey. This process informed the study on the prototype's effectiveness at narrowing the participants' KMC gaps. The results of the prototype field test could also be used as a tool to

make improvements to the prototype. Additionally, the results of the prototype field test were used to make the following recommendations for change.

The results of the prototype field study informed this study that the current recruitment processes, utilized within the Black community, need improvement. After being solicited by the Registry, the results of the nine observations and four observation surveys indicated the participants had a lack of knowledge about the Registry, its processes, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process. In contrast, the prototype field test yielded more positive results. Like the observations and the post-observation surveys, the pre-prototype field test survey indicated that none of the participants were aware of the Registry, its processes, or the critical need for Blacks to join the Registry and participate in the bone marrow donation process. On the other hand, the participants' level of awareness increased significantly after being exposed to the prototype, which entailed the viewing of three videos about the Registry, its processes, and the critical need, as well as listening to the experiences of Black bone marrow donors and asking them questions. Additionally, two of the participants joined the Registry immediately after the prototype field test, indicating that building relationships in the Black community and providing knowledge about the Registry, its processes, and the critical need may increase the number of Blacks that join the Registry and participate in the bone marrow donation process. Based on the aforementioned results of this study, I offer two recommendations in an attempt to narrow Blacks' KMC needs gaps. The first recommendation is to build relationships within the Black community. The second recommendation is to open the donor-recipient pathway with African registries in Nigeria and South Africa.

Relationships. Presently, the Registry, its partners, and other recruitment organizations recruit new registrants of all ethnicities through blood and bone marrow drives. This has proven to be effective in some communities, but not in the Black community, as demonstrated through the registry's population. Blacks represent 13% of the United States population; however, they only represent 7% on the Registry (Confer & Robinett, 2008; Johansen et al., 2008; Kaster et al., 2014; Lown et al., 2014; Switzer, Bruce et al., 2013).

Building relationships. To form relationships, the Registry, its partners, and other recruitment organizations need to implement two measures. First, they need to develop brochures about the Registry and its processes aimed specifically toward the Black community. The purpose of the brochure is to educate the Black community on the KMC needs identified by the participants in this study. Based on the results of this study, I recommend the brochure include the following:

- The Registry and its purpose
- What is bone marrow and why it is needed?
- Black blood-borne cancer statistics in comparison to the White community
- The bone marrow matching process
- The Black donor match rate in comparison to the White community
- Why is the Black HLA genetic marker so diverse and how does it affect the Black matching rates?
- The critical need for Blacks to join the Registry and participate in the bone marrow donation process
- The bone marrow donation processes

- What to expect: The medical checkup
- The financial costs to the donor
- Time commitment

Educational symposia. The second way to build relationships in the Black community is through education. The Registry, its partners, and other bone marrow recruitment organizations need to focus on educating the Black community about the Registry, its purpose, its processes, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process. Education can be done by replicating the prototype utilized in this study that was developed by the prototype development groups. The prototype test was referred to as a bone marrow educational symposium for ease of understanding. It is referred to that as such throughout the remainder of this study.

For effectiveness with the Black community, it is recommended the symposium be facilitated by a Black bone marrow donor. The symposium should begin with a pre-prototype survey to measure the current KMC needs of the participants, followed by an introduction about the symposium, its purpose, and the agenda. Then the participants should view videos about the Registry, its processes, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process. This would give them an understanding of the Registry and its processes. Next, a panel consisting of three Blacks who had donated bone marrow in the past to a non-related recipient is given for three to five minutes wherein they share their experiences. The panelists should share the following:

- Why did they join the Registry?
- How long were they on the Registry before they became a match?

- What were their experiences with the Registry from the time they became a match through to the donation process?
- Which bone marrow extraction process did they undergo?
- What were their side effects?
- What do they know about their recipient?
- Have they met the recipient?

After each panelist shared their experiences, at least 15 to 20 minutes should be allocated to allow the participants to ask the panelists questions. This should be followed up with the post-prototype survey, which would allow the Registry, its partners, and other recruitment organizations to determine if the participants' KMC needs were met. Participants should be given an opportunity to join the Registry at this time if they choose to do so.

Partnerships with African registries. On April 20, 2018, I attended a strategic planning meeting at the Registry headquarters in Minneapolis, Minnesota. The Registry had also invited oncologists, molecular biologists, molecular geneticists, community bone marrow recruitment organizations, and bone marrow registries from Nigeria and Cape Town. I was invited to attend this meeting to contribute my findings as a volunteer in the field, as well as my initial findings from this study. The purpose of the strategic planning meeting was to collaboratively develop more effective recruitment strategies in the Black community.

During this meeting, I learned key data from the CEO of the Registry: that the Registry needs 22 million black registrants for Blacks to realize a 75% bone marrow match rate (C. Mills, personal communication, April 20, 2018). The new awareness leads to my second recommendation for the Be The Match Registry to form a two-way donor-recipient partnership

with registries in Africa. Currently, the Be The Match Registry has a two-way donor-recipient partnerships with other registries all over the world, allowing Be The Match and other registries to locate donor matches for recipients from around the world; however, Be The Match does not have a two-way donor-recipient match relationship with the only two registries on the continent of Africa. The Registry allows Bone Marrow Nigeria and the South African Bone Marrow Registry to locate matches from the Be The Match Registry for recipients in Africa; however, this is not a two-way donor-recipient match partnership. Be The Match Registry does not utilize Bone Marrow Nigeria or the South African Bone Marrow Registries to locate matches for Black recipients in need in the United States.

Currently, over 7.4 million White people are on the Registry with a 70% match rate (Fingrut, 2015). Due to Blacks' diverse HLA genetic marker ("Be The Match Tells," 2013; Fingrut, 2015; Glasgow & Bello, 2007; Laver et al., 2001; Switzer, Bruce et al., 2013), 22 million Black registrants in the United States would represent half of the Black population. This is not accounting for Blacks not between the ages of 18 and 61 or with those medical conditions that prohibit them from joining the Registry. It is highly recommended the Registry create a two-way donor-recipient match partnership with the African registries. If it is needed, assistance should be given to the African registries to bring them up to compliance with that of the United States.

Benefits of these recommendations. These recommendations would enable the Registry, its partners, and other bone marrow recruitment organizations to possibly realize several positive returns. The development of brochures specific to the needs of the Black community and the facilitation of educational symposia may foster trust and encourage more Blacks to join the Registry and participate in the bone marrow donation process. Once trust has

been built, more Blacks would be inclined to share with others, through word-of-mouth, about the Registry and the critical need for Blacks to join and participate in the bone marrow donation process. An increase of Blacks on the Registry would also increase the number of Black donor-recipient matches and possibly save more lives. Additionally, the Registry, its partners, and other bone marrow recruitment organizations will also benefit from the Be The Match Registry establishing a two-way donor-recipient matching partnership with African registries. It would increase the Black match ratios, which also may save more lives.

Next steps. The first real-world steps should include the recruitment of an advisory committee to include Black representation. The purpose of the advisory committee would be to help guide the content of the Registry's brochure aimed at the Black community. Next, the advisory committee should assist with the development and implementation of the educational symposia, as well as select five major cities with high Black populations to test market the symposium in the field at health fairs and conferences geared towards the Black community. In addition, a steering committee should be developed to research how to create a viable two-way donor-recipient matching partnership with the Bone Marrow Nigeria and South African Bone Marrow Registries.

Future research. This study opens the door for additional research in four key areas: (a) post-match attrition rates, (b) longevity of emotional appeals, (c) online registration, and (d) prototype testing in larger markets. During my literature review, I encountered many studies around attrition rates. Attrition was viewed in broad terms that included registrants who aged out after turning 62 years of age, registrants who had developed a medical condition prohibiting them from donating, those who simply asked to be taken off of the Registry, or those who decided not to move forward with the donation process after becoming a match. I labeled this

phenomenon post-match attrition, which occurs when the potential donor decides not to donate bone marrow after being identified as a bone marrow match. Research needs to be conducted on those who refuse to donate after matching with a recipient along with their original motives to join the Registry.

The second key area in need of research is around the effectiveness of emotional appeals in the donation process. Frequently, the Registry conducts bone marrow drives for a specific individual in need. Studts et al. (2010) conducted a study on the effectiveness of emotional appeals. The results of this study indicated that 85% of individuals solicited to join the Registry utilizing an emotional appeal had joined. No studies show the longevity emotional appeals have on an individual. For example, are Blacks likely to follow through with the donation process one month, one year, or 10 years after joining due to an emotional appeal campaign? Also, what is the likelihood an individual who joined due to an emotional appeal will follow through with the donation process versus a person who had joined for other reasons.

The effectiveness of an online registration recruitment effort is the third key area in need of research. It was recently discovered, on July 1, 2018, the Registry will employ a new hands-off approach. The Registry would still host bone marrow drives; however, they will direct potential registrants to go online to complete the registration process remotely. The results of this study indicate relationship-building and education are needed to meet the KMC needs of the Black community; thus, a hands-off approach offers a new opportunity to investigate its effects.

The fourth key area in need of research is the prototype developed during this study. The results of this study indicate that participants' KMC needs gaps were narrowed after being exposed to the prototype symposium, which included relationship building and education. Additionally, this study could be expanded to explore the results of the prototype test conducted

in five major cities with a high Black population or at five historically black colleges and universities.

