

ASIAN AMERICAN WOMEN'S PERSPECTIVES ON  
DONATING HEALTHY BREAST TISSUE:  
IMPLICATIONS FOR RECRUITMENT METHODS AND MESSAGING

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## **Dedication**

I dedicate this body of work to my daughter, Ridley V. Morgan, to whom I send the message to never stop learning, and to the memory of my mother, Mary Louise Ridley, who taught me that if we do not continue to learn, we are not really living.

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Katherine E. Ridley-Merriweather

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Asian women have a lower risk than Caucasians, African Americans, and Latinas of developing breast cancer (BC). Yet, once Asians move to the U.S. their risk rates measurably increase. The Susan G. Komen® Tissue Bank at the IU Simon Cancer Center (KTB), the only biobank of its kind in the world, collects healthy breast tissue from women of all racial groups to use as controls in BC research. The KTB represents a critical tool in efforts to treat and prevent BC; however, Asian American (AA) women display marked reticence towards donating tissue to the KTB. The purpose of this study is to use the basic components of Grounded Practical Theory to explore potential messaging that may result in AAs' more positive outlook on breast tissue donation.

This study recruited seventeen (N=17) AA women to share their perspectives on donating breast tissue for research purposes. Participants took part in an interactive focus group exploring potential messaging for successfully recruiting AA women to the KTB study. Findings revealed that: a) participants retained a culturally-embedded discomfort with donating, and a general distrust that their donation would be handled ethically and appropriately; b) the women possessed an extraordinary need for knowledge about all facets of the donation process; c) participants perceived that they lack a personal connection to BC, making it difficult for them to generate any truly altruistic tendencies

to perform the desired behavior, or to understand a need to do so; and d) they possess a strong desire to learn why it seems important to the KTB to collect their tissue, and especially about the increased BC rates and risk for Asians who move to or are born in the U.S. The findings from this study have important implications for others who work in applied clinical settings and are interested in addressing racial disparities in medical research through more effective and targeted recruitment messaging.

John Parrish-Sprowl, PhD, Chair

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## **Introduction**

Breast cancer is the predominant cancer among women in the United States aside from skin cancer (American Cancer Society, 2015b; C. DeSantis, Ma, Bryan, & Jemal, 2014), and is also the most common cancer affecting women globally (Centers for Disease Control and Prevention, 2015) . It is the second highest cause of cancer death in women, exceeded only by lung cancer (American Cancer Society, 2015b). Disparities in occurrence and mortality rates of breast cancer, as well as screening, can be distinctly drawn along racial and ethnic lines. The highest incidence of breast cancer is found in white women, while African-American women have the highest mortality rate from the disease (Office on Women's Health US Department of Health and Human Services, 2014).

New cases of breast cancer and death rates are lower for Asian American and Pacific Islander women than for non-Hispanic white and African-American women, still, it is the second leading cause of cancer death in Asian American and Pacific Islander women (Centers for Disease Control and Prevention, 2015), and has developed as the most common female malignancy in the majority of Asian countries (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007). Over the last few decades, clinical trials like the Susan G. Komen® Tissue Bank at the IU Simon Cancer Center (hereafter referred to as Komen Tissue Bank or KTB) have been the basis for much of the progress that has been made in breast cancer research (National Breast Cancer Coalition, 2015). The Komen Tissue Bank, the only biobank of its kind in the world, collects healthy breast tissue to be used as normal controls in research projects, and is critically important to ongoing efforts to find new methodologies for the treatment and prevention of breast cancer (Sherman et al., 2012). However, the barriers to collecting tissue from a diverse sampling of the

population are great for the KTB and other biobanks and genetic resources. These barriers, which I will explore in more detail in the review of literature, work against the successful representation of Asian Americans in clinical trials, which is both a scientific and an ethical problem.

Ethical and scientific integrity mandate that all subgroups of the population are represented appropriately in research (Centers for Disease Control and Prevention, 2015). This is not to say that every study must include all racial or ethnic minority groups, but rather that there is enough of a minority presence to offer meaningful opportunities to study the complex relationship of the influences of ancestry as well as environmental and social factors (Oh et al., 2015). The National Institutes of Health prioritize the promotion of inclusion of minorities in clinical trials and cancer studies in particular (Salman, Nguyen, Lee, & Cooksey-James, 2015). Currently there are few breast registries in existence, and so far donations to those other than the KTB have been limited to tissue from patients already diagnosed with cancer (C. I. Lee et al., 2012). Breast tissue biobanks must include a diverse donor population, including a large proportion of minority women and healthy women with no evidence of cancer (C. I. Lee et al., 2012). James, Yu, Henrikson, Bowen, and Fullerton (2008) wrote that resources facilitating examination of genetic and environmental contributions to health and disease, such as biobanks and clinical trials, are anticipated and even mandated to recruit from minority populations in numbers on par with identified community demographics.

With increased minority participation in clinical research comes diverse representation and a more extensive description of genetic susceptibility to disease (James et al., 2008). Distinctions in biology and genetics impact the competence of

treatment (Kraschel & Roberts, 2014). Recruiting Asian Americans, of all backgrounds or cultures, to participate in the KTB and other clinical trials, therefore, is crucial for the increased understanding of the relationship between the genetics of Asian Americans and their rates of breast cancer incidence. Encouraging increased Asian American participation, however, has proven to be quite difficult to accomplish (A Storniolo, KTB Executive Director, personal communication, Aug. 1, 2014). This study was designed to explore the perspectives of Asian American women regarding donating healthy breast tissue to the Komen Tissue Bank, and to examine the communication surrounding the recruitment of these women, and its effectiveness.

## Literature Review

### Asian Americans and Breast Cancer

The U.S. Census Bureau defines an Asian as, “a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.” The 2010 Census reports that the current number of Asian Americans residing in the United States is 17,320,856, which translates to 5.6% of the total U.S. population (United States Census Bureau, 2015).

Asian Americans are a highly diverse population whose family roots trace to the Far East, Southeast Asia, or the Indian subcontinent. Grouping all Asian Americans into a single category conceals the health risks of specific subgroups (Office on Women's Health US Department of Health and Human Services, 2014). Not only do Asian Americans speak different native languages, they also have different faiths, ways of life, and cultures from each other (T.-Y. Wu, Bancorft, & Guthrie, 2005) that might impact cancer rates. Currently however, due to a near absence of breast tissue samples from *any* Asian American women, researchers are unable to conduct the studies necessary to understand either collectively or in comparison to other Asian cultures, what their specific issues and concerns may be.

Overall incidence of breast cancer is lower in Asian countries than in the United States (American Cancer Society, 2015a). Studies have examined this, and put forth a number of plausible explanations. It is possible that breast cancer rates in Asian countries are lowered because women bear children early in most Asian societies, and breastfeed for a long period, factors which can guard against breast cancer (Collaborative Group on

Hormonal Factors in Breast Cancer, 2002). Also, typical Asian diets are low-fat and high in fiber and are therefore good for the body and perhaps for fighting cancer (Johns Hopkins, 2015). Finally, Asian women's usage of hormone replacement therapies (HRTs) and oral contraceptives is low. As HRT and oral contraceptive use are known to increase risk, lack of their use could also reduce risk rates (Agarwal et al., 2007). Consequently, due to these lower rates, Asian countries do not tend to focus much attention on breast cancer.

One resulting, unfortunate impact of this lack of attention is that South Asian women demonstrate a paucity of knowledge about breast cancer and do not practice habits for detection (Choudhry, Srivastava, & Fitch, 1997). Accordingly, most breast cancers in the majority of Asian societies are diagnosed at a relatively late stage. An organized large-scale breast cancer screening program is almost non-existent in India, which is typical of a developing Asian country. India's diverse population shares similarly challenging economic and physical living standards with other developing Asian countries (Agarwal et al., 2007). These examples evidence the problems arising in Asian countries resulting from a need for more awareness, however, most important to the present study is that although the population's knowledge of breast cancer may not increase, the risk level measurably escalates when women emigrate from Asian countries to the United States (Yip, 2009).

**Effects of migration.** One common finding in several studies is the measurable elevation of breast cancer incidence in all types of Asian women who migrate to or are born in the United States (Lim & Ashing-Giwa, 2013; T.-Y. Wu et al., 2005; Ziegler et al., 1993). Ziegler et al. (1993) conducted a case-control study of breast cancer in women



of Chinese, Japanese, and Filipino descent who were living in San Francisco, Los Angeles, and Oahu between the years of 1983-1987. The researchers found that in the cases of all three ethnicities, Asian Americans born in the West had a 60% higher risk of contracting breast cancer than those born in the East. However, because of the lower rates in cancer incidence in Asian American women when compared with White women and other minority groups, the public is not as cognizant of these health-related issues and elevated rates of risk (T.-Y. Wu et al., 2005). Asian Americans have a lower awareness of the American Cancer Society, the National Institutes of Health, and other information sources, and have a general perception that their cancer risk is generally low in comparison to Whites (G. T. Nguyen et al., 2010). In actuality, the group is experiencing swiftly escalating breast cancer incidence (A. H. Wu, Mimi, Tseng, Stanczyk, & Pike, 2009). Researchers have documented that women of Asian descent who migrate to the U.S. develop, over a period of generations, breast cancer rates equaling those of Caucasian women, who have the highest incidence of all women in America (Ziegler et al., 1996; Ziegler et al., 1993).

In a more current study, Gomez et al. (2010) found that breast cancer rates were high among U.S.-born Chinese and Filipina women, and were increasing quickly enough that current rates may equal or exceed those of non-Hispanic Whites. These findings support the idea that immigration status is a relevant factor for assessing trends in breast cancer incidence in places with significant levels of immigration, such as California (Gomez et al., 2010). Also interesting is that even though the overall cancer mortality rates in the United States are lessening, Asian Americans, for whom cancer has been the leading cause of death since 1980, are not benefiting from this trend (C. I. Lee et al.,

2012). It is likely that the Asian women's assimilation into a different culture affects non-genetic breast cancer lifestyle and reproductive factors (Gomez et al., 2010), which in turn may affect their rates of breast cancer risk. A. H. Wu et al. (2009) explored the role of Asian Americans' diet with respect to their rates of breast cancer incidence, while Ziegler et al. (1996) considered height and weight as determining factors in her work. Many other possibilities and suppositions, however, remain untested and unproven as a result of lack of medical research participation. Unfortunately, regardless of their country of origin, Asian American women are consistently under-represented in clinical trials (Durant et al., 2014; Evelyn et al., 2001; Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014; Y.-H. Lee, Salman, & Wang, 2012), something that is explored in the next section.

### **Asian Americans and Clinical Trials**

The participation of minority racial and ethnic groups in clinical trials, primarily those whose racial/ethnic backgrounds are non-European, is a fairly new area of research that merits attention. Although they have been included in experimental studies since the 1940s, people in racial and ethnic minorities whose primary origins are non-European have not been involved in significant numbers in clinical trials for cancer (Bull, 1959; McCarthy, 1994; Roberson, 1994). In his research, Roberson (1994) reported that this underrepresentation of racial and ethnic groups in cancer clinical trials had become evident over the past several decades. Recent research shows that not much has changed since Roberson's study was conducted. Many researchers have reported difficulties experienced in trying to recruit racial and ethnic minorities for clinical trials (Gao, Ma, Tan, Fang, Weaver, Jin, Lai, et al., 2014; Ibrahim & Sidani, 2014; Kraschel & Roberts, 2014; Y.-H. Lee et al., 2012; Nicholson, Schwirian, & Groner, 2015; Salman et al.,

2015). As an example of potential long term consequences of the absence of minorities' participation in clinical trials, Schmotzer (2011) submitted that lack of full patient participation in clinical trials was a major factor in slowing down the development time for testing new drugs. The same low participation of minorities can also be found in organ donation (Quick, LaVoie, Scott, Bosch, & Morgan, 2012). There is very little research pertaining to Asian American women's donation of tissue, on which this study focuses particularly. More specifically, with respect to the samples stored at the Komen Tissue Bank, as of 2015, Asian American women of all types are grossly underrepresented (A Storniolo, KTB Executive Director, personal communication, Aug. 1, 2014), evidencing that this problem is ongoing. It could be helpful to examine identifiable barriers to learn more about why this is so.