Conclusion

In this study, I identified three key areas that contribute to the reason Blacks are not on the Registry or do not participate in the bone marrow donation process—(a) knowledge, (b) motivation, and (c) culture—which framed this study. A lack of knowledge about the Registry, the matching and donation processes, and the critical need for Blacks to join the Registry and participate in the bone marrow donation process is a hindrance. This study also explored the motivations and cultural constructs that inspired people to join or not join and participate in the bone marrow donation process. Participatory collaboration and co-creation research were employed utilizing an iterative brainstorming design thinking process to develop a possible solution or prototype aimed at narrowing the participants' KMC needs gaps. The prototype was tested in the field to measure its effectiveness and viability in the Black community. The results of the prototype test indicated that the Registry, its partners, and other recruitment organizations must employ relationship building and education for Blacks to overcome their KMC needs, allowing them to join the Registry and participate in the bone marrow donation process. Additionally, this study used the results of the prototype test to inform the recommendations and next steps.

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APPENDIX A

POST-OBSERVATION SURVEY SOLICITATION INVITE (BE THE MATCH AND
BLACKBONEMARROW.COM)

Hello. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. I am working on my dissertation. The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. You were selected as a possible participant in this study because you fit the criteria needed: Black, between the ages of 18 – 61 attending this blood and bone marrow drive.

I just observed the Be The Match bone marrow registry recruitment process in their attempt to recruit you to join the Be The Match bone marrow registry. I would like to invite you to participate in my dissertation study by completing a post-observation survey. The purpose of the survey is to obtain some demographic information. The survey will also ask questions to obtain your knowledge about the Be The Match bone marrow registry and their processes, as well as what would motivate you to join. The survey will take 15 minutes to complete. If you do decide to participate I will need for you to review and sign a consent form, which will take 5 – 10 minutes. I will also read a brief introduction providing you with more information about this study, which will take an additional five minutes. In total, I need approximately 30 minutes of your time.

If you do decide to participate, I must inform you that there are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing their viewpoints and experiences. To minimize these risks any information that is obtained in connection with this study and that can be identified with you will remain confidential and will

be disclosed only with your permission. To minimize a breach of confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. Additionally, you may withdraw from this study at any time without any adverse repercussion.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

You are interested in participating in this study?

Thank you for your time and cooperation.

Indria Gillespie

APPENDIX B

DONOR INTERVIEWEE INVITE (EMAIL OR FLYER)

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow Registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. I am seeking volunteers to participate in a study. You may volunteer if you are: Black, between the ages of 18 – 61, previous bone marrow donor, and living or working in the Sacramento area.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short survey and interview. Your participation in this study will take approximately one hour.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences with me. To minimize these risks you may elect to be interviewed face-to-face or telephonically, whichever you are most comfortable. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. You may withdraw from this study at any time without any adverse repercussion.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to

participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Any information that is obtained in connection with this study will remain confidential. The data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. I will be the only person that will have access to the gathered data. Voice recordings will be saved onto a flash drive and stored in a locked filing cabinet. The original recording will be deleted from the computer. After the study, all data and recordings will be destroyed after 3 years.

If you are interested in participating, please email me at i_gillespie@u.pacific.edu. Also, please inform your friends and family that are also Black between the ages of 18 – 61 who live or work in the Sacramento area.

Thank you for your time and cooperation.

Indria Gillespie

APPENDIX C

SOLICITATION INVITE (BE THE MATCH AND BLACKBONEMARROW.COM)

Hello! My name is Indria Gillespie. I am a student at the University of the Pacific, Benerd School of Education in Sacramento, California. I need your assistance with identifying possible participants to be interviewed for my dissertation study. I need three or four Blacks that are previous bone marrow donors, between the ages of 18 – 61, that live or work in the United States. You are encouraged to use the attached email solicitation (Donor Interviewee Invite – Appendix B) inviting potential participants to participate in this study.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process.

There are some possible risks involved for participants. Participants may experience some anxiety or discomfort in sharing their viewpoints and experiences. To minimize these risks participants will be given the option to be interviewed face-to-face or telephonically over the telephone or using video conferencing, whichever makes them most comfortable. Also, any information that is obtained in connection with this study and that can be identified with participants will remain confidential and will be disclosed only with your permission. To minimize a breach of confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. Additionally, participants may withdraw from this study at any time without any adverse repercussion.

Participation is entirely voluntary and participants' decision whether or not to participate will involve no penalty or loss of benefits to which they are otherwise entitled. If a participant

decides to participate, they are free to discontinue participation at any time without penalty or loss of benefits to which they are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Their participation as a previous donor interviewee will take one hour. During the hour, participants will be asked to complete a demographic survey and sign a consent form. Before conducting the interview, I will introduce myself and explain the purpose of this study. The interview questions are aimed at obtaining their knowledge, motivation, and culture needs when they joined the Be The Match bone marrow registry and participated in the bone marrow donation process.

If you have any questions about this research, please feel free to email me at i_gillespie@u.pacific.edu or my dissertation chair, Dr. Githens at 916-739-7332. I may be contacted at 916-236-9844.

Thank you,

Indria

APPENDIX D

PROTOTYPE DEVELOPMENT GROUP INVITE (FOR UNIVERSITY OF THE PACIFIC,
SACRAMENTO STUDENTS)

Hello! My name is Indria Gillespie. I am a student at the University of the Pacific, Benerd School of Education in Sacramento, California. Your attendance is needed to participate in a focus group for my dissertation research study. The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018.

In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints while working in a group setting. You may withdraw from this study at any time without any adverse repercussion.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Your participation in this focus group will take two hours. During the 2 hours, you will be asked to complete a demographic survey and sign a consent form. The focus group will include viewing three videos (approximately 11 minutes) and design thinking processes to

include: concept development utilizing iterative ideations, convergent exercises, and prototype development and testing.

You must meet the following criteria to participate in this focus group:

- Self-identify as Black
- Between the ages of 18-61
- Live, work, or attend school in the Sacramento, CA area

Location:

Date:

Time:

Please RSVP at i_gillespie@u.pacific.edu.

Thank you,

Indria

APPENDIX E

PROTOTYPE DEVELOPMENT GROUP INVITE (EMAIL OR FLYER)

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow Registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. You were selected as a possible participant in this study because you fit the criteria needed: Black, between the ages of 18 – 61, and living or working in the Sacramento area.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short survey, view a short video, and participate in a prototype development group. Your participation in this prototype development group will take two hours.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints while working in a group setting. You may withdraw from this study at any time without any adverse repercussion.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018.

In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

If you are interested in participating, please email me at i_gillespie@u.pacific.edu. Also, please inform your friends and family that are also Black between the ages of 18 – 61 who live or work in the Sacramento area. Thank you for your time and cooperation.

Indria Gillespie

APPENDIX F

VIDEOS

Prototype Development Groups One and Two

Name	URL	Purpose	Length
Be The Match: A	https://www.youtube.com/watch?v=l0mdh9P4rY0&list=	<ul style="list-style-type: none"> About the Be The Match bone marrow registry Its purpose How it began 	4 minutes
History of Curing Blood Cancers	PLN6j63JxfTC5y7jKChQheYNHuq2VgDTA_&index=8		15 seconds
Be The Match Pays	https://www.youtube.com/watch?v=vMFeiqhXEPc	<ul style="list-style-type: none"> Matching process Critical need for Blacks to join and participate in the bone marrow donation process 	3 minutes
Tribute to Dr. Rex	_&index=6&list=PLN6j63JxfTC5y7jKChQheYNHuq2VgDTA_		28 seconds
Crawley	_&index=6&list=PLN6j63JxfTC5y7jKChQheYNHuq2VgDTA_		
If You Are a Match:	https://www.youtube.com/watch?v=VEoJwcdV3BQ	<ul style="list-style-type: none"> Donation process 	2 minutes
Bone Marrow	_&list=PLN6j63JxfTC5y7jKChQheYNHuq2VgDTA_&index=1		31 seconds
Donation Process	PLN6j63JxfTC5y7jKChQheYNHuq2VgDTA_&index=1		

APPENDIX G

PROTOTYPE GROUP PARTICIPANT SOLICITATION

Hello! My name is Indria Gillespie. I am a student at the University of the Pacific, Benerd School of Education in Sacramento, California. I am conducting a study for my dissertation. The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process.