The study results of Kraschel and Roberts (2014), expose an array of barriers to minority enrollment in clinical trials, and Nicholson et al. (2015) found that, although some progress was evident, there is still great room for improvement in the representation of minorities and women in clinical research studies. Examples of the validity of these findings are quite evident within the Asian American community, as is detailed in the next section.

#### **Barriers to Asian American women's participation rates in clinical trials.**

Low minority recruitment is a problem that, according to James et al. (2008), are representative of several major barriers. Researchers have always struggled with successful recruitment of women and minorities, who often reported a mistrust of scientific investigators and their sponsoring agencies (Schmotzer, 2011). According to Schmotzer (2011), the patients' emerging themes revolved around fear of the process and

of randomization, and mistrust of the medical community. The next paragraph details the extent of this fear.

People of Asian descent experience many fear-related barriers to participation in clinical trials (Tong et al., 2014; Yen, Davey, & Ma, 2015). According to research, the main barriers to the participation of this group are fear of side effects, problems associated with language, distrust, family reluctance, and fear of experimentation or of being used as a “guinea pig” (Durant et al., 2014; T. T. Nguyen, Somkin, Ma, Fung, & Nguyen, 2005; Otado et al., 2015; Schmotzer, 2011). This outlook even extends into blood donation, a common behavior for many Whites and other minorities, but far less common in Asian cultures (Tong et al., 2014; Yen et al., 2015). Gao, Ma, Tan, Fang, Weaver, Jin, and Lai (2014) found that in addition to these concerns, Asian Americans are afraid that research results may stigmatize their community, and are therefore reluctant to consent. There are also structural and language barriers to consider.

The structural barriers affecting Asian Americans’ comfort level with clinical trial participation include lack of time to commit and lack of resources such as transportation, childcare, and financial obstacles (Ibrahim & Sidani, 2014). Language barriers abound, particularly with regard to understanding difficult medical terminology and a lack of availability of language-appropriate materials. The likelihood of participation can be improved by building and maintaining trust between the participant and the medical team members (Ibrahim & Sidani, 2014; Stanford University School of Medicine, 2015). Regina Lee, Chief Development Officer of the Charles B. Wang Community Health Center in New York, NY, observed that her organization has conducted a few organ/tissue donation campaigns over the past few years with very limited success. Ms.

Lee remarked in an email interview that there were many challenges to reaching their primarily Chinese immigrant population. She lists a low level of awareness about organ/tissue donation, low health literacy, and a lack of available Chinese language outreach materials as primary problems. Ms. Lee also opined that Chinese concepts of altruism are markedly different from Western concepts, and that the Chinese prefer to donate to and/or support needs within their own family networks, and are less likely to support “stranger” donations (R. Lee, personal communication, January 11, 2016). In addition to the barriers presented here, a review of available literature also produced several suggested facilitators for increasing Asian American research participation.

**Facilitators to Asian American clinical trial participation.** Physician enthusiasm, good communication skills, a healthy provider-patient relationship, evidence of perceived benefit, and feelings of altruism are factors that have been identified as facilitators to the participation of ethnic and racial minorities in medical research (Schmotzer, 2011). In one focus group biobank study concerning mostly lower-income minority participants, the reasons for donating tissue were often altruistic; they wanted to help others and take part in something they felt was for a good cause (Streicher et al., 2011). Another facilitator, according to Ibrahim and Sidani (2014), is to have members of the research team who are ethnically and culturally diverse, as this promotes trust in potential study participants. Researchers who pay attention to and work to include some of these facilitators may help to increase the low rates of racial and ethnic minority participation in clinical trials, and therefore help counter-effect any negative impact on the research and treatment that would directly affect them (Gao, Ma, Tan, Fang, Weaver,

Jin, & Lai, 2014). It might be helpful to look at the source of these negative impacts, which may be part of Asian Americans' cultural legacy.

Participants in a study conducted in Singapore expressed concerns such as fear of discovery of disease, fear of discrimination, weakness, shame, and lack of self-benefits (Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014). Chinese participants in a focus group were concerned that donating blood might be harmful to their health, and also that once their blood was taken it could not be replenished (Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014). Sanner and Frazier (2007) found that being of East Indian descent was a good predictor of abstention from participation in biobanking. Taking these examples under consideration, it could be possible that these fears, concerns, and misperceptions accompanied the immigrants to America. If this line of reasoning is followed further, it could be surmised that if Asian American women are not participating in clinical trials, then their unique genetic makeup is not being represented in breast cancer research. Therefore, women from this racial group may not be able to benefit as much from the findings; according to (Tong et al., 2014) few Asian American women take part in cancer clinical trials. Yen et al. (2015) presented study results showing that Asian Americans contribute to biobanks in lesser numbers than other racial groups. It could be that these discoveries connect to the study findings that Asian Americans' rate of breast cancer risk is rising while that of other groups falls.

Research shows that Asian American community members are more open, willing participants in biospecimen research when they can relate to the disease or cause being studied. Potential participants are more inclined to donate tissue if they have a family member or friend who has been affected by the disease, or if they agree strongly with or

feel a relationship to the merits of scientific research (Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014). From all of this, one possible conclusion that could be drawn is that the communication methods developed to successfully address and reduce or eliminate barriers to Asian Americans' participation in research might need a culturally aware, accepting, respectful approach. This idea will be more fully explored in the next section.

### **Asian American Communication and Culture**

Pursuing diversity in clinical trials presents a complex communication challenge: how to approach solving a multi-faceted problem that creates significant barriers (Kraschel & Roberts, 2014). Communication and culture are a complex set of communication practices that are highly interwoven (Dutta, 2007; Gudykunst, 2000); in sum, communication practices design, change, and transmit culture. The cultural contexts in which it lives influence a population's communication (Lim & Ashing-Giwa, 2013). According to Hearnden (2008), communication between two people involves each trying to understand the other through usage of frames of reference defined by their own personal cultures. Individuals rely on commonly shared assumptions and expectations for clarity of meaning, but how words are comprehended fluctuates from person to person and culture to culture (Hearnden, 2008). Asian Americans possess a legacy and a heritage of collectivist cultures, but find themselves immersed in the individualistic culture of the U.S. (Samovar, Porter, McDaniel, & Roy, 2014). The Asian Americans who are immigrants teach their native-born Asian American children their collectivistic cultures, but these children also learn individualistic traits and norms from their schools and peer interactions (Gudykunst, 2000). In an effort to maintain the harmony of their community groups, collectivists tend to use indirect methods of communication, while individualists

are more likely to communicate in a direct manner (Gudykunst, 2000). Utilizing a health communication framework that is culturally aware and culturally sensitive could be helpful when engaging a campaign focused on taking into account these differences.

Mohan Dutta (2007) posited that culture must be considered while theorizing about and practicing health communication. Fueled by the views of Dutta and other like scholars, two approaches have evolved, one focusing on cultural sensitivity and another on culture centrality. The culturally sensitive approach works to adapt existing health communication practices to fit the cultural characteristics (R. Brislin, 1993; R. W. Brislin & Yoshida, 1993; Dutta, 2007), while the premise of the culture-centered approach is that culture is viewed as the foundation of health communication practices (Dutta, 2007, 2015). These two approaches are distinct yet similar and represent two sides of the same coin; one based in education, the other in resistance. Developing a set of skills to facilitate working in or with a certain community may be a key to gaining the trust necessary to serve minority communities (Hearnden, 2008) who may not even be aware that culture can be a main factor for communicative misunderstandings (Olivares & Pena, 2015). Employing a culturally sensitive or culture-centered approach while interacting with prospective study participants might be of assistance in addressing the challenges of employing positive, constructive communication with Asian Americans when encouraging them to consider participation in the current study.



## Current Study

Until the Susan G. Komen® Tissue Bank at the IU Simon Cancer Center (Komen Tissue Bank or KTB) was founded in 2007, there was no known repository in the world for normal breast tissue (Sherman et al., 2012). The Komen Tissue Bank, still the only biobank of its kind in existence, collects, annotates, and stores healthy breast tissue samples from women with no evidence of cancer, and makes them available to researchers around the world (Komen Tissue Bank, 2015). At the time I conducted this study, the KTB held over 4,000 tissues and over 10,000 blood samples in storage (T. Mathieson, KTB Biospecimen Manager, personal communication, June 1, 2015). Although there is no shortage of women willing to donate to the KTB, most are Caucasian which is a concern ("Improving campaign message and strategy for the susan g. Komen for the cure tissue bank: Insights from donor interviews," 2011) due to the documented need for and lack of availability of minority and particularly Asian American biospecimen donors, the percentages of whose collected samples are growing most slowly (A. Storniolo, KTB Executive Director, personal communication, August 1, 2014).

As the Communication and Minority Outreach Coordinator of the Komen Tissue Bank, I am aware that established communication practices that have been successfully applied to efforts to increase participation of African-American breast tissue donors to the KTB have proven to be relatively ineffective when adapted for the purpose of recruiting Asian Americans. As an example, having conversations with African-American women about the possible benefits of tissue donation for their children and grandchildren, rather than for themselves, has generated great interest and willingness to consider participation.

In previous research I have referred to this phenomenon as the “legacy norm”. While this practical experience demonstrates the efficacy of approach to African-Americans, it is important to consider whether or not there might be cross contextual application in the conversational practices of other groups of Americans (see Craig and Tracey, 2014). For example, attempts to apply the legacy norm as a precept of recruitment communication with the Asian American population have failed, which fuels the question of what the difference in the communication practices might be that could lead to greater participation in the donation of tissue samples. This poses a great problem because of the lower breast cancer incidence of Asian Americans in general (Centers for Disease Control and Prevention, 2015), and due to evidence that the rate of incidence is adversely affected by changes related to a move to the United States (Gomez et al., 2010; C. I. Lee et al., 2012), researching the causes of these developments could generate data to be applied to finding treatments or a cure for breast cancer. These treatments could conceivably be applied not only to the Asian American population from whom the data was generated, but to anyone who contracts the disease.

At the time of this study, 131 of the 4,124 stored tissue samples at the KTB, or 3.2%, were procured from donors of Asian descent. Ethical and scientific reliability demand that all subgroups of the population are represented appropriately in research (Centers for Disease Control and Prevention, 2015). Additionally, Anna Maria Storniolo, Principal Investigator and Executive Director of the Komen Tissue Bank, forecasts an increase in breast cancer research concerning racial and ethnic minorities in the upcoming years, suggesting that oversampling is appropriate for tissue from all minority donors (A. Storniolo, personal communication, August 1, 2014). Moreover, while 3.2% of the

KTB's stored samples are from Asian American women, Stewart, Bertoni, Staten, Levine, and Gross (2007) found that a sampling totaling less than 3% of a population limits the validity of conclusions about the representation of those groups in trials. Some researchers such as Stewart et al. (2007) claim that it may be necessary to over-sample for these groups to acquire enough data for significant subgroup analyses. It follows that further communication research designed to illuminate the communication practices necessary to boost donor rates is necessary. The next section will detail reasoning why Grounded Practical Theory provides a useful lens for this purpose.

### **Theoretical Framework – Grounded Practical Theory**

This study takes a Grounded Practical Theory approach. Grounded Practical Theory (GPT) was formulated by Craig and Tracy (1995), and grew from Craig's earlier work (1989) wherein he proposed that communication studies should be pursued as a practical discipline, rather than a traditional scientific one (Craig & Tracy, 2014). "As a practical discipline, our essential purpose is to cultivate communicative praxis, or practical art, through critical study. All of our work does, or should pursue that purpose." (Craig, 1989, pp. 97-98). Tracy supplied a second major source for GPT through her empirical work on multiple goals in discourse (K. Tracy & Coupland, 1990). The combined work of these scholars defined GPT's focus on reconstructing particular communication practices. Closer study of the components can promote greater understanding of this complex theory (Smarandache & Vlăduțescu, 2014).