Your attendance is needed to participate in prototype group for my dissertation research study. The purpose of the prototype group is to test a prototype or solution developed to address the knowledge, motivation, and cultural needs of Blacks to join the Be the Match bone marrow registry and participate in the bone marrow donation process. Your participation in the prototype group will take 1 – 1.5 hours. During which time, you will be asked to review and sign a consent form. This will take 5 – 10 minutes to complete. You will be asked to complete a pre-prototype survey to measure your current knowledge, motivation, culture needs to join the Be the Match bone marrow registry and participate in the bone marrow donation process. This will take 15 minutes to complete. You will also be asked to review videos, brochures, and other literature about the Be The Match bone marrow registry and their processes. This will take 20 - 40 minutes. Last, you will be asked to complete a post-prototype survey to ascertain your knowledge, motivation, and culture needs to join the Be the Match bone marrow registry and participate in the bone marrow donation process. This will take 15 minutes. Again, this entire process will take 1 – 1.5 hours of your time.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

You must meet the following criteria to participate in this prototype group:

- Self-identify as Black
- Between the ages of 18-61
- Live, work, or attend school in the Sacramento, CA area

Location:

Date:

Time:

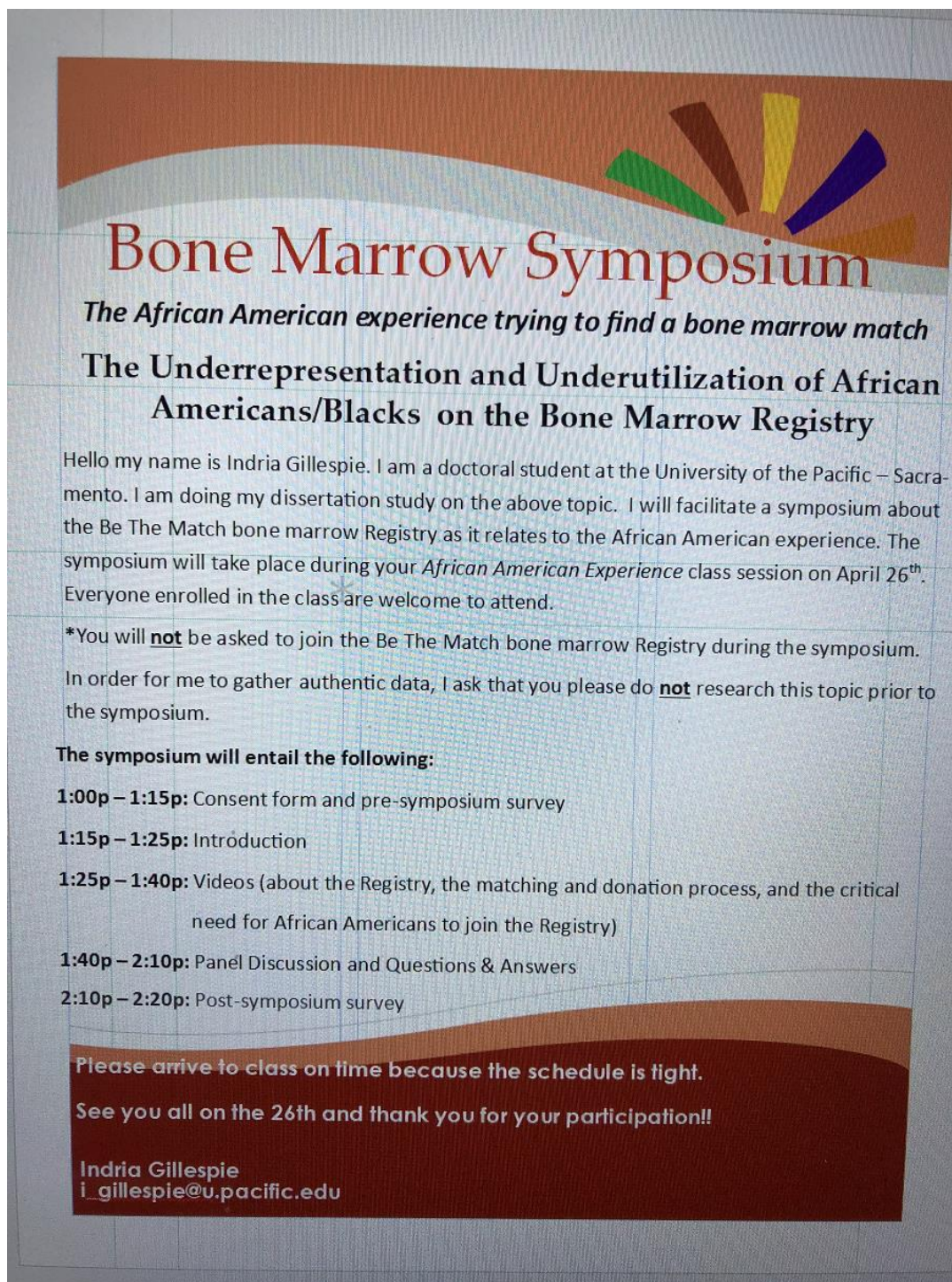
Please RSVP at j_gillespie@u.pacific.edu

Thank you,

Indria

APPENDIX H

PROTOTYPE FIELD TEST SOLICITATION



Bone Marrow Symposium

The African American experience trying to find a bone marrow match

The Underrepresentation and Underutilization of African Americans/Blacks on the Bone Marrow Registry

Hello my name is Indria Gillespie. I am a doctoral student at the University of the Pacific – Sacramento. I am doing my dissertation study on the above topic. I will facilitate a symposium about the Be The Match bone marrow Registry as it relates to the African American experience. The symposium will take place during your *African American Experience* class session on April 26th. Everyone enrolled in the class are welcome to attend.

*You will **not** be asked to join the Be The Match bone marrow Registry during the symposium. In order for me to gather authentic data, I ask that you please do **not** research this topic prior to the symposium.

The symposium will entail the following:

- 1:00p – 1:15p:** Consent form and pre-symposium survey
- 1:15p – 1:25p:** Introduction
- 1:25p – 1:40p:** Videos (about the Registry, the matching and donation process, and the critical need for African Americans to join the Registry)
- 1:40p – 2:10p:** Panel Discussion and Questions & Answers
- 2:10p – 2:20p:** Post-symposium survey

Please arrive to class on time because the schedule is tight.

See you all on the 26th and thank you for your participation!!

Indria Gillespie
i_gillespie@u.pacific.edu

APPENDIX I

OBSERVATION CHECKLIST

Observations	Completed	Notes
How the Registry engages potential registrants?		
What type of information is being disseminated to the potential registrants?		
What type of questions are being asked by both parties?		
How are the answers being addressed?		
The reactions of those being observed		
Participant joins Be The Match?		
They request literature to review? What?		
Participants have questions about the Be The Match Bone Marrow Registry		
Participants have questions about the bone marrow matching process?		

Participants have questions about the bone marrow donation process?		
Participants have questions about the critical need for Blacks to join the Be The Match bone marrow registry?		

APPENDIX J

DESIGN BRIEF

DESIGN BRIEF	
Project Description	The Registry and other bone marrow recruitment organizations may improve recruitment outcomes in the Black community by narrowing the participants KMC needs gaps.
Intent Scope	The initial scope is to identify the participants' KMC needs and to discover how they can overcome or bridge those needs using design thinking / participatory research. The development of a prototype that addresses bridging the gap is within this scope. I am not sure what the prototype would encompass, so testing it may be outside of the scope of this project to test it due to time and/or financial constraints.
Exploration Questions	<ul style="list-style-type: none"> • What knowledge in the following areas (the Registry, matching and donation process, and the critical need) do Blacks need for them to join the Registry and participate in the bone marrow donation process? • What are the motivational needs of Blacks that would galvanize them to join the Registry and participate in the bone marrow process? • What are the cultural needs of Blacks that would galvanize them to join the Registry and participate in the bone marrow donation process?
Target Users	<p>The participants of the design team are designing for the Black prototype field test participants. The goal is to conduct additional test in the general Black community.</p> <p>I will screen participants to ensure that they meet the requirements of this study:</p> <ul style="list-style-type: none"> • Self-identify as Black • Between the ages of 18-61 (age range allowable to join the Registry) • Any gender • Living or working in the Greater Sacramento or North Bay Area
Research Plan	The goal is to test the prototype in the field using participants that meet the aforementioned demographic criteria.
Expected Outcomes	<p>I expect the following outcomes:</p> <ul style="list-style-type: none"> • The prototype designed by the participants could be tested in the field • The results of the field test narrow the participants KMC needs gaps • The prototype is viable to best tested in the general Black community
Success Metrics	<p>Success would be measured by the following:</p> <ul style="list-style-type: none"> • If the prototype is viable (no time or financial constraints) to be tested in the field.

	<ul style="list-style-type: none"> • If the prototype is effective at narrowing the KMC needs gaps of the participants.
Project Planning	<p>I will need the following resources:</p> <ul style="list-style-type: none"> • Participants that meet the aforementioned demographic criteria to complete the post-observation survey, participate in the prototype development groups, donor interviews, and the prototype field test during the data collection phase (April 2018) • Space to conduct the above (April 2018) • IRB approval (March 2018) <p>I plan to conclude this study during the summer of 2018.</p>

*Figure 8. Design Brief. Adapted from *Designing for growth: A design thinking tool kit for managers*, by J. Liedtka and T. Ogilvie, 2011.*

APPENDIX K

POST-OBSERVATION SURVEY INTRODUCTION

Thank you for volunteering to participate in this study as post-observation survey participant. Again, my name is Indria Gillespie and I am a doctoral student at the University of the Pacific's Benerd School of Education. I am conducting a study to understand the knowledge, motivation, and cultural needs for Blacks to register on the Be The Match bone marrow registry and participate in the donation process.

You were selected as a possible participant in this study because you fit the criteria needed: you are a previous bone marrow donor, Black, between the ages of 18 – 61 years of age, attending this blood and bone marrow drive.

As I had stated before there are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. To minimize these risks any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018.

In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Again, I appreciate your participation. Do you have any questions?

APPENDIX L

INFORMED CONSENT (POST-OBSERVATION SURVEY)

The Knowledge, Motivation, and Culture Needs for Blacks to join the Be The Match bone marrow registry and Participate in the Bone Marrow Donation Process

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow Registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. You were selected as a possible participant in this study because of you fit the criteria needed: Black, between the ages of 18 – 61, and attending this blood and bone marrow drive.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short survey and participate in an interview. Your participation in this study as survey participant will last about five to ten minutes.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. To minimize these risks any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

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There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the

University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

If you have any questions about the research at any time, please call me at 916-236-9844, or my dissertation chair, Dr. Githens at 916-739-7332. If you have any questions about your rights as a participant in a research project please call the IRB Administrator, Research & Graduate Studies Office, University of the Pacific (209) 946-7367.

Your signature below indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

If you would like a copy of results of this study, please email me at i_gillespie@u.pacific.edu. You will be offered a copy of this signed form to keep.

Signature

Date

APPENDIX M

POST-OBSERVATION SURVEY

1. Are you between the ages of 18 and 61?
Yes ☐ No ☐
2. What is your gender?
3. What is your ethnicity?
4. What brought you to the blood/bone marrow drive today?
Donate blood ☐ Bone marrow drive ☐ Other ☐
5. What did you take into consideration when deciding whether to join the Be The Match bone marrow registry?
6. What did you know about the Be The Match bone marrow registry prior to today?
7. What did you learn about the Be The Match bone marrow registry today?
8. What would motivate you to join the Be The Match bone marrow registry?
9. Who would support you in your decision to join the Be The Match bone marrow registry?
10. What would motivate you to donate bone marrow to a non-family member?

11. Who would support you in your decision to donate bone marrow to a non-family member?

12. Did you join the Registry?

13. Why did you make this choice?

APPENDIX N

DEMOGRAPHIC SURVEY (PRE-PROTOTYPE GROUP)

1. Are you between the ages of 18-61?

Yes ☐ No ☐

2. When did you first hear of the Be The Match bone marrow registry?

3. Are you aware of the bone marrow matching process?

Yes ☐ No ☐

4. Are you aware of the bone marrow donation process?

Yes ☐ No ☐

5. Are you aware that 90% of bone marrow matches are made within the same ethnicity?

Yes ☐ No ☐

6. Are you on the Be The Match bone marrow registry?

Yes ☐ No ☐

7. Have you ever been a bone marrow match to someone that is not a relative?

Yes ☐ No ☐

8. Do you know of anyone ever in need of a bone marrow/ peripheral blood stem cell transplant?

Yes ☐

No ☐

9. Do you know of anyone that is on the Be The Match bone marrow registry?

Yes ☐

No ☐

10. Do you know of anyone that had donated bone marrow/ peripheral blood stem cell?

Yes ☐

No ☐

APPENDIX O

INFORMED CONSENT (SURVEY AND DONOR INTERVIEW)

The Knowledge, Motivation, and Culture Needs for Blacks to join the Be The Match bone marrow registry and Participate in the Bone Marrow Donation Process

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow Registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. You were selected as a possible participant in this study because you fit the criteria needed: you are a previous bone marrow donor, Black, between the ages of 18 – 61, and living and working within the United States.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short survey and participate in an interview. Your participation in this study as an interviewee will last one hour.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences with me. To minimize these risks you may elect to be interviewed face-to-face or telephonically, whichever you are most comfortable. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the

University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

If you have any questions about the research at any time, please call me at 916-236-9844, or my dissertation chair, Dr. Githens at 916-739-7332. If you have any questions about your rights as a participant in a research project please call the IRB Administrator, Research & Graduate Studies Office, University of the Pacific (209) 946-7367.

Your signature below indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

If you would like a copy of results of this study, please email me at i_gillespie@u.pacific.edu. You will be offered a copy of this signed form to keep.

Signature

Date

APPENDIX P

PRE-INTERVIEW DEMOGRAPHIC SURVEY (DONORS)

1. Are you between the ages of 18-61?

Yes ☐

No ☐

2. When did you join the Be The Match bone marrow registry?

3. Did anyone that you know join with you? Yes ☐ No ☐

4. If so, what relation were they to you?

5. Prior to joining the Be The Match bone marrow registry did you know of anyone that had joined before?

Yes ☐

No ☐

6. Prior to joining the Be The Match bone marrow registry did you know of anyone in need of a bone marrow/ peripheral blood stem cell transplant?

Yes ☐

No ☐

7. Prior to joining the Be The Match bone marrow registry did you know of anyone who had donated bone marrow/ peripheral blood stem cell?

Yes ☐

No ☐

8. How many times were you a bone marrow or peripheral blood stem cell donor for a non-relative?

9. When were you (first) notified that you were a match for a non-relative?

10. What date(s) did you donate for a non-relative?

11. Which procedures did you undergo?

Bone marrow surgical procedure ☐ Non-surgical process ☐

APPENDIX Q

INTRODUCTION FOR INTERVIEWEES

Thank you for volunteering to participate in this study as an interviewee. My name is Indria Gillespie. I am a doctoral student at the University of the Pacific's Benerd School of Education. I am conducting a study to understand the knowledge, motivation, and cultural needs for Blacks to register on the Be The Match bone marrow registry and participate in the donation process.

You were selected as a possible participant in this study because you fit the criteria needed: you are a previous bone marrow donor, Black, between the ages of 18 – 61 years of age, and living and working within the United States.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences with me. To minimize these risks you may elect to be interviewed face-to-face or telephonically, whichever you are most comfortable. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. You may withdraw from this study at any time without any adverse repercussion.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Any information that is obtained in connection with this study will remain confidential. The data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed. I will be the only person that will have access to the gathered data. Voice recordings will be saved onto a flash drive and stored in a locked filing cabinet. The original recording will be deleted from the computer. After the study, all data and recordings will be destroyed after 3 years.

APPENDIX R

INTERVIEW QUESTIONS (DONORS)

Again, your participation in this interview is completely voluntary. You may withdraw your participation at any time without consequence. All of your responses are confidential. I would like your permission to tape record this interview, so I may accurately document the details. May I record this interview? Do you have any questions before we start recording?

Underrepresentation questions pertaining to Knowledge (K) of the KMC framework

1. Tell me about your decision to join the Be The Match bone marrow registry.
2. How did you first become aware of the Be The Match bone marrow registry?
3. Prior to joining, what did you know about the Be The Match bone marrow registry?
 - a. How did you learn about the Be The Match bone marrow registry?
 - b. When did you learn about the Be The Match bone marrow registry?
4. Prior to joining, what did you know about the Be The Match bone marrow registry's bone marrow matching process?
 - a. How did you learn about the Be The Match bone marrow registry's bone marrow matching process?
 - b. When did you learn about the Be The Match bone marrow registry's bone marrow matching process?
5. Prior to joining, what did you know about the Be The Match bone marrow registry's bone marrow donation process(es)?
 - a. How did you learn about the Be The Match bone marrow registry's bone marrow donation process(es)?

- b. When did you learn about the Be The Match bone marrow registry's bone marrow donation process(es)?
- 6. Prior to joining, what did you know about the need for Blacks to join the Be The Match bone marrow registry?
 - a. How did you learn about the need for Blacks to join the Be The Match bone marrow registry?
 - b. When did you learn about the need for Blacks to join the Be The Match bone marrow registry?
- 7. What information do you wish you had known prior to deciding to join the Be The Match bone marrow registry?
 - a. How did this affect your decision to join?
 - b. What information do you wish you had known about the matching process prior to donating?
 - i. How would this have affected your decision to join?
 - c. What information did you wish you had known about the donation process prior to donating?
 - i. How would this have affected your decision to join?
 - 1. Why would this have affected your decision to join?
 - d. What information did you wish you had known about the need for Blacks to join the Be The Match bone marrow registry?
 - i. How would this have affected your decision to join?
 - 1. Why would this have affected your decision to join?

Underrepresentation questions pertaining to Motivation (M) of the KMC framework

1. Prior to joining, describe your thoughts about the Be The Match bone marrow registry?
 - a. What things did you take into consideration before joining the Be The Match bone marrow registry?
 - b. How did your decision to join make you feel?
2. What motivated you to join the Be The Match bone marrow registry?
3. Who supported your decision to join the Be The Match bone marrow registry?
 - a. How did your supporters show their support?
 - b. How did it make you feel having people support you in your decision to join the Be The Match bone marrow registry?

Underrepresentation questions pertaining to Culture (C) of the KMC framework

1. Describe what your family thought of your decision to join the Be The Match bone marrow registry.
 - a. How did your family influence your decision to join the Be The Match bone marrow registry?
 - b. How did your family support your decision to join the Be The Match bone marrow registry?
2. Describe what your friends thought of your decision to join the Be The Match bone marrow registry.
 - a. How did your friends influence your decision to join the Be The Match bone marrow registry?
 - b. How did your friends support your decision to join the Be The Match bone marrow registry?

3. Describe what your church thought of your decision to join the Be The Match bone marrow registry.
 - a. How did your church/religious beliefs influence your decision to join the Be The Match bone marrow registry?
 - b. How did your church support your decision to join the Be The Match bone marrow registry?

Underutilization Questions pertaining to Knowledge (K) of the KMC framework

1. Describe your feelings when you were first notified that you were a bone marrow match?
2. What questions did you have about the Be The Match bone marrow registry that was critical to your decision to donate?
 - a. Why was this information critical to your decision to donate bone marrow?
 - b. How were your questions addressed?
3. What questions did you have about the matching process that was critical to your decision to donate?
 - a. Why was this information critical to your decision to donate bone marrow?
 - b. How were your questions addressed?
4. What questions did you have about the donation process that was critical to your decision to donate bone marrow?
 - a. Why was this information critical to your decision to donate bone marrow?
 - b. How were your questions addressed?
5. What questions did you have about the need for Blacks to donate bone marrow that was critical to your decision to donate?
 - a. Why was this information critical to your decision to donate bone marrow?

- b. How were your questions addressed?