According to Craig and Tracy (2014), GPT is an approach to cultivating practice-based theories such as, in this case, of determining the communication practices between KTB and Asian Americans of all types might engage to boost tissue donation from that

sector of our community. Primarily, GPT seeks to foster particular communication practices from people within a context, using their own expressions, and it offers positive suggestions to feed reflection about practical behavior. Its goal is to develop an analysis of a communication practice that will be useful for reflection about the practice and its accomplishments (Craig & Tracy, 2014). As a framework, GPT is both metatheoretical and methodological. Metatheories consist of interconnecting rules, principles, or a narrative that both describes and proposes what is acceptable and unacceptable as theory, while methodology contains interlocking rules, principles, or a story that describes and proposes the nature of acceptable *methods* in a discipline (Willis F Overton, 1990; Willis F. Overton & Müller, 2013). GPT also makes use of theoretical reconstruction (Craig & Tracy, 2014). In theoretical reconstruction, particular features of an ideal social practice are redefined in general terms, with a goal of clarifying the inherent values and principles of that practice. These values and principles would be critically assessed and appraised, and ultimately used in the development of a normative model applicable to circumstances similar to those in the original setting (Koenig, Wingard, Sabee, Olsher, & Vandergriff, 2014). GPT seeks to achieve this reconstruction of communication practices at three correlated conceptual levels, as outlined by Craig and Tracy (2014): the problem, the technical, and the philosophical levels, which are explained further in the next paragraph.

GPT is an approach intended to solve communication practice challenges in the real world (Smarandache & Vlăduțescu, 2014). GPT study begins at the problem level, which is considered the entry point; “problem level” refers to the tensions or dilemmas that exist in any significant communication practice. Identifying the tensions in a practice can result in arriving at the technical level, the underpinning where the particular

discourse actions that reveal and manage those tensions are pinpointed (Craig & Tracy, 2014). At the same time, naming the tensions or dilemmas can also result in arriving at the higher, philosophical level, where the situated ideals (the participants' views about how they should perform inside a communication practice), that guide choices about the management of the dilemmas, are identified (K. Tracy, 1997). In the current study, the tensions and dilemmas become evident through careful examination of the Asian American women's discourse, underlining the suitability of applying GPT as the theoretical framework. In the next paragraph I offer an examination of some studies exhibiting a comparable need, that could be helpful in supporting this outlook.

Koenig et al. (2014) studied the communication practices between physicians and their diabetic patients who demonstrated a need for insulin. The physicians were able to find a balance between what the patients needed and what they preferred through practicing a method the authors termed *interactional sensitivity*. As in the current study, analyzing discursive data provided insight into original sources of patients' concerns. This research resulted in the proposal of a normative model for reflecting on how physicians navigate challenging negotiations with patients during routine visits (Koenig et al., 2014). In another health communication study using a GPT approach, Bloom (2014) examined how individuals from different nations, who are brought together to work in medical and dental clinics in rural Dominican Republic, develop strategies to navigate language differences with regards to patient communication. The researcher combined ethnographic methods (methods acknowledging the participants' individual cultures) and GPT. In particular, she was curious as to what a GPT approach could disclose about the program's discursive strategies (Bloom, 2014). Bloom posits that her

work offers an important contribution for future GPT study and applied health communication research, through the provision of rich descriptions and self-reflective analysis, both of which are crucial to GPT. In addition, she submits that the GPT approach of analysis through examination of the problems, techniques, and philosophical rationales promoted deeper study of the communicative practices in place (Bloom, 2014). Bloom’s research as well as that of Koenig et al., share a similarity of need with the current study. As well as having a health communication focus, both studies exemplify research successfully approached through discursive analysis for purposes of examining cultural or societal narratives. Both also display a promise of eligibility for theoretical reconstruction. In my view, a desirable goal of applying GPT is, after identifying the problem then digging deeper and thinking higher to arrive at the technical and philosophical levels, to recognize implications that are fed by examining the reconstruction of communication practices. Figure A depicts my visual translation of the ideas of GPT. Creating this diagram was instrumental in helping me sift through and categorize the components of the results of the current study through the lens of GPT.

**Grounded Practical Theory diagram**

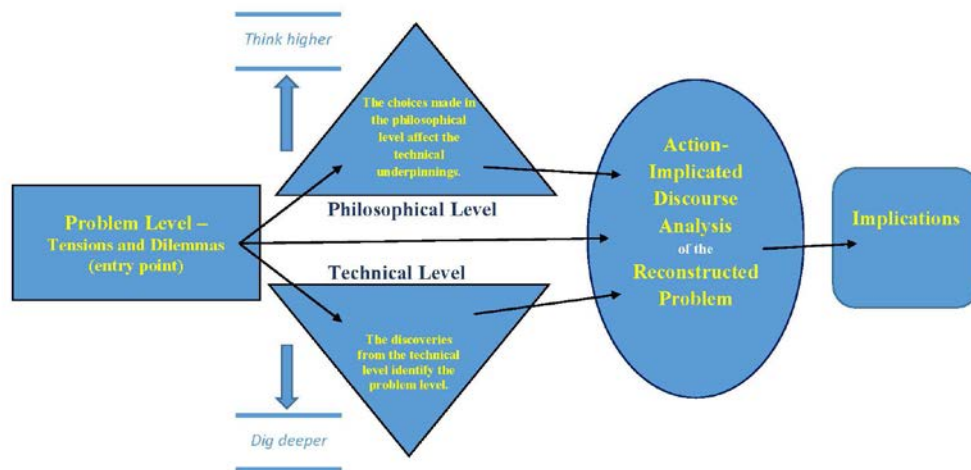


Figure A

GPT focuses on reconstructing certain communication practices (Craig & Tracy, 2014), and is most beneficial when the objectives of a practice comprise value-based normative dilemmas promoting reflective thinking at the philosophical level. Framing of the current study by GPT facilitates the identification of the normative dilemmas arising from the focus group findings. The KTB is unique; at the time of this study there is no other biobank or clinical trial in the world collecting healthy breast tissue for breast cancer research. As was previously noted, the KTB is bound by scientific ethical standards to collect a diverse array of samples such that the ethnic and racial subgroups of the U.S., if not the global, population is reflected (Centers for Disease Control and Prevention, 2015; Salman et al., 2015). Also, we can find abundant literature indicating the need to study the relationship between breast cancer and women of different genetic, cultural, and racial backgrounds (Centers for Disease Control and Prevention, 2015; McCarthy, 1994; Schmotzer, 2011; Swanson & Ward, 1995; Symonds, Lord, Mitchell, & Raghavan, 2012; Wissing et al., 2014). Current recruitment methods and messaging have proven relatively ineffective with Asian Americans, as is demonstrated by the particularly low percentages of breast tissue donors in this group when compared to Caucasians and even to other racial and ethnic minorities. These reflections lead me to ask: how are we to collect these samples from Asian American women? What do we need to say to them to encourage them to consider donating their healthy breast tissue? Upon reflection, I propose several factors to guide the search for answers to these communication questions.

- 1) It is important to set goals regarding the development of an understanding of these women's perceptions (K. Tracy & Coupland, 1990) toward this practice or behavior, and of their attitudes regarding participation. Exploring these

perceptions and attitudes can reveal a story such as is described by Willis F. Overton and Müller (2013) in the definitions of GPT's metatheoretical and methodological discipline.

- 2) By establishing the unique nature of the KTB and its distinctive goals, I also demonstrate the lack of other researchers successfully collecting this kind of tissue sample, especially in the necessary and appropriate quantities.
- 3) An extensive search of the existing literature revealed no previous work framed by any theory that outlines a process fitting the particular considerations of this study, but did illuminate works exhibiting a comparable, practical need, that were guided by GPT (Black & Wiederhold, 2014; Bloom, 2014; Koenig et al., 2014; K. Tracy & Hughes, 2014).

There is an expanding body of literature on knowledge, perceptions, and attitudes in regard to biospecimen research. Despite this, few studies have submitted data on actual biospecimen donation behaviors resulting from outreach and educational programs, particularly in Asian American populations (Gao, Ma, Tan, Fang, Weaver, Jin, Lai, et al., 2014). Given all of these factors, I approach this research through Grounded Practical Theory, which considers communication as a practical discipline (Craig, 1989).

To begin the reconstruction of the recruitment of Asian American women into this clinical trial, which is the communication practice of this particular study, it is necessary to gain knowledge about any opinions that may have been influenced by the cultural and societal background of the members of this group. A challenge arises when the presence of these pervasive opinions raise barriers and create a problem. I seek to identify these



opinions, and therefore work to alleviate the resulting problems, through the application of GPT.

Once the group members' opinions are identified, there follows a primary need to illuminate any barriers the opinions may raise. Reaching the technical level and illuminating any resulting barriers ideally would result in the revelation and management of any tensions, leading to a more successful reconstruction of the communication practice. Philosophically speaking, managing the tensions created by the existing barriers should be addressed in a manner that encourages a connection from the group members to the desired behavior, with the outcome that any resulting messaging is delivered through methods that will effectively engage and enlighten the receivers. Taking all of this under consideration, I ask the following research questions:

RQ1: What are the opinions expressed by Asian American women about donating healthy breast tissue?

RQ2: What are the communication-related barriers that prevent Asian American women from donating healthy breast tissue?

RQ3: What outreach communication tools and strategies would positively affect Asian American women's outlook toward donating their healthy breast tissue?

## **Methods**

To provide the analyses for this study on Asian women's perceptions about donating healthy breast tissue, I gathered data from a single focus group comprising Asian American women of various ethnic and cultural descent. Most of the women had little to no knowledge of the Komen Tissue Bank before participating in the focus group. The session lasted for two and one-half hours, including a 30-minute break for lunch to prevent fatigue (S. J. Tracy, 2012). All study procedures were approved by the university's IRB before beginning the project, and all participants were consented and asked to sign media release forms as they arrived at the location where the focus group was held.

### **Participants**

I recruited participants for this study through several channels, including the following:

- Collected the names and email addresses of social and business associates of mine, as well as those of my work colleagues and invited them by email to participate.
- Posted fliers in the student center and in lab and research buildings of a large Midwestern university
- Reached out to Asian American affinity groups (groups of people connected through the same organization who are aligned through a similar interest or purpose) at two large local companies and asked for assistance in recruiting their members.

- Emailed students and staff of a large Midwestern university who possessed Asian surnames and invited them to participate.

I contacted all potential participants through an email that contained directions to contact me either by email or phone, and to say whether they were interested, were over 18 years old, and whether they were “not at all”, “somewhat”, or “very” knowledgeable about the KTB. The focus group recruitment email contained a simple explanation of the criteria for participants in the study, the subject matter, and the date and location of the meeting.

Females who were 18 years of age or older and self-identified as Asian American were eligible for the study. I registered the eligible, interested women who responded to my invitation, and sent reminder emails three days before the meeting date. Seventeen women (N=17) attended the focus group. The women ranged in age from 21-48; the median age was 26. Most participants did not have children. Ten of the women were single; seven were married. The participants reported being of several different cultural, racial, and ethnic backgrounds: Chinese, Indian, Indonesian, Japanese, Korean, Malaysian, and Thai. More than half had been born in the country of their heritage. Only five of the women said they had ever been personally affected by breast cancer. I preferred but did not mandate the participants had little or no familiarity with the KTB. As it turned out, while only five of the women said they had never heard of the KTB before, those who had, for the most part, possessed very limited knowledge of any details about the organization.

Throughout the procedure of gathering participants for this study, I was conscious of the amount of outreach I had to do to procure them. Several of the affinity groups to which I reached out did not answer, even though their purpose is to disseminate and act

upon information that is culturally interesting to their constituents. Most of the women whose names were collected for me by my friends and colleagues either did not reply to the email, or they replied to say they were not interested. I distributed thousands of emails to university students and staff, all to gain a respectable number of participants for one focus group. While I hoped that this would not be so difficult, the challenges did not really surprise me. It was three years ago, when I began focusing on diversity and minority communication and outreach for the KTB, that I started to notice that while in general, all minorities exhibited at least some resistance to the broad concept contributing to a medical research study, Asian Americans' reluctance was by far the most evident. Even the Asian American surgeons and researchers who volunteer for the Komen Tissue Bank and promote our mission have donated only in miniscule numbers. Because of all of these factors, I knew that even though there was no clinical procedure involved in conducting this focus group, it might still be a tough sell.