Underutilization questions pertaining to Motivation (M) of the KMC framework

1. Describe your thoughts when you were first notified by the Be The Match bone marrow registry that you were a bone marrow match.
2. Describe what made you decide to move forward with the bone marrow donation process.
 - a. Why was this critical in your decision to move forward with the bone marrow donation?
3. What things did you take into consideration before deciding to move forward with the bone marrow donation?
 - a. Why were these considerations important in your decision making?
4. After you were first notified that you were a match with whom did you share this information?
 - a. Who supported your decision to donate?
 - i. Family?
 - ii. Friends?
 - iii. Church/clergy?
 - iv. How did your supporters show their support?
 - b. Describe how their support made you feel?
 - c. Who did not support your decision to donate?
 - i. How did they show their lack of support?
 - ii. Describe how their lack of support make you feel?
5. Describe how the potential need of others influenced your decision to move forward with the bone marrow donation?

- a. Describe how it made you feel being able to donate bone marrow/ peripheral blood stem cell to someone in need?

Underutilization questions pertaining to Culture (C) of the KMC framework

1. Describe what your family thought of your decision to join the Be The Match bone marrow registry.
 - a. How did your family influence your decision to donate bone marrow through the Be The Match bone marrow registry?
 - b. How did your family support your decision to donate bone marrow through the Be The Match bone marrow registry?
2. Describe what your friends thought of your decision to donate bone marrow through the Be The Match bone marrow registry.
 - a. How did your friends influence your decision to donate bone marrow through the Be The Match bone marrow registry?
 - b. How did your friends support your decision to donate bone marrow through the Be The Match bone marrow registry?
3. Describe what your church thought of your decision to donate bone marrow through the Be The Match bone marrow registry.
 - a. How did your church/religious beliefs influence your decision to donate bone marrow through the Be The Match bone marrow registry?
 - b. How did your church support your decision to donate bone marrow through the Be The Match bone marrow registry?

Thank you for your participating in this study. If you have any questions, you may contact me at i_gillespie@u.pacific.edu.

APPENDIX S

DESIGN CRITERIA

DESIGN CRITERIA	
Design Goal	<ul style="list-style-type: none"> • My target customer <ul style="list-style-type: none"> ○ Blacks between the ages of 18-61 living and/or working in the Sacramento or North Bay Area ○ The donor interviewees can live in work anywhere in the United States because the interviews can be conducted telephonically. • I have learned that the target customer, in general, have no to little knowledge about the Registry, its processes or the critical need for Blacks to join the Registry. Some of them are motivated by fear and distrust of the medical community due to past medical atrocities that used Blacks as medical guinea pigs. While others may have cultural attributes and beliefs that limit them from joining the Registry and participating in the donation process. • This study aims to create awareness through education for the participants in this study. • This project is important because the outcomes could result in possibly saving lives
User Perceptions	<ul style="list-style-type: none"> • This study is important to the well-being of the participants and the Black community because it may possibly save lives through education and increasing the number of Blacks on the Registry and participating in the bone marrow donation process. • Ease-of-use to the target customer would probably represent awareness and an understanding and important of the commitment.
Physical Attributes	<ul style="list-style-type: none"> • The prototype must be designed for the understanding of those that have no to little awareness about the Registry, its processes, and the critical need • It must be able to be facilitated, launched or presented within a 1 to 2- hour range. • The language and commitment requirements must be clear.
Functional Attributes	<ul style="list-style-type: none"> • I am not aware of any use-case scenarios at this time until after the design team establishes them. • The prototype must be in alignment with the purpose of the Registry, which is to recruit potential donors within the constraints of the aforementioned demographics.
Constraints	<ul style="list-style-type: none"> • I need the prototype development to be completed by early to mid-April to allow me the time at the latest give me the time to test the prototype in the field and still meet my goal of completing this study this summer. • Other constraints or fears is the ability to recruit enough participants for the various data collection protocols.

Design criteria. Adapted from Liedtka & Ogilvie (2011)

APPENDIX T

INFORMED CONSENT (PRE-PROTOTYPE DEVELOPMENT GROUP SURVEY AND
PROTOTYPE DEVELOPMENT GROUPS ONE AND TWO)

The Knowledge, Motivation, and Culture Needs for Blacks to join the Be The Match bone marrow registry and Participate in the Bone Marrow Donation Process

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. You were selected as a possible participant in this study because you fit the criteria needed: Black, between the ages of 18 – 61, and living or working in the Sacramento area.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Also, please inform your friends and family that are also Black between the ages of 18 – 61 who live or work in the Sacramento area. and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short survey, view a short video, and participate in a focus group. Your participation in this study as a focus group participant will last two hours.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to

participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

If you have any questions about the research at any time, please call me at 916-236-9844, or my dissertation chair, Dr. Githens at 916-739-7332. If you have any questions about your rights as a participant in a research project please call the IRB Administrator, Research & Graduate Studies Office, University of the Pacific (209) 946-7367.

Your signature below indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

If you would like a copy of results of this study, please email me at i_gillespie@u.pacific.edu. You will be offered a copy of this signed form to keep.

Signature

Date

APPENDIX U

INTRODUCTION (PROTOTYPE DEVELOPMENT GROUPS ONE AND TWO)

The purpose of this study is to gain an understanding of Black's knowledge, motivation, and cultural needs regarding joining the Be The Match bone marrow registry and participate in the donation process.

The National Marrow Donor Program is the parent company to Be The Match bone marrow registry. Be The Match bone marrow registry is a nonprofit organization that was founded in 1987 by the federal government. The Be The Match bone marrow registry maintains a worldwide database of potential bone marrow donors. The primary focus of the National Marrow Donor Program's (NMDP) Be The Match bone marrow registry is to match volunteer donors with those in need of a bone marrow transplant.

Be The Match is the largest bone marrow registry in the world with nearly 11 million unrelated potential donors; however, Blacks are underrepresented on the Be The Match bone marrow registry with less than 800,000 registrants. The disparity of Blacks on the Be The Match bone marrow registry leads to a Black bone marrow match rate of less than 30% in 2007. This number has increased significantly due to the new process, peripheral blood stem cell (PBSC) donation. The peripheral blood stem cell donation is one of two methods of collecting blood-forming cells for bone marrow transplants. The same blood-forming cells that are found in bone marrow are also found in the circulating (peripheral) blood. Peripheral blood stem cell donation is a nonsurgical procedure, called apheresis.

One of the major factors contributing to Blacks being underutilized on the Be The Match bone marrow registry is due to Blacks' having the most diverse and less common Human Leukocyte Antigen (HLA) types than any other ethnicity. HLA is the genetic marker used to determine a donor-recipient match.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be

identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

If you decide to participate, you will be asked to complete a short survey, view three short videos, and participate in a focus group entailing design thinking iterative ideation/brainstorming. Your participation in this focus group will take two hours.

APPENDIX V

KNOWLEDGE, MOTIVATION, CULTURE DEFINITIONS

(Read to: Prototype Development Group one and two and
Prototype Field Test Group)

Culture – Is the shared values, norms, attitudes, and behaviors that guide decisions and actions (O'Reilly & Chatman, 1996).

Knowledge - Is merely an awareness of the effects and outcomes of actions based on past experiences (Ackoff, 1972).

Motivation – Is the work and fervency aimed at achieving a learning or performance goal (Hoffman, 2015).

References

Ackoff, R. L. & Emery, F. E. (1972). A note on systems science. *Interfaces*, 2(4), 40-41.

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Hoffman, B. (2015). *Motivation for learning and performance*. San Diego, CA:
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O'Reilly, C. A., Ill, & Chatman, J. A. (1996). Culture as social control: Corporations, cults, and commitment. In B. M. Staw & L. L. Cummings (Eds.), *Research in organizational behavior*, 18, (pp. 157-200). Greenwich, CT: JAI Press.

APPENDIX W

PROTOTYPE DEVELOPMENT GROUPS ONE AND TWO IDEATION PROMPTS

What information do you need before you decide to join the Be The Match bone marrow registry?

What information do you need before you decide to donate bone marrow for a non-family member?

What would motivate you to join the Be The Match bone marrow registry outside of a family member in need?

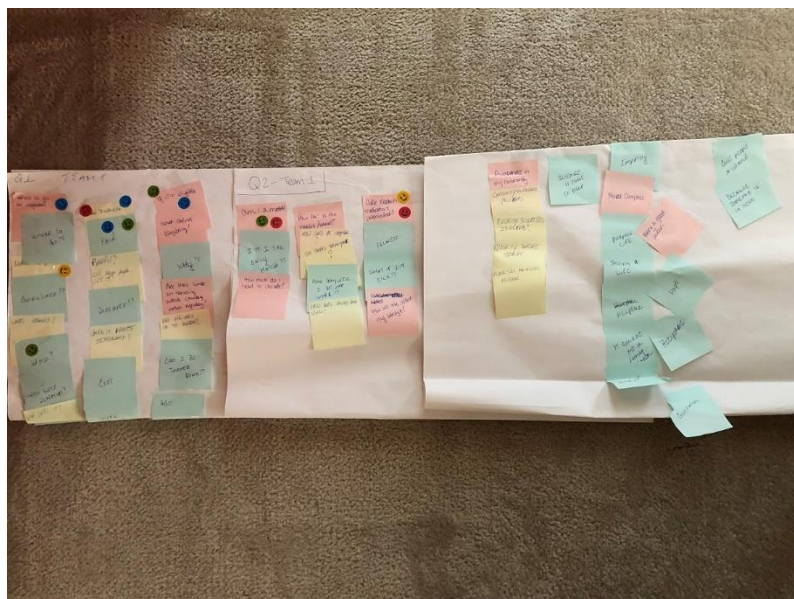
What would motivate you to donate bone marrow to a non-family number?

How would your beliefs affect your decision to join the Be The Match bone marrow registry?

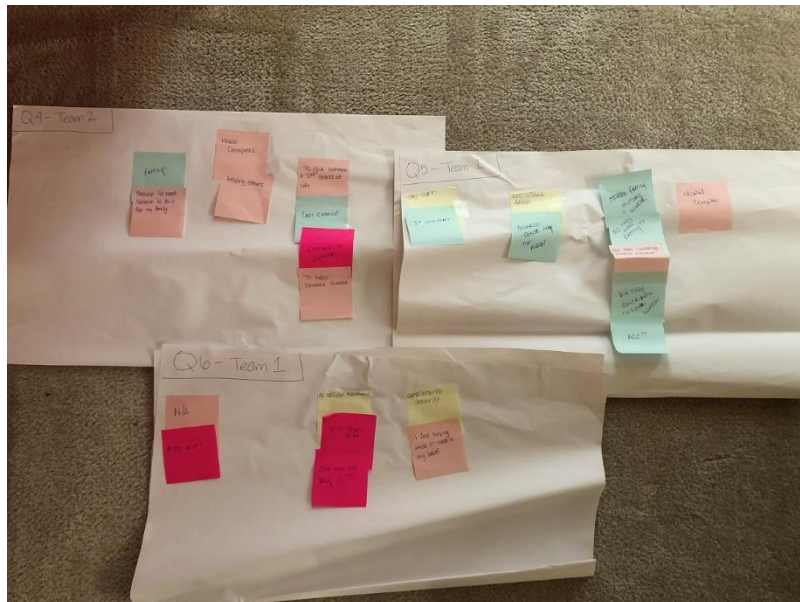
How would your beliefs affect your decision to donate bone marrow?

APPENDIX X

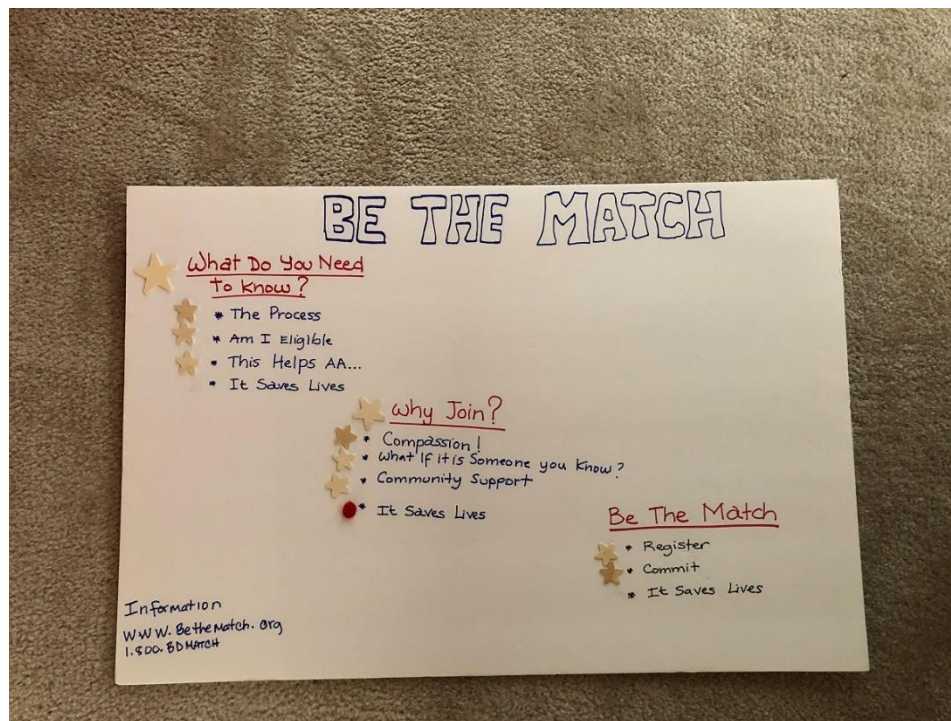
PROTOTYPE DEVELOPMENT GROUPS - ITERATIVE PROCESS



Prototype Development Group 1: Team 1 - questions 1-3



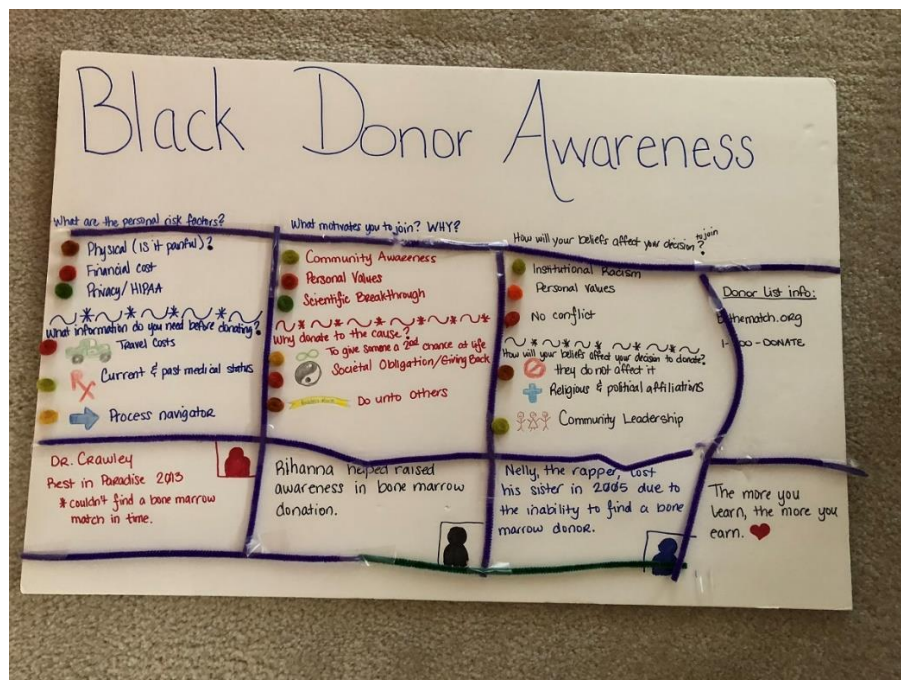
Prototype Development Group 1: Team 1 - questions 4-6



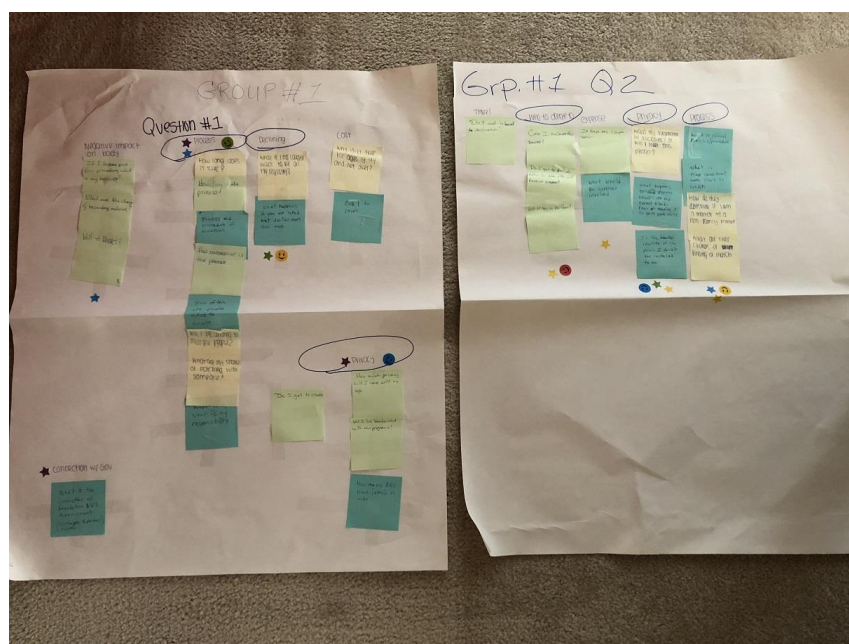
Prototype Development Group 1: Team 1 - Prototype

[illegible]

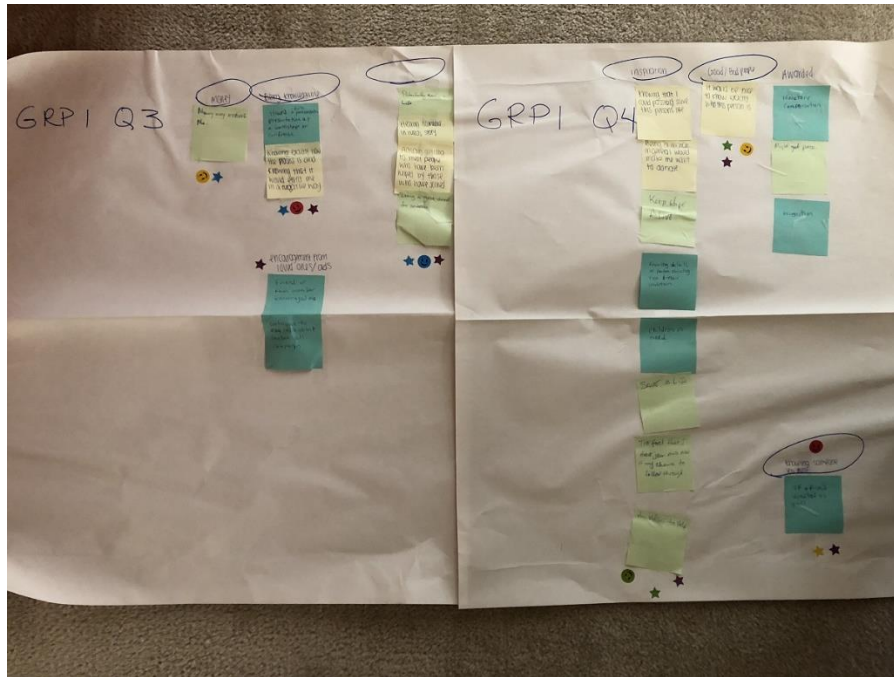
Prototype Development Group 1: Team 2 - Questions 4 - 6