### **Data Collection**

In an effort to maximize the scope of the focus group, encourage the highest participation rates, and to reduce bias on my part as much as possible, I partnered with the Indiana Clinical and Translational Sciences Institute (CTSI) Patient Engagement Core (PEC), an interdisciplinary group of researchers with patient engagement experience. The CTSI PEC assists individual investigators by making patient- (or in this case, participant-) engaged research more accessible. My goal was to design an interactive atmosphere wherein the participants of the focus group were encouraged to get to know more about each other to encourage comfort when responding to questions. I enlisted members of the CTSI PEC to aid me in the development of planned question / answer and activity

sessions, and to moderate the focus group, keeping me free to primarily observe and take notes from the sidelines. As an African-American, I know how impact can be affected based on the differences of my own feelings when faced with a moderator or speaker who looks like me rather than someone who does not. At my request, the CTSI PEC arranged for an Asian American female, Helen to moderate my focus group.

I audio recorded the focus group in its entirety using a micro recorder and two cell phones as backup, and also took copious handwritten notes. In order to provide a reference of the methodological processes of the activities as well as any visual results, I took photos of the room and of participants who had completed media release forms.

With assistance from the CTSI PEC, I had carefully planned activities to produce a well-rounded body of information (Asbury, 1995; Morgan, 1997). In total, there were five separate tasks/activities presented to the women attending the focus group. In order to collect basic information, I asked participants to complete a demographic questionnaire (see Appendix A) containing questions relating to their race/ethnicity, place of birth, marital and parental status, and familiarity with the KTB. In addition to this questionnaire, the participants participated in four guided processes designed for use in this study.

The activities, also referred to here as tools, used in this study stem from participatory design practices. Participatory design is a practice that enables non-designers (users or others who may come to the project from other areas such as marketing or engineering) to make use of different tools and techniques to fulfill a research purpose (Sanders, Brandt, & Binder, 2010). The techniques vary based on the purpose for their use. For this study, the focus was on developing techniques that used

motivator cards, opinion storyboards, recruitment motivator madlibs, and people cards (the tools) to promote guided communication. More information about each of these activities follows. For ease of understanding, and because we were working together to answer questions and moderate, I will use “we” to denote the collaboration of tasks between me and Helen.

**Motivator cards.** Each participant told the group her name and something that she had felt motivated to do recently. As I did not want to assign parameters which may have made the women feel restricted, any answers were considered acceptable. For example, a participant may have felt motivated to finally clean the kitchen floor, or she may have started to train for a marathon or found the courage to ask a friend for a favor. We captured the motivators onto pages of a flip chart and then transferred them to index cards we called “motivator cards”, to be used later in the Motivator Mad Lib exercise.

This was definitely a warm-up activity, and was greatly needed. As I observed the women it was easy to detect a hesitancy and reserve. They were quite slow to volunteer to speak up, and Helen had to wait patiently while gently encouraging responses. She finally suggested we go around each table, which relieved the need for the women to volunteer, subsequently easing the “feel” of the room. The participants seemed to welcome the structure that accompanied the suggestion, and each happily answered when it was her turn. By the end of the exercise the women were visibly more relaxed as we moved into the introduction of the opinion storyboards.

**Opinion storyboards.** Storyboards have been around for a very long time and are used in a diverse assortment of practices to facilitate the visual promotion of ideas. We distributed a storyboard of the breast tissue donation process along with a red and a green

pen to each of the women taking part in the focus group. The storyboard contained color pictures of people speaking to the audience through dialogue bubbles as well as screenshots of different parts of the Komen Tissue Bank brochure and some highlighted text choices from the website and other printed materials. The graphics and text used in the storyboard represented the types of language and imagery typically used by the KTB. As an example, the first page contained a picture of a Caucasian woman sitting behind an information table, smiling and saying, “Get involved, be a tissue donor! The Komen Tissue Bank is the only repository in the world for normal breast tissue. By studying normal tissue, we can accelerate research for the causes and prevention of breast cancer.” (see Figure B)

We asked the participants to work alone to go through each of the fifteen pages of the storyboard determining what they found to be positive (things that made them want to donate) or negative (things they saw that made them not want to donate). They circled or marked the positive visuals and text with green pen, and the negative with red. We then led the group in a page-by-page discussion about the items they marked, identifying recruitment motivators and barriers.



Figure B

By the time this activity had been fully explained, it was time for lunch. The food (pizza and tossed salad) had already been delivered to our location, and all the participants agreed that it would make sense to eat while the pizza was hot. After everyone had been served most of the women opened their storyboard packets and began to look them over. Many began to start using their green and red pens to show their positive or negative feelings about what they were seeing. It appeared to me that the participants really started to open up to each other over lunch. They chatted as they ate, comparing notes about how the text and graphics made them feel. It was my impression that during this period, for the participants, the focus group evolved from something they had agreed to do into something they were enjoying. As we moved from lunch into the motivator madlibs activity, I observed the women relax completely, and the one or two who had still been holding back finally participated willingly.

**Motivator Madlibs.** This tool was inspired by the actual game of Mad Libs, wherein one player calls for a list of words which are then used to fill in the blanks in a sentence, paragraph, or story. Throughout the focus group the list of motivators had continued to grow. We transferred all of the motivators from the first activity and from the continuing conversation onto motivator cards. (see Figure C)

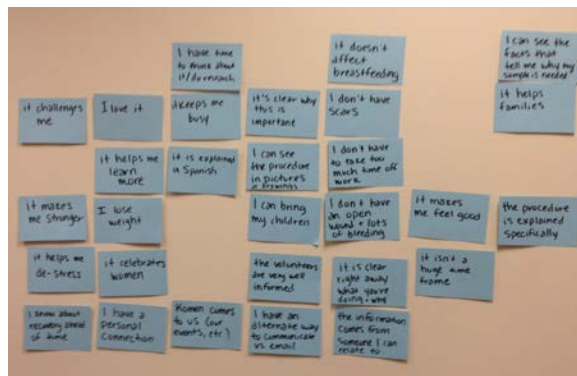


Figure C



For the motivator mad lib activity, we posted a sentence on the wall that read, “*It would be worth it to donate breast tissue if \_\_\_\_\_.*” We taped all of the motivator cards to the wall and then asked the participants to choose which of the cards best completed the sentence. (see Figure D) After the women were satisfied that they had added all the cards they thought were applicable, the result was that well over half of the cards had been posted as possible motivators to breast tissue donation. Next, we gave each woman two green sticky voting dots, and asked them to place one dot next to two of the motivator cards that they felt completed the sentence best for them personally. Through this method we identified the majority’s top motivators to breast donation.

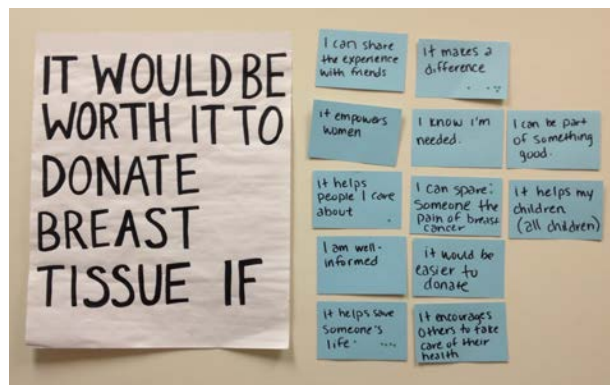


Figure D

During this exercise the participants demonstrated a total turnaround from their attitudes during the first activity. There was no hesitation to speak up and make suggestions for which motivator cards applied for them, and no need to suggest that we go from table to table. The women indulged in a true discussion. When it was time to stand and come to the wall to vote with their dots, everyone was ready and willing to take part. This activity did not take very much time at all, and we transitioned easily into handing out the people cards, which were used for the final exercise of the day.

**People cards.** The final activity, the people cards exercise, was designed by the CTSI team, and uses storytelling techniques to encourage writing based on the participants' own experiences. They were asked to imagine a hypothetical situation and incorporate participatory envisioning and enactment for the purpose of understanding (Sanders et al., 2010). We gave each participant three "people cards" folded in half so that only the right side of each card showed. This prevented incorporating knowledge of the contents of the rest of the card into any answers. At the top of the right side of the card was a blank line. We asked the women to think of three people whose opinions they most valued, and to write the name of each of the three people on the blank line on one of the folded cards. Finally, we asked them to unfold the card so that the left side was revealed. Once it was fully open, the people card read, *"If I decided to donate breast tissue... I (would) (would not) tell my [blank filled in with the name or a person whose opinion was valued] because \_\_\_\_\_."* There were also two prompts for the participant to complete which read, *"He/She would think \_\_\_\_\_,"* and *"He/She would say \_\_\_\_\_."* (see Figure E)

**If I decided to donate breast tissue...**

I  would  wouldn't **tell my** boyfriend

**because**  
 it is important to let him understand the procedures and consequences/risks/benefits, and also to get his support.

HE/SHE WOULD THINK: it is fine as long as it is safe.

HE/SHE WOULD SAY: "Go ahead. You will have my support."

Figure E

The focus group participants took this exercise very seriously. They took their time completing the people cards, and really seemed to be thinking about their answers fully. There was not much chatter while they were completing these. Occasionally one of them would ask something of a neighbor, perhaps checking to see if the other woman had the same thoughts, but for the most part they worked individually.

Once all of the people cards were collected, I stood to thank all of the women for coming, gave a five-minute overview of the KTB and what we do, and invited any of them who wanted to keep in touch to go to our website and join our mailing list. I then released them all promptly, two and a half hours after they had arrived.

### **Data Analysis**

To prepare the information for the first round of coding, I began by collecting, cataloguing and categorizing all data from the People Cards, Motivator Madlibs, and Storyboard activities, as well as the transcript of the focus group dialogue. I created a separate Excel spreadsheet for each activity, as well as for the demographic information. This seemed to me to be the best method to enable me to see all the data clearly, and to manipulate the data into different themes and categories after I was finished. After considering my options, I decided to hire a professional to transcribe the audio recordings. As I am working on this project alone, and working a full time job, I determined that the best use of my time was to spend it with the data. I estimated the transcription would take at least 15 hours that would be better put to use for coding. I read and re-read the transcription of the focus group conversations, ensuring that the transcription was well done. I made some adjustments where necessary; for example, on

several occasions I was able to interpret language the transcriber found inaudible. When this was complete I began the coding process.

S. J. Tracy (2012) describes coding as an “active process of identifying data as belonging to, or representing, some type of phenomenon. This phenomenon may be a concept, belief, action, theme, cultural practice, or relationship” (p. 199). Once I had completed the data entry from the activities and the transcription into the spreadsheets, I conducted primary-cycle coding, which Tracy describes as starting with examining the data then assigning words or phrases that describe the heart or the core of what is expressed (S. J. Tracy, 2012). To do this, I immersed myself in the extracted focus group data (S. J. Tracy, 2012) from the activities and the transcription. While listening to the recordings I paid attention to each participant’s tone of voice so that this information could be included in my observations. Keeping my theoretical framework in mind, while looking through my data I focused in particular on searching out barriers to breast tissue donation that were presented by the Asian American participants, and any mention of cultural norms. Through these methods I was able to identify distinctive categories and begin to allocate themes (Saldaña, 2009).

Utilizing my own previously developed, organized system of categorizing primary codes through the use of excel spread sheets, I loosely determined themes and concepts using methods suggested by S. J. Tracy (2012). After completing the primary coding and making note of potential themes, I moved into second-level coding, deriving them from further examination and analysis of the data through a Grounded Practical Theory approach. During this process I solidified themes and chose appropriate sections of the transcript to use as examples of my findings. Before committing fully to the

categories leading to the thematic outcomes, I carefully reviewed the data through my own professional lens – that of the Minority Outreach Coordinator of the Komen Tissue Bank. It is my job to reach out to women in all racial and ethnic minority groups for purposes of recruiting them into our clinical trial. Since the KTB is the only biobank of its kind, and as the responsibilities of my job are not shared with anyone, I am, in effect, the person with the most actual and practical knowledge and experience of the identified challenges of recruiting Asian American women with whom we come into contact.

Holding this position generates both affordances and constraints with regards to analyzing the data in this study. The unique insight I enjoy certainly helps when reflecting on the data. As the only KTB team member belonging to a racial minority, and as the person charged with seeking out minority individuals and groups for purposes of communicating directly with them to educate them about and generate their interest in the KTB, I am afforded a first-degree view of the initial and successive reactions these women experience. On numerous occasions I have spoken at length about clinical trials in general and our clinical trial in particular, to women of minority racial and ethnic heritage, primarily African-American, Asian American, and Hispanic. The experience and knowledge gained from this intimate and recurring exposure is helpful when deriving themes from my data. At the same time, however, I must account for what that familiarity might mean for obscure themes or ideas that might present themselves sooner to a more naïve observer of the data. It could be that my familiarity may both lead me to assumptions while limiting me from thinking about the data in a new way. To consider that there could be a new way, however, implies that there are old ways, but this is not the case here. There is inadequate research concentrating on the communication involved

in positively affecting the recruitment of minorities to clinical trials, particularly to tissue donation for cancer research. It follows that any degree of familiarity with this topic is helpful. In addition, some knowledge on the researcher's part of emerging patterns within one group could illuminate possible differences in that pattern in other minority groups. These differences may lead to discovery of deficits that could identify "non-findings" that are themselves important results. Realizing that all researchers live with their own constraints and affordances as they analyze data and look for themes to emerge, in this particular case I believe that, because of the reasons outlined above, the affordances from which I benefitted while analyzing this data outweigh the constraints. My findings, which will be outlined in detail in the next section, were derived from studying all coded data from both verbal and written input, and were framed by GPT.

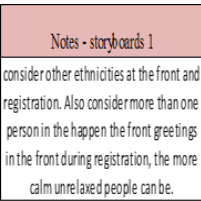
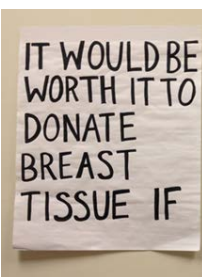
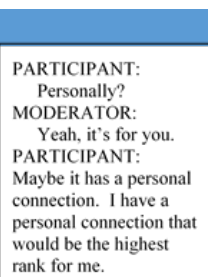
<b>EXPLANATION OF ACTIVITIES</b>	<b>Opinion Storyboards</b>	<b>Motivator Madlibs</b>	<b>People Cards</b>	<b>Discussion</b>								
<b>Description of Activity</b>	Designated feelings and suggestions on pages showing KTB literature and situations.	Answers entered into the sentence, <i>“It would be worth it to donate breast tissue if _____.”</i>	Outlining whom participants would/would not tell about donating, and why.	Constant discussion throughout participation in the activities.								
<b>Data Emerging from Activity</b>	Desire for knowledge of everything to expect from pre-signup through recovery.	Actual, comfortable dialogue; support of need for knowledge; selfish altruism.	Lack of personal experience with breast cancer, least likely to talk to mothers about donating.	Lack of faith in donation being handled responsibly, lack of knowledge of breast cancer incidence, especially after migration to U.S.								
<b>What Did Data Look Like?</b>	Participants used green (good) and red (bad) pens to show feelings, and wrote comments to clarify. (see Figure B)	Motivators gleaned from dialogue were transferred to cards, then participants chose (as a group) which ones applied most here. (see Figure D)	Participants completed individual cards with their choices of people and reasons. (see Figure E)	Transcription of dialogue recorded throughout the session. (see Appendix C)								
<b>Example of Data Analysis</b>			<table border="1" data-bbox="1024 1098 1224 1276"> <thead> <tr> <th>would/wouldn't</th> <th>tell my...</th> </tr> </thead> <tbody> <tr> <td>Wouldn't</td> <td>Mom</td> </tr> <tr> <td>Would</td> <td>Boyfriend</td> </tr> <tr> <td>Would</td> <td>Dad</td> </tr> </tbody> </table>	would/wouldn't	tell my...	Wouldn't	Mom	Would	Boyfriend	Would	Dad	
would/wouldn't	tell my...											
Wouldn't	Mom											
Would	Boyfriend											
Would	Dad											
<b>Main Outcome</b>	Participants want detailed knowledge of the science involved in donation.	Participants may be more willing to donate if they knew they could help their family or community.	Participants show a marked lack of personal connection to breast cancer.	Details and support for data derived from activities. Concern about pain from procedure not a priority.								
<b>GPT Conceptual Level</b>	Problem and technical level	Philosophical level	Problem level	Technical and philosophical levels								

Table 1

### **Findings - The Problem (Tensions and Dilemmas)**

To re-examine the foundations of Grounded Practical Theory, before determining my study results I developed a checklist that became an effective tool for organizing my thoughts as I worked to sort the abundance of information gleaned from my research. My checklist listed the foci and components of GPT:

- GPT focuses on reconstructing particular communication practices (Smarandache & Vlăduțescu, 2014);
- The approach helps to develop an analysis of a communication practice that will be useful for reflection about the practice and its accomplishments (Craig & Tracy, 2014);
- It seeks to reconstruct communication practices at three correlated conceptual levels: the problem level (referring to tensions and dilemmas existing in any significant communication practice), the technical level (the underpinning reached through identifying the tensions), and the philosophical level (the higher level where participants' views of how they should perform inside a communication practice are identified) (Craig & Tracy, 2014);
- GPT is an approach intended to solve communication practice challenges in the real world (Smarandache & Vlăduțescu, 2014).

The research questions for this project concerned the attitudes of Asian American women toward donating healthy breast tissue, the communication-related barriers that may restrict the behavior, and the possible development of communication tools and strategies that may help ease the perceived restrictions and allow a higher level of comfort in



performing the behavior. I chose to analyze the data, which was plentiful, guided by GPT's concept of the correlation of the problem, technical, and philosophical levels of communication practice.

In the Methods section I explained that we used three main activities during the focus group to stimulate discussion about the perceptions of the attendees toward donating their healthy breast tissue for research. Throughout this results section I will refer to these activities as Opinion Storyboards, Motivator Madlibs, and People Cards. Each of these tools was chosen to assist in determining influences and motivators of the Asian American focus group participants. For assistance with understanding these activities and the data they produced, please refer to Table 1.

The encapsulated results of this study are divided into four themes, each of which was derived from examining the data through the lens of Grounded Practical Theory. The first theme focuses on the influences of culture and society. The second theme highlights the idea that for these women, knowledge is power. The third theme concerns the focus group participants' need for information currently missing from KTB outreach communication, and the final theme illuminates pieces of KTB messaging that are not hitting the mark for successful recruitment of potential Asian American donors.

### **Influences of Culture and Society**

This theme focuses on the cultural inheritance of these Asian American focus group participants, and is divided into two subthemes: norms affecting those who have not donated tissue, and norms affecting those who have.

**Non-donor participants.** It became quite clear while analyzing the data from the focus group discussion that donating tissue was considered to be outside the social norms

of many Asian cultures. Giving tissue, blood, or organs is seen as a larger, more significant sacrifice than it is in America, and this perception filters down to affect even to Asian Americans born in this country. Whether or not the prospective donor herself perceives differently, she may face resistance from others here or in the Asian country of her heritage. When she planned to donate blood, one young American-born study participant told her grandmother, who lives in Japan, that blood drives take place on college campuses across the United States.

“...my family in Japan ... don’t believe me that there’s a blood drive that, you know, college campuses have and people just go in and get their blood drawn.”

Strong cultural bonds seem to reach across oceans and generations to perpetuate ancestral norms. The same woman went on to outline other societal barriers:

“And I think also another thing you have to realize is that there’s a lot of like religious, but also cultural stigmas to giving something of your body for research.”

Should this young woman choose to donate tissue, it is clear that she may face deeply rooted opinions founded in her cultural heritage that would serve as societal obstacles to carrying out her decision.

Societal distrust of the idea of fair and regulated organ and tissue donation also plays a major role for Asian Americans who emigrated to the U.S. One woman spoke of the reputation of exploitation and black market trade surrounding some countries when it comes to organ donation, making her question the truth, safety, and legality of the entire idea.

“And then there’s like the black market of trading blood and tissues and some ... poor people, leaving the wage to actually do that for a living. ...They call it donation on the surface, but you know, it’s just a cover up

for their trading. So then we have that kind of concern deep in our mind that that may get you, you know, bacteria, at least virus.”

The participant described how the stigma attached to these shady dealings can make her feel dishonorable and disgraced enough on behalf of her home country, that she is very hesitant to even talk about such things here in America:

“So here ...sometimes I would feel a little bit shameful to talk about that because we heard so many scandals and sometimes we think okay it might be just happen in China, but will that happen here? Is that okay to talk about it?”

The fear of suspicion or disgrace that might befall someone who chose to act outside of these societal norms causes many Asian Americans in the study to be wary of donating to the KTB, and to be fascinated by any who might not think this way.

**Donor participants.** Most of the focus group participants either had little previous knowledge of the Komen Tissue Bank and its mission, or had not donated tissue to the KTB, or both. However, two of the women in attendance (Donor 1 and Donor 2) were previous KTB tissue donors. Other participants were curious about what factors had influenced them to donate. In both cases the decision had been made somewhat impulsively, and were the results of positive exposure to the organization or one of its members.

Donor 1: I think one of the things I was inspired by when I went [to volunteer] and one of the things that helped me have more confidence to do it was that there were a lot of people my age.

Donor 2: [The researcher] said oh we're looking for people of like Asian decent to donate. I was like okay. Then I said okay, then I said oh what do they do? Then she explained. She basically explained this part to me and I was like okay.

Both donor participants agreed that the key to their decision to donate was based on feeling a tenuous thread of trust, and having taken a leap of faith.

Donor 1: It's a good thing and it's people who were like used to the process. They are helpful, supporting you, so it wasn't a challenging process to go through once you got your head into it. But I think when people initially hear about it, especially because it's a foreign idea, it's a little bit like whoa wait a second. If you don't think about it, you just go.

While the other group members were indeed curious about the actions of these two outliers, and were interested to discover what led to their decisions to donate, learning more did not seem to generate any thoughts about or desires to do the same.

In sum, these participants displayed an underlying foundation of distrust that their donation would be handled and used well and in good faith. Added to this, voluntarily giving up part of your body, whether or not it is needed or will regenerate, is seen by members of this group as a larger sacrifice than is perceived by others. Unfortunately, there is currently no easily accessible KTB recruitment communication that deals with either of these issues.

### **Knowledge is Power**

Despite the broad diversity of Asian races represented in the focus group, through analyzing the data from the Storyboard activity in particular (see Appendix D). I found pervasive evidence of a common universal need for highly detailed information among the attendees, which forms this second theme. At times this need seemed almost to be a craving, an ever-present set of rhetorical luggage, carried everywhere and packed full of questions to which the women must have every answer. For the most part, the knowledge the participants sought can be separated into two subthemes: knowledge about the tissue donation procedure, and knowledge about the science involved.

**Knowledge about the procedure.** The women's questions and comments covered a litany of topics, including a few, but not many, common ones such as general information about the procedures for donating breast tissue,

“When can you go back to work? Normal life? Shower? Nutrients? Exercise?”

“I think one of the things that's a little bit unsettling is like is this normal; when can I take this bandage off; when can I shower?”

In response to pages in the Storyboard Activity that featured descriptions of the donation process, several participants wrote comments expressing a need for explanation of medical terminology and requests to “keep it simple”. In addition to these somewhat expected responses, however, the participants also wanted, or needed, detailed information about other topics and factors surrounding donation not commonly requested by potential tissue donors. There was some anxiety about the quantity of tissue that would be taken, and how the procedure would affect the look of their breasts.