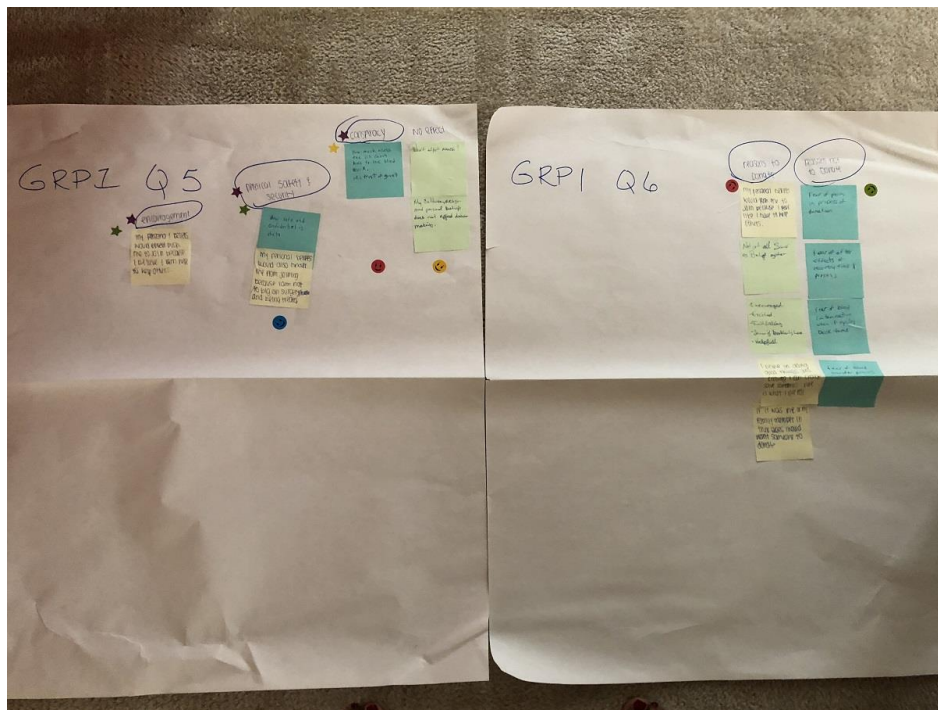
Prototype Development Group 1: Team 2 - Prototype



Prototype Development Group 2: Team 1 – Questions 1 and 2



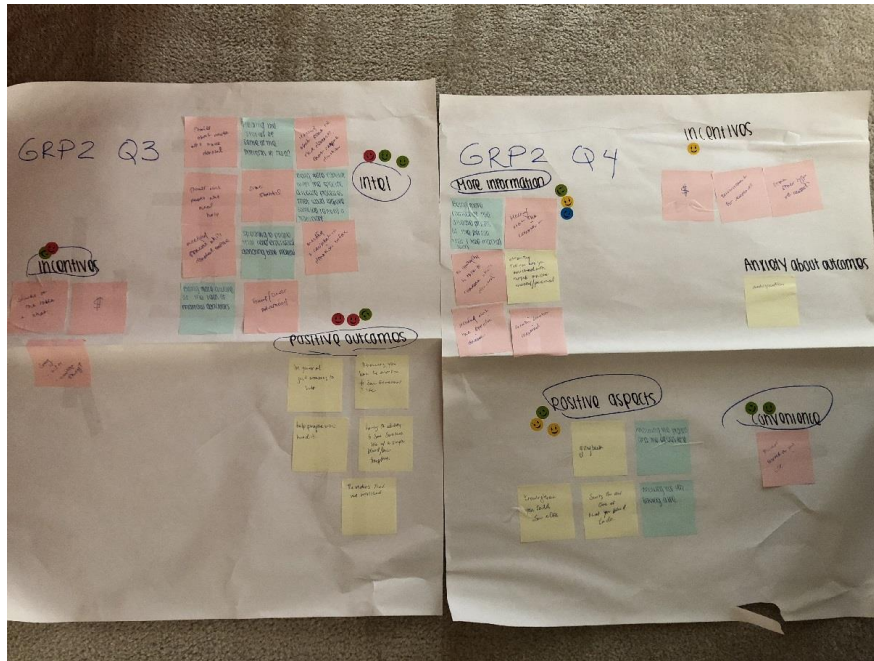
Prototype Development Group 2: Team 1 – Questions 3 and 4



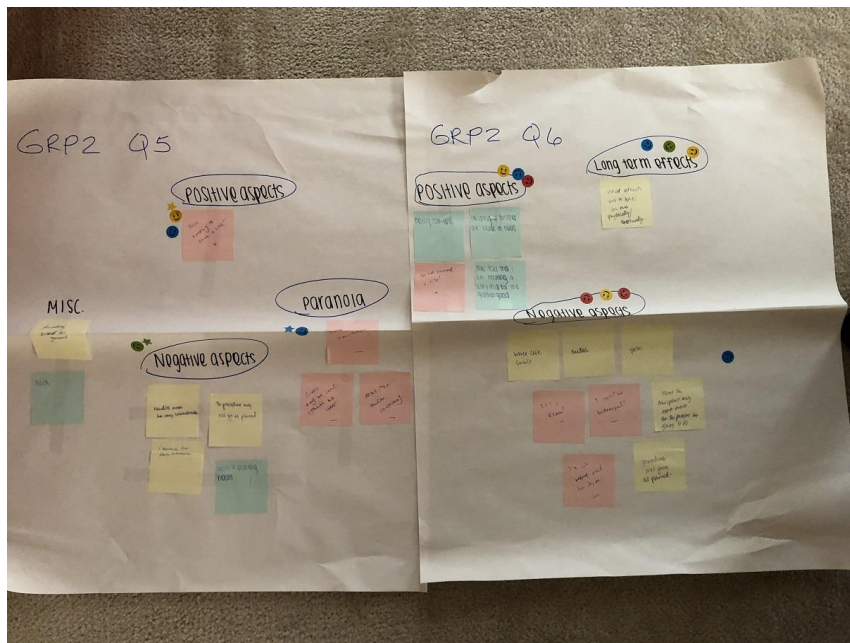
Prototype Development Group 2: Team 1 – Questions 5 and 6

The left photograph shows a group of students' work for 'Group #2'. The poster board has a central title 'Questions' and a bubble labeled 'Physical effects'. Numerous sticky notes are attached, covering the board. The right photograph shows another group's work for 'GRP 2 Q2'. This poster board also has a central title 'Questions' and bubbles for 'Health risks' and 'Patient benefits'. It features a similar arrangement of sticky notes.

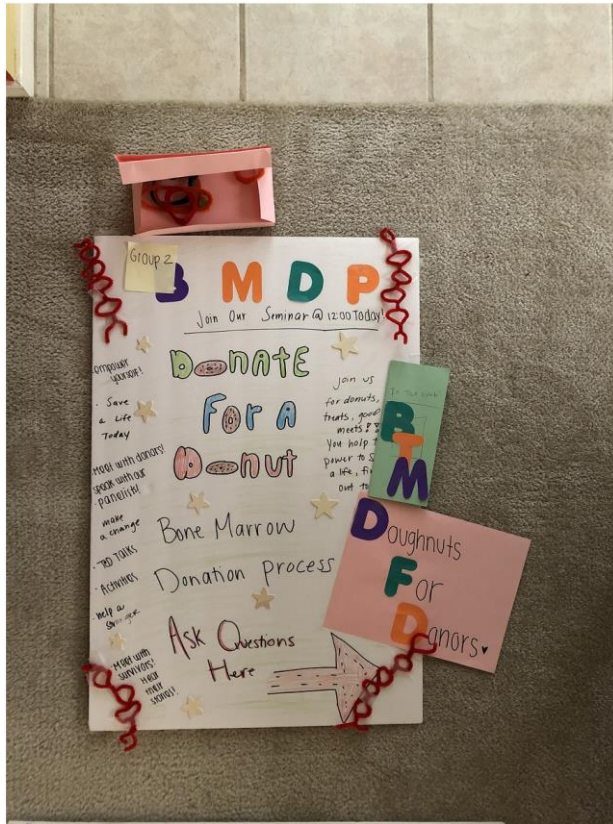
Prototype Development Group 2: Team 2 – Questions 1 and 2



Prototype Development Group 2: Team 2 – Questions 3 and 4



Prototype Development Group 2: Team 2 – Questions 5 and 6



Prototype Development Group 2: Team 2 – Final Prototype

APPENDIX Y

NAPKIN PITCH

Figure 10. Napkin Pitch. Adapted from *Designing for growth: A design thinking tool kit for managers*, by J. Liedtka and T. Ogilvie, 2011.