“I think putting into perspective how much of tissue you actually have and how much is actually taken.”

“...putting into perspective how little you're giving, but how much impact it can have.”

“Also like, you know, you're afraid that hey is it going to disfigure my breast. Is it going to leave me lopsided afterwards?”

Pages four and five of the storyboard detailed the actual donation process. The written reactions clearly illustrated a communal demand for more detailed information, both in words and images, from a majority of the women.

“Might be helpful to provide support and Q&A...”

“On number 3 and 4 include pictures...”

“Is there a recovery period?”

“What does that look like?”

“Maybe include a brief summary of side effects or something. ”

“Is it going to be 3 times or one time [to get the] cores?”

“It would be helpful to add how to take care about yourself after donation.”

“...maybe include how much tissue from start to finish.”

In addition to the written feedback from the Storyboards, some notable indications of this group’s collective need were evidenced by the depth and breadth of questions presented during the discussion regarding the consent form. The informed consent is signed prior to involvement in a study to confirm that the participant agrees to the procedure and is aware of any risks that might be involved. In my experience of meeting and talking with potential donors over the past several years, it is unusual for prospective donors to pay much attention to the informed consent document until they are actually in the presence of an informed consentor who explains all the details and nuances of everything to which the donor is agreeing. The majority of the women in this study displayed no such lack of awareness.

“Do people take the consent forms home and read them or do they not have that chance?”

“Before they sign a consent do they have a chance to take it home and read it?”

These and other remarks revealed a mindfulness of what a consent form was and what purpose it served, and they wanted to read it. Furthermore, they sought to be able to have

access to the consent before arriving at the event; they wanted to have ample time to read and process it fully before registering for an appointment to donate.

**Knowledge about the science.** The participants had several questions about the science involved in the procedure, and about the idea of collecting healthy breast tissue in the first place. They wanted and needed clarification of unfamiliar vocabulary:

PARTICIPANT: I just have no clue about all these medical words and jargon.

MODERATOR: That's all – that's the type of information that we want to learn.

PARTICIPANT: When you said three sample cores, it's kind of like your – is it liquid? Tissue? What kind of part of that is from the gland?

MODERATOR: What comes to mind? Does any kind of image come to mind? Or what's your initial understanding of that?

PARTICIPANT: I don't know what's inside. I don't know what they draw. What they take, is it a piece of muscle, is it is liquid, or is it the blood? You see what I'm saying?

While looking at page two of the Storyboard, which depicts the current KTB brochure, the participants suggested that high output of information would positively affect recruitment.

“If people understand how this is so important to the whole scientific environment I think they would be more motivated.”

“Better have more info about [the necessary] qualifications of a donor or what a ‘normal cell’ means...”

Some participants also demonstrated great concern and soul-searching in their spoken comments about how the donation would affect them as wives and mothers now and in the future.

“I think, if I have a spouse who’s against that, but I can evaluate enough information to reassure him that it’s fine, that it’s okay, other women are doing that.”

“I think it’s better to clarify, like [whether] this donation will [have] any impact for your marriage or for your pregnancy for breastfeeding or even for your partner life, whatever, you know.”

“Explain it so that people fully understand that it’s not just me, you know, maybe it is for my children, for my spouse, and for my other part of life.”

This second theme addresses the group’s aggregate need for comprehensive knowledge of the donation procedure and the science behind it. The codes described in this section include seeking general information and vocabulary definitions, knowledge of the donation process, the effect on ability to be good wives/mothers, and full knowledge of and familiarity with the consent form. The two participants who had impulsively donated tissue, and about whom we learned in the first theme of this study, were in complete agreement with the group about this comprehensive desire for detailed information, confirming their behaviors as outliers. Despite the diversity of the group members’ countries of heritage, they were of one mind on this topic, making it the mostly strongly supported finding of this study. The deeper message of this theme that makes it significant, however, is that for the women who participated in this study, knowledge is not only power, it is a prerequisite to action. Withholding it at any level could be a major deterrent to promoting the desired behavior.

### **Personal Connection: Communication Gone Missing**

Through the People Cards activity (see Appendix D) and the focus group dialogue, the discussants introduced an array of influences from family and close friends. On the surface, the data reviewed in this third theme points to how the impact of others



affects the participants’ perspectives toward breast tissue donation. Upon deeper analysis, however, I realized that these women perceive that they have little to no personal connection with breast cancer, and that this perceived lack is the true finding.

The People Cards tool was developed for purposes of studying influences through participatory envisioning that might be at play with regards to breast tissue donation. The participants were asked to identify the people important to them whom they would or would not tell about a hypothetical decision to donate breast tissue, and the reasoning behind their choices. The women were encouraged to choose three people about whom to divulge their thoughts. Thirteen participants chose their moms, 13 chose their significant others, 10 chose a friend and nine selected a sibling (see Figure F). These categories held the largest numbers of People Card selections. Other, much less prevalent choices were dad, parents, child, and aunt. The participants seemed to focus on the people they *would* tell about their hypothetical decision, rather than those they *would not* tell.

PEOPLE CHOSEN IN PEOPLE CARDS

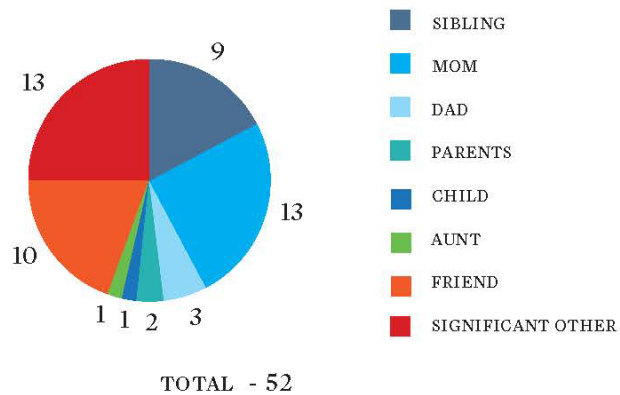


Figure F

Some of the reasoning of the focus group participants’ was unanimous. Every woman who used her significant other as a choice, indicated that she *would* tell her spouse/fiancé/partner about her decision. Most reasons surrounded showing respect for

that person, having a need for that individual's support, or not wanting to keep secrets. Like the women who said they would talk to their significant others about the decision, each of those who selected a sibling also indicated she would tell. Although most of the women specified sisters, three noted they would tell their brothers. They gave reasons of being very close to their siblings, always telling them things, wanting their feedback, and hoping they would join them in donating or volunteering. The results for the participants' who wrote about telling friends were nearly identical to those for significant others and siblings. They overwhelmingly wrote about wanting the support of that friend. More than one expressed a hope that her friend would choose to do something like this along with her. The only participant who noted that she would not tell her friend went on to clarify that this was only because the friend would not really care one way or another about this kind of thing (tissue donation).

In contrast to these very similar results for whether the participants would or would not talk about their decision to donate with their significant other, sibling, or friend, the responses for those who chose to write about the same decision with regards to their mothers varied widely. Two-thirds of the women who chose to list their mothers on their People Cards indicated that they would tell her, while one-third indicated they would not. Their reasoning was diverse.

“I would tell my mother, because she's important to me ... and she takes care of [me] ... financially and other stuff.”

“I would tell my Mama because I think it'd be great for her to participate.”

“I would tell my mom because I tell her everything.”

“I would tell my mother, because it is my body and I can do what I want with it.”

“I would not tell my mom because she worries a lot even if everything is well explained, and we may share different opinions.”

“I would not tell my mom because [she would say] ‘It's unnecessary. No! You should respect your body.’”

The attitudes of the focus group participants toward informing their mothers are interesting and may warrant further examination, but they do not seem to be particularly relevant here for the purposes of this study. In fact, of far more interest to me was not the people whom the women would opt to tell, and not even the revealed reasoning for their decisions. Rather, the real discovery here is in what the women did not say. Focusing on the identification through the People Cards of whom the participants would tell could lead to an assumption – one that has so far been proven false – that this group is relatively open to tissue donation. Someone reading the responses in this activity may believe these women could be recruited for donation without too much difficulty. However, when one looks more closely, a sense of detachment between the women and the real reason behind this activity is illuminated. The reasons for the choices are couched in general language: “I tell him/her everything”, “I value his/her support”. There is no mention of breast cancer in the reasoning for the choices. Not one woman wrote about perhaps telling her best friend because that friend’s mom had died of breast cancer, or encouraging a sibling to donate with her to honor their mother, who is a survivor, or even considering donating in honor of a co-worker. This realization prompted me to re-examine data from all other activities and resulting discussions from the focus group. Over the course of the two-and-one-half hours this group was convened, there is no mention from any participant, about knowing, or knowing of, someone with breast cancer. This includes the Motivator Madlibs wherein the women were asked what would inspire them to donate breast tissue.

For the past five years I have been speaking with both large and small groups of Caucasian, African-American, and Hispanic women about tissue donation, and in my experience, a gathering of a group of women under these circumstances has never failed to produce at least one mention from a group member about having known or known of someone diagnosed or suffering with breast cancer. The participants' perception of lack of personal connection is the real finding here, and it is pervasive and durable enough to nullify other instincts that may have led to eventual tissue donation by these and other Asian American women.

In summary of this theme of missing communication, from the viewpoint of Asian American women there is a lack of individual connection to breast cancer. Only five of the 17 participants indicated on their demographic information sheet that breast cancer had affected them personally, and none brought it up verbally. This, perhaps along with the single-minded, determined quest for knowledge described in the second theme, gave some of the women an air of detachment when speaking about what others may think of their possible tissue donation. This is significant because in order to fully understand the possible positive impact of participating, potential donors must first understand from what they may be helping to save someone. As one participant noted:

“...but Asian families usually do not have a close relative going through the problems associated with breast cancer so we don't really get to see the pain involved. On the other hand, Caucasian families, they do have some instances of their grandmother or mother, someone going through it. So they are more eager to help because they see what impact it could have.”

Thorough examination of this theme reveals its technical foundations and leads to careful consideration of possible philosophical levels of the identified problem: when it comes to illuminating the prevalence of breast cancer for all cultural groups in the U.S., the KTB

minority recruitment messaging lacks necessary information to engage certain members of the target audience.

### **Race Is Personal: Communication Gone Wrong**

The fourth and final theme of this study concerns the idea that the wealth of minority recruitment communication already in place and disseminated through several channels from the KTB, contains important information for this group to hear, but may need to be refined and reworded to show different emphases. Data for this theme was gathered largely through analysis of the Motivator Madlibs activity, with further support generated by data derived from the Storyboard tool and participant discussion.

First level coding data analysis resulting from the Motivator Madlibs tool revealed decidedly altruistic-looking tendencies in the participants. The sentence starter, “It would be worth it to donate tissue if...” was completed by the participants with several variations of the same theme comprising fifty percent of the responses.

It would be worth it to donate tissue if...

“... it makes a difference.”

“... I can be part of something good.”

“...it helps people I care about.”

“...I can spare someone the pain of breast cancer.”

“...it helps my children.”

As discussion ensued following this activity, however, these statements were refined, until it became clear that the real issue was more personal. Rather than true altruism, they displayed more of a self-serving version. If they donated, these women wanted

to be able to see the effect their donation made, and especially to see how their donation would help other women like them. They were more interested in impact at the individual level than any difference their donation may make on a large scale.

MODERATOR: What do you think the more important cards are? Which ones rank the highest?

PARTICIPANT 1: Personally?

MODERATOR: Yeah, it's for you.

PARTICIPANT 1: Maybe it has a personal connection. I have a personal connection that would be the highest rank for me.

MODERATOR: Personal connection, okay.

TEAM MEMBER: And by personal connection, can you expand on that just a little?

PARTICIPANT 1: My family or really close friends, if it helps them then yeah I'll consider it.

TEAM MEMBER: So a personal connection to breast cancer.

PARTICIPANT 1: Yes. (general agreement from the group)

And yet, despite this perceived lack of personal connection to the topic, there was a seed of interest within the group that seemed to have the potential to sprout. In a subtheme of knowledge is power, the second theme described in this study, evident cultural and societal norms of distrust and suspicion, along with the presence of elements concerning ancestral loyalty and possible shame, were revealed through some of the dialogue. Despite this, there was curiosity throughout the group about why recruitment of Asian Americans for tissue donation is important. Exploring this curiosity led to the discovery of the focus group participants' fascination for the idea

that their tissue donations could make a difference, and could perhaps cause a palpable impact, especially to members of their own communities.

MODERATOR: So tell me if I heard this right. It could be important to know why or how Asian breast tissue is going to be used and if it's going to be used specifically for things that are specific to Asian women. So do you want to know yes Asian women have this thing and this is why we're recruiting specifically from Asian women? Is that important to know?

PARTICIPANT 2: Sometimes it makes people think why you gathered Asian people here and not other, you know, ethnic groups.

PARTICIPANT 3: Yeah, it's definitely important to know if this specific information is going to help other Asian women. I think it's important for me.

There is a wealth of KTB messaging regarding the need for minority tissue so that those same minorities can benefit, but somewhere there is a disconnect with this group.

TEAM MEMBER: So would knowing [that the breast cancer risk for Asians is higher when they move to the U.S.] make a difference for you?

PARTICIPANT 4: Yes, exactly. Because I understood that I'm a part of the Asian community that can make an impact exactly on this.

TEAM MEMBER: How many of you were aware that ... the risk increases when you go from maybe your native country or your ...

PARTICIPANT 4: Ancestry is to the United States.

TEAM MEMBER: ... ancestry is to the United States.

PARTICIPANT 4: I just learned it now from this video. I didn't know about that. I assumed since I was Asian, I would have the same rate [as I had when I was in my native country].

TEAM MEMBER: I'm just curious how wide spread that knowledge was and then if you didn't know about it whether that would be a motivation for wanting to donate tissue to try and specifically figure out what was going on, you know, with Asian American women to increase their risk.

PARTICIPANT 5: Yeah, just know, you know, your living environment changes, you know, pollution and then your food, diet, you know. It just changed your risk then to expose to the . . .

PARTICIPANT 6: (breaking in to the conversation) So that is a fact then that ...? And do we know why?

TEAM MEMBER: No, I don't think so. I think that's part of why folks are so interested in breast tissue donation among Asian women.

This finding reveals importantly that if knowledge about the differences between breast cancer risks of Asians and Asian Americans was more widespread, the group as a whole may be more open to the idea of being tissue donors. In summary, the focus group participants want the messaging to be about their race; they want it to be personal. Interestingly, this finding connects to the women's overarching need for knowledge described in the second theme. That theme revealed that a decision from members of this group to donate breast tissue would result only from the women first accruing as much knowledge as possible about the procedure and the science behind it. Instead, most of them are making a decision *not* to donate, which, ironically, is a decision made without the advantage of the exact thing they profess to need most, important, powerful information that is integral to their health and well-being.

### **Pain: An Absent Finding**

In my reflections at the end of the Methods section, I defined my views on the affordances and constraints that affected my data analysis. I outlined the possibility that possessing a high degree of familiarity with the subject matter could assist the researcher in identifying an important “non-result”; this is indeed the case here. Results from my own as yet unpublished research, as well as other published work (Hopper, 2007; Schapira et al., 2014), reveal within other racial and ethnic



minority groups, a noticeable and pervasive expressed fear of needles and great concern about the possibility of pain resulting from participation in clinical trials involving an invasive process. My experiences in meeting and speaking at length with African-American women in particular, both individually and in groups, for purposes of recruiting them for breast tissue donation, have illuminated a clear pattern of fielding remarks and questions focused on pain and the use of needles. The subject is usually raised early in the conversation, often within the first few minutes, and invariably is revisited several times throughout the session. To date I have not yet experienced a meeting with a group of African-American women, concerning their participation in our clinical trial, wherein fear of pain and needles has not been an underlying theme. In direct contrast, careful analysis of the data derived from the focus group of Asian American women in this study revealed a complete and absolute deficit of questions, comments, or concerns, whether in the general dialogue or during the activities, regarding pain or a possibility of pain accompanying the procedure. Several participants admitted to fearing or not wanting to be around needles, but interestingly their concern did not seem to be pain-oriented; rather, they appeared simply to be averse to them. Only one focus group participant spoke about a personal needle aversion:

“[The researcher and I are] best friends pretty much. She talks about [the KTB] all the time and I was like no I am not letting anyone come near with a needle no matter what you say.”

Another participant related her thoughts about some members of her community:

“Uh most the people, they’re afraid of needles. This is just physiological reaction, I know.”

One final expression of personal fear resulted from the Storyboard activity:

“I have a huge fear of needles - this would immediately turn me off.”

Even though this aversion to needles is strikingly similar to the outlook of many African-American women with whom I have spoken, this group expressed no fear of pain and furthermore, did not even speak the word “pain” once during the two-and-a-half hour session. As both a researcher and a professional, I find this remarkable, and possibly quite important. I am not implying that Asian Americans in this study had no concern for or fear of pain, merely that, as no one voiced it voluntarily, for this group pain seemingly may not attain the same priority as a barrier as it does in other groups. We know there is something different between Asian Americans and other racial or ethnic minority groups; one of the main points of this study is to develop communication that will assist in identifying what that difference is, and this finding highlights a major dissimilarity. Questions for future research of this outlier are: Why didn’t these Asian American women talk about pain? Why did they not seem to care about it when most others apparently do? What are their thoughts about the pain that may or may not be involved in this procedure? These questions define this (non)finding as an outlier, a divergent piece of data (S. J. Tracy, 2012). In the upcoming discussion section I will focus on exploring and further substantiating primarily my two main themes of missing and irrelevant KTB messaging. However, knowing the answers to these questions derived from this “non-finding” may help begin to unlock what is different about this group and how we should talk to them.

## **Discussion – The Philosophical Level Revealed**

The purpose of this study was to examine the attitudes of Asian American women toward donating breast tissue as participants in a clinical trial for medical research, to identify any communication-related barriers to this behavior, and to define and explore communication practices that may help to promote the behavior. The focus group participants indicated that:

- they retained a culturally-embedded foundation of discomfort with voluntarily parting with a piece of their bodies, and a general distrust that their donation would be handled ethically and appropriately;
- they possessed an extraordinary need for knowledge about all facets of the process and the science supporting it, and desired to have a regular flow of information before, during, and after the procedure;
- they lack a personal connection to breast cancer, making it difficult for them to generate or understand any truly altruistic desires to perform the desired behavior, or to understand a need to do so; and
- their need for knowledge applies to having a strong desire to learn about why it seems important to the KTB to collect their tissue, and especially about the increased breast cancer rates and risk for Asians who move to or are born in the U.S.

Using Grounded Practical Theory as a framework, and focusing on applying a philosophical rationale, I will discuss the implications of these findings.

## **Influences of Culture and Society**

The participants in this study exhibited strong connections to the cultural and societal norms of their home countries or, in the case of those who were American-born, of their family heritage. The cultural bonds were resilient enough that even after having spent years away from their native land, or in some cases, of rarely even having visited there, their behaviors reflected the bond. Gudykunst (2000) posits that all Asian cultures are collectivistic, and therefore “Asian Americans tend to learn shared cultural characteristics when they are socialized in the United States” (p. 51). This can mean that despite having been born in the U.S., Asian Americans who are raised while surrounded by the Asian people and culture of their heritage may display behaviors more influenced by their Asian traditions than their American ones.

Choosing to act outside of deeply embedded societal norms can be difficult for members of any collectivist culture, wherein decisions are made by families or groups rather than individuals (McLaughlin & Braun, 1998). Well-documented cultural factors among Asian American women highlight the prominence of modesty, especially surrounding health issues concerning women (Bottorff et al., 1998), and fatalistic life viewpoints (H. Y. Lee, Ju, Vang, & Lundquist, 2010). Families in collectivistic society are particularly concerned about privacy, in fact, in one study concerning Asian Americans and biobanking, the highest ranking concern was loss of privacy (Tong et al., 2014). Researchers conducting a study of Chinese women with breast cancer found that women would try to keep their illness a secret to avoid being stigmatized (Leng et al., 2014). In addition to these characteristic norms, there are widely held views by members of varied Asian groups suspecting harm resulting from some medical procedures.

According to McLaughlin and Braun (1998), it is common to the Filipino and Vietnamese cultures, as well as to the Chinese, to believe that any puncturing of the skin can “cause bad things to happen to the body”. This means even the small cut made for tissue donation could be enough reason for some women of these cultural heritages to balk at going through with the procedure.

There are clearly important implications for health education here. Many Asian women – particularly women from South Asia, which encompasses China, Hong Kong, Japan, South Korea, Taiwan, and others, relate health information to each other through stories (Bottorff et al., 1998). If the KTB organized semi-regular meetings enabling women of this culture to get together to hear from someone from their community willing to tell her story of having donated tissue to the KTB and the reasoning behind it, they may be encouraged to ask questions and talk through their thoughts with each other. Ideally, after a period of time, a level of comfort could be found that would eventually lead to the women sharing a more open mind to the idea of breast tissue donation.

### **Need for Information and Knowledge**

Although the members of this focus group were from a diverse array of Asian cultures and backgrounds, their outlook on the need to have all possible available information at hand about breast tissue donation was universal. First, they seek extensive, detailed knowledge about the procedure itself, including the quantity of tissue taken, as well as the exact steps taken and the reasoning behind the process. They want to read the consent in advance to familiarize themselves with the content. In addition to pursuing familiarity with the donation process, the women also want to understand the science involved, including a working knowledge of any medical terminology that is used, and

they displayed particular interest in knowing how their breasts would be affected, and whether there would be an adverse impact on their ability to be effective wives and mothers.

In a study that focused on the communication between oncologists and their Chinese-American and Korean-American breast cancer patients, the oncologists agreed that some of their Asian patients sought extremely elemental information about everything, for example, they (the patients) wanted to know exactly what they could or could not eat (S. Lee, Chen, Ma, & Fang, 2012). When they were given the general instruction to eat a healthy and balanced diet, they were surprised, and pushed for more detail.

Asian Americans' attention to education and detail is well-documented, even with regard to biobanking (Tong et al., 2014). According to Kiviniemi et al. (2013), Asian Americans' knowledge and comprehension of biobanking and research benefited from using a community based participatory research approach to expand participation rates in biobanking. To enhance awareness of and participation in biobanking in Asian American communities, Gao, Ma, Tan, Fang, Weaver, Jin, and Lai (2014) posit that an interdisciplinary scientific team must work together with community partners to educate the public. Through this method, an effective, high-quality biospecimen collection, processing, and storing system, featuring research that assesses psychosocial and cultural beliefs, barriers, and facilitators can evolve within this group's communities (Gao, Ma, Tan, Fang, Weaver, Jin, & Lai, 2014).

Although the written and verbal information disseminated from the Komen Tissue Bank is plentiful, there is quite a bit more that can be done to address the extensive need

for details knowledge identified in this current study. By reviewing all printed materials, newsletters, and the website, we can identify and enhance particular areas, such as the descriptions of the procedure, add more pictures, and post a downloadable copy of the consent form online for easy access. Having been enlightened through these study participants that in this case less is certainly not more, it would be prudent to display complete transparency to promote increased trust.

### **Personal Connection: Race Is Personal**

Asian American women experience a lack of personal connection to breast cancer. Few of them seem to know or know of people who have been diagnosed with and suffered from breast cancer. Although some, now that they live in the United States, can point to colleagues or casual acquaintances who have been stricken with the disease, results of this study show a decided disconnect between these participants and any insight into what it may be like to experience this disease. This is troublesome, not only because the *effect* of this perception is that these women cannot relate or react to messaging telling them they can help themselves by donating their healthy breast tissue, but also because the perception of safety is a false one. Since breast cancer is the leading killer of women in the 30-to-55 range (Centers for Disease Control and Prevention, 2015), it could be considered surprising that these women cannot relate to the seriousness of the issue. It is possible that other cultural factors surrounding this group, such as strong privacy concerns (Leng et al., 2014), may have led to the group members' ignorance of their true breast cancer connections.