NAPKIN PITCH: The Underutilization and Underrepresentation of Blacks on the Registry	
<p>Need</p> <ul style="list-style-type: none"> • The front-end customer is the Registry and other bone marrow recruitment organizations and potential Black donors. • The end-user customers are Blacks in need of a bone marrow transplant. • This study serves to provide the bone marrow Registry with the potential means to meet the KMC needs of the Black community. 	<p>Approach</p> <ul style="list-style-type: none"> • This approach is aimed at leveraging upon awareness and education to motivate Blacks within the set demographics to join the Registry and participate in the bone marrow Registry. • I also leveraging upon the full support of the Registry and a couple of community-based bone marrow recruitment organizations. • The value of this project is the potential lives saved.
<p>Benefit</p> <ul style="list-style-type: none"> • The Registry would benefit by obtaining more Black bone marrow matches. • The end-user may benefit by receiving a life saving bone marrow transplant. 	<p>Competition</p> <ul style="list-style-type: none"> • The goals of this study reduce the competitive spirit because the end goal of this study and of the competition is to potentially save lives.

APPENDIX Z

LEARNING GUIDE

LEARNING GUIDE						
Strategic Intent	The goal of this project is to develop a prototype using a collaborative participant effort employing design thinking. The prototype is aimed at narrowing the KMC needs gaps of the Black participants.					
Remaining Key Assumptions to Be Tested	<p>I have not been able to test the following yet:</p> <ul style="list-style-type: none">• Whether KMC are the key needs limiting Blacks from joining the Registry and participating in the process.• That the prototype is viable• The participants would respond positively to the prototype test• That the target market would care about the need for Blacks to join after being exposed to the prototype.• That narrowing the KMC needs gaps of the participants would motivate them to join the Registry and participate in the bone marrow donation process.• That the prototype is viable to be tested in the general Black community in the future.					
In-Market Test Plan	<table><tr><th>Untested Assumptions</th><th>Success Metric for Learning Launch</th></tr><tr><td><ol style="list-style-type: none">1. Whether KMC are the key needs limiting Blacks from joining the Registry and participating in the process.2. The participants would respond positively to the prototype test and that the participants would care.</td><td><ol style="list-style-type: none">1. The success of this assumption will be tested using the pre- and post-prototype field test surveys.2. The success of this assumption will also be based on the results of the pre- and post-prototype field test surveys, as well as the questions and answers session with the panelists.</td></tr></table>		Untested Assumptions	Success Metric for Learning Launch	<ol style="list-style-type: none">1. Whether KMC are the key needs limiting Blacks from joining the Registry and participating in the process.2. The participants would respond positively to the prototype test and that the participants would care.	<ol style="list-style-type: none">1. The success of this assumption will be tested using the pre- and post-prototype field test surveys.2. The success of this assumption will also be based on the results of the pre- and post-prototype field test surveys, as well as the questions and answers session with the panelists.
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Financial Capital to Be Expended	<p>Very little financial capital is needed for the launch. I purchased folders for the participants and I had to pay for about 250 copies of various materials.</p> <p>The most valuable capital resource needed for the launch is people. I need participants for the prototype field test group and three Black previous bone marrow donors to serve as panelists. Additionally, I need the corporation of a professor of an Black studies class to allow me to take over a class session to facilitate the prototype symposium.</p> <p>Time is a huge capital for this launch because I only have 1 hour and 20 minutes of class time to complete the entire symposium.</p>
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Learning Guide. Adapted from Liedtka & Ogilvie (2011)

APPENDIX AA

INFORMED CONSENT (PROTOTYPE FIELD TEST GROUP)

The Knowledge, Motivation, and Culture Needs for Blacks to join the Be The Match bone marrow registry and Participate in the Bone Marrow Donation Process

You are invited to participate in a research study which will involve ascertaining the needs of Blacks that would motivate them to join the Be The Match bone marrow registry. My name is Indria Gillespie, and I am a doctoral student at the University of the Pacific, Benerd School of Education. You were selected as a possible participant in this study because you fit the criteria needed: Black, between the ages of 18 – 61, and living or working in the Sacramento area.

The purpose of this research is to ascertain the knowledge, motivation, and culture needs for Blacks to join the Be The Match bone marrow registry and participate in the bone marrow donation process. If you decide to participate, you will be asked to complete a short pre-prototype survey to assess your knowledge, motivation, and culture needs regarding joining the Be The Match bone marrow registry and participate in the bone marrow donation process. You will also be asked to review or listen to videos, brochures and articles about the Be The Match bone marrow registry, the bone marrow matching and donation process, and the critical need for Blacks to join the Be The Match bone marrow registry. Your participation in this study as a focus group participant will last one hour to one and one-half hours.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to

participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

If you have any questions about the research at any time, please call me at 916-236-9844, or my dissertation chair, Dr. Githens at 916-739-7332. If you have any questions about your rights as a participant in a research project please call the IRB Administrator, Research & Graduate Studies Office, University of the Pacific (209) 946-7367.

Your signature below indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

If you would like a copy of results of this study, please email me at i_gillespie@u.pacific.edu. You will be offered a copy of this signed form to keep.

Signature

Date

APPENDIX BB

PROTOTYPE FIELD TEST GROUP INTRODUCTION

The purpose of this study is to gain an understanding of Black's knowledge, motivation, and cultural needs regarding joining the Be The Match bone marrow registry and participate in the donation process.

The National Marrow Donor Program is the parent company to Be The Match bone marrow registry. Be The Match bone marrow registry is a nonprofit organization that was founded in 1987 by the federal government. The Be The Match bone marrow registry maintains a worldwide database of potential bone marrow donors. The primary focus of the National Marrow Donor Program's (NMDP) Be The Match bone marrow registry is to match volunteer donors with those in need of a bone marrow transplant.

Be The Match is the largest bone marrow registry in the world with nearly 11 million unrelated potential donors; however, Blacks are underrepresented on the Be The Match bone marrow registry with less than 800,000 registrants. The disparity of Blacks on the Be The Match bone marrow registry leads to a Black bone marrow match rate of less than 30% in 2007. This number has increased significantly due to the new process, peripheral blood stem cell (PBSC) donation. The peripheral blood stem cell donation is one of two methods of collecting blood-forming cells for bone marrow transplants. The same blood-forming cells that are found in bone marrow are also found in the circulating (peripheral) blood. Peripheral blood stem cell donation is a nonsurgical procedure, called apheresis.

One of the major factors contributing to Blacks being underutilized on the Be The Match bone marrow registry is due to Blacks' having the most diverse and less common Human

Leukocyte Antigen (HLA) types than any other ethnicity. HLA is the genetic marker used to determine a donor-recipient match.

There are some possible risks involved for participants. You may experience some anxiety or discomfort in sharing your viewpoints and experiences. There is also a chance that other members of the group may share confidences. To minimize these risks as a participant I ask that you keep shared information within the group in order to create a safe space and ensure confidentiality. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. To minimize a breach of your confidentiality, all data obtained will be maintained in a safe, locked location and will be destroyed after a period of three years after the study is completed.

Your participation is entirely voluntary and your decision whether or not to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to participate, you are free to discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

There are some benefits to this research. I will use this study to speak at various professional and academic conferences. I am currently submitting a proposal to discuss this study and its results at the International Urban Educators Association Conference in November 2018. In the future, I also plan to submit a proposal to speak at other conferences. For example, the University of Illinois Health Communication: Barriers, Breakthroughs and Best Practices Conference in February 2019. Also, the results of this research will be shared with the Be The Match bone marrow registry to assist with the development of a more targeted marketing, recruitment, and educational effort towards the Black community.

Your participation in the prototype group will take 1 – 1.5 hours. During which time, you will be asked to review and sign a consent form. This will take 5 – 10 minutes to complete. You will be asked to complete a pre-prototype survey to measure your current knowledge, motivation, culture needs to join the Be the Match bone marrow registry and participate in the bone marrow donation process. This will take 15 minutes to complete. You will also be asked to review videos, brochures, and other literature about the Be The Match bone marrow registry and their processes. This will take 20 - 40 minutes. Last, you will be asked to complete a post-prototype survey to ascertain your knowledge, motivation, and culture needs to join the Be the Match bone marrow registry and participate in the bone marrow donation process. This will take 15 minutes. Again, this entire process will take 1 – 1.5 hours of your time.

Do you have any questions?

Great, let's begin.

APPENDIX CC

PRE-PROTOTYPE FIELD TEST SURVEY

1. What do you know about the Be The Match bone marrow registry?
2. What do you know about the bone marrow matching process?
3. What do you know about the bone marrow donation process?
4. What information do you need before you decide to donate bone marrow for a non-family member?
5. What do you know about the need for Blacks to join the Be The Match bone marrow registry?
6. What would motivate you to join the Be The Match bone marrow registry outside of a family member in need?

7. What would motivate you to donate bone marrow to a non-family member?
8. How would your beliefs affect your decision to join the Be The Match bone marrow registry?
9. How would your beliefs affect your decision to donate bone marrow?

APPENDIX DD

POST-PROTOTYPE SURVEY

1. What did you learn about the Be The Match bone marrow registry?
2. What did you learn about the bone marrow matching process?
3. What did you learn about the bone marrow donation process?
4. What information do you still need before you decide to donate bone marrow for a non-family member?
5. What did you learn about the need for Blacks to join the Be The Match bone marrow registry?
6. What would motivate you to join the Be The Match bone marrow registry outside of a family member in need?

7. What would motivate you to donate bone marrow to a non-family member?

8. How would your beliefs affect your decision to join the Be The Match bone marrow registry?

9. How would your beliefs affect your decision to donate bone marrow?