When asked for reasons why they might donate tissue, these focus group participants used language that, although it contained a surface reflection of altruism, in

reality applied a deeply personal caveat to their possible participation. They might be willing to consider donation if their closest loved ones or members of their own cultural groups would reap the benefits of their sacrifice. In addition, in direct threat to their demonstrated need to acquire all available knowledge about a thought or idea, they are missing a crucial piece of information about their personal breast cancer risk and that of those they hold dear: the longer they remain in the United States, the greater their breast cancer risk. Moreover, by the time they bear children here, the risk of those children is at a level equal to that of Caucasian women, who have the highest incidence of breast cancer.

These third and fourth themes are joined together because although they are two separate findings, their technical underpinnings are interchangeable and their philosophical rationales are linked. Addressing one of these themes entails adapting the existing outgoing KTB recruitment communication by adding information and details that at the present time are lacking or insufficient. Addressing the other theme involves making a thorough examination of that same communication, then identifying and adjusting the focus such that the altered, updated message more accurately reflects the intended objectives.





(ww5.komen.org)

Figure G

Literature showing that Asians and Asian Americans do indeed develop breast cancer is plentiful (C. DeSantis et al., 2014; Kim et al., 2008; Liu, Zhang, Wu, Pike, & Deapen, 2012; Ziegler et al., 1996). (see Figure G) Recent research is also showing that breast cancer incidence is rising rapidly in many Asian countries as well as among Asian immigrants in the U.S (Deapen, Liu, Perkins, Bernstein, & Ross, 2002; C. E. DeSantis et al., 2015; Liu et al., 2012). How is it, then, that the focus group participants in this study experience such a dearth of personal connection to breast cancer? Research-supported speculation could suggest the idea that the desire for privacy and fear of stigma kept women in these families from admitting, even sometimes to family members, that they had been diagnosed with breast cancer (Leng et al., 2014; Tong et al., 2014). In traditional Chinese culture, for example, anything considered a private concern may be kept closeted with the family, hidden from outsiders and other members of the family as well (McLaughlin & Braun, 1998). It could be that this sense of secrecy also extends to

other family members, perhaps in an effort to protect them. If this is the case, it is possible that many Asian Americans do not have a fully accurate perception of whether they do or do not have a personal connection to breast cancer through a loved one or close friend. Whatever the reasons are, the perceived lack of connection presents a wall to climb before any link can be drawn between these women and breast cancer, that will lead them to a new understanding of the documented higher breast cancer incidence in store for members of their communities. It is completely understandable that members of a community are more willing to take part in biospecimen research when the disease is relevant to them. The current study fully supports the idea that people are more motivated to donate tissue if a family member has been affected by the disease (Luque et al., 2012).

The third discovered theme in this study involves lack of connection or familiarity at the technical level, while the fourth theme illuminates the need for concern regarding the escalating risk of breast cancer for Asian Americans. The fourth theme also reveals that members of this group want to do what they can to help their families and other women like them. In her study concerning biospecimen collection from a diverse population, Tong et al. (2014) reported that the most persuasive motive for Asian American donation is that future generations would benefit. If the members of this group could be made fully aware that their perceptions of a lack of personal breast cancer connection are deceptive, the effects of the results of the third theme could be eradicated. In turn, initiating the possibility that their willingness to help other women in their communities could be directed toward openness to conversations about tissue donation as well as other important implications for research (Alam, 2006).

A key to solving the disconnect described in the preceding paragraph is held within the second theme, the great appreciation of and need for knowledge. There is a philosophical rationale for addressing that problem and adding information to the recruitment messaging about the increasing risk for breast cancer for this group. Efficaciously growing the awareness of this one factor could conceivably positively affect the success of implementing the implications for all discovered themes.

### **Implications Based on Philosophical Rationale**

The implications of this study are determined by examining, at the philosophical level, the fundamental nature of the communication patterns of this group, in partnership with the discovered cultural norms at play. What technical strategies can be applied that may help in achieving the desired behavior change of considering breast tissue donation?

1. Put as much information as possible on the KTB website
  - a. Include a downloadable version of the informed consent.
  - b. Make the Asian American targeted videos readily available and easy to find.
  - c. Incorporate a page targeted toward Asian Americans and include testimonials from Asian American women who have donated.
2. Have all donors watch a detailed informational video about the donation procedure before donating. If the video is visual only without dialogue, voiceover can be added in as many languages as is necessary and/or appropriate.
3. Implement recruitment communication individually targeted to Asian Americans alone, rather than as one of several minority groups.

- a. Incorporate particular messaging containing current information about breast cancer risk of Asian Americans and how it may differ from rates in their home countries.
- b. Include pictures of women who look like the targeted group.
- c. Consider hosting small, casual gatherings of Asian American women for informal informational sessions. Encourage past Asian American donors to invite friends, family members and colleagues to these sessions.

Future study should include acknowledgement of the affordances that come with my position, the role I have with the KTB. There was no opportunity in this data collection to really explore further the interesting non-finding of fear of pain not being a priority as it is in other groups to which I have been exposed during other research projects. This is a case wherein a researcher less familiar with the KTB may have missed the importance of this topic not entering into the discussion.

### **Limitations**

Avoiding the argument of whether or not GPT is scientific, which is perhaps a topic for a different paper, one can say that in contemporary research there has been a lot of argument for multi-method, multi-theoretical approaches to understanding problems. GPT, which is based on the principles of communication as a practical discipline, is such an approach. It is likely due to the implementation of GPT that evidence previously not considered was discovered in this study. If this newly revealed evidence had been known beforehand, it is more than likely that the communication needed to address these revelations would already have been in place on the existing website and literature.

Taking into consideration that this approach yielded unexpected illuminative results, a limitation of this study is that it takes a particular theoretical and methodological course; it may be that more or different information might have been exposed if another researcher engaged a different theoretical lens and methodological approach to help us understand this practical problem.

The logic behind GPT is that until we know the answer to the practical problem, more research is needed. Examining a second constraint, the findings of this study indicate that holding additional focus groups would be beneficial. This assessment applies both for purposes of increasing the number of older and younger generation members, as well as for multiplying the numbers of the different cultural groups.

It is a limitation that, while the participants in this study represent a mathematically wide range (based on the sample size) of Asian subgroups, this work does not contain a large representation of every sub-culture in Asia. The basis for this limitation was briefly previewed in the Literature Review, where I referenced the existence of numerous Asian subgroups containing their own distinct languages, religions, cultures, and histories. While I acknowledge that the practice of gathering the numerous Asian subgroups under one heading of “Asian Americans” could contain drawbacks, I must also point out that this is an extremely common practice in existing literature examining Asian culture and health behaviors (Agarwal et al., 2007; American Cancer Society, 2015a; R. Brislin, 1993; Dutta, 2015; Hearnden, 2008; T. T. Nguyen et al., 2005; Seung, 2013). Clearly, and importantly for this study, the prevalence of this practice also demonstrates the existence of commonalities of Asian American cultures.

Further research is needed both to define those commonalities and to examine the differences of the various Asian cultures and sub-cultures.

## **Conclusions**

This study sought to identify the attitudes of Asian American women toward donating healthy breast tissue, and the communication-related barriers that prevent Asian American women from donating healthy breast tissue. With the assistance of the Patient Engagement Core, part of the Indiana Clinical and Translational Sciences Institute, I conducted a focus group involving both structured and semi-structured activities (tools) as well as open dialogue, and discovered that with regards to their willingness to donate healthy breast tissue, Asian American women are largely influenced by the cultural and societal norms of their ancestral homeland. In addition, an all-encompassing need for knowledge drives them to be hesitant to take action before this need is addressed and satisfied. Despite this foundational desire for information, these women are ignorant of the escalating changes in breast cancer rates of Asians who move to the U.S. that will directly affect them in the future. Because of this ignorance, this group is also unaware that their perceived lack of personal connection to breast cancer is a false perception, prohibiting them from acting on another revealed finding: the desire to initiate anti-cultural behaviors under conditions that will directly help their families and/or other people like them in their communities.

Understanding how this minority group feels about tissue donation, and how to encourage the behavior, is important because their participation in medical of this kind will lead to increased knowledge of the science behind why they get breast cancer the way they do, why the breast cancer risk rates in their home countries are lower than the rates of American women, and why their risk severely escalates once they move here to the States. The major finding from this study is the degree to which all themes of the

findings are interwoven and related, to the degree that fully and thoughtfully addressing the discovered theme of their need for knowledge from the view of the philosophical level may well result in solutions for the other technical-level problems described in this work.



**Appendix A**

**DEMOGRAPHIC QUESTIONNAIRE**

What is your age? \_\_\_\_\_ Do you have any children? Yes \_\_\_\_\_ No \_\_\_\_\_

If you have children, how many do you have? \_\_\_\_\_ How many are daughters? \_\_\_\_\_

What is your current marital status? Please choose only one:

Single \_\_\_\_\_ Married \_\_\_\_\_ Divorced \_\_\_\_\_ Widowed \_\_\_\_\_

What is your race &/or ethnicity? Please circle all that apply:

ASIAN

Laotian

Bangladeshi

Malaysian

Bhutanese

Mongolian

Burmese

Nepalese

Cambodian

Okinawan

Chin

Pacific Islander

Chinese

Pakistani

Filipino

Russian

Hmong

Sri Lankan

Indian

Thai

Indonesian

Turkish

Japanese

OTHER (please clarify) \_\_\_\_\_

Korean

In what country were you born? \_\_\_\_\_

Have you, or has anyone close to you (family member or family friend) had breast cancer?

YES \_\_\_\_\_ NO \_\_\_\_\_

Have you ever heard of the Komen Tissue Bank?

YES \_\_\_\_\_ NO \_\_\_\_\_

If you answered “yes” to the previous question, please briefly explain your knowledge of the Komen Tissue Bank.

## Appendix B

### DEMOGRAPHIC QUESTIONNAIRE DATA COMPILATION

Age	Children?	# of children	Daughters?	Marital Status	Race / Ethnicity	Birth Country	Personally affected by BC?	Have you heard of the KTB before?
25	No	N/A	N/A	Single	Japanese	USA	Yes	Yes, I used to volunteer with the breast tissue drive with my friends when I went to University.
48	Yes	2	No	Married	Chinese	P.R. China	No	Very limited. My friend works there. That's it.
41	Yes	N/A	Yes, she passed away last Dec.	Married	Chinese	China	No	Yes, I know it collects tissue.
36	Yes	1	No	Married	Korean	USSR	No	No.
27	No	N/A	N/A	Single	Indian	USA	No	Yes. Heard of it in a class discussing where public health money and funding is going. (Planned Parenthood, Susan G. Komen, etc.)
26	No	N/A	N/A	Married	Japanese	USA	Yes	Yes, during the super bowl XLVI, I did an anthropology research project on philanthropic efforts with the Super Bowl so I donated tissue at that time.
22	No	N/A	N/A	Single	Japanese	USA	No	Yes, Research Breast Cancer and they use pink to represent breast cancer awareness.
21	No	N/A	N/A	Single	Malaysian	Malaysia	No	No.
21	No	N/A	N/A	Married	Indonesian	Indonesia	No	No.
22	No	N/A	N/A	Single	Malaysian	Malaysia	No	Yes, in one of my classes, the professor

								mentioned about the tissue collections during Super Bowl last time when it was held in July.
27	No	N/A	N/A	Married	Indian	India	No	Yes, they provide assistance with breast cancer awareness, outreach models, and health companies.
25	No	N/A	N/A	Single	Chinese	China	No	No.
25	No	N/A	N/A	Single	Malaysian	Malaysia	Yes	Yes, The Komen Tissue Bank collects breast tissue to understand the functions of breast cells.
29	No	N/A	N/A	N/A	Indian	India	Yes	Yes, I regularly volunteer as a lab assistant to process tissues at KTB events. Also, my lab closely is associated with KTB.
25	No	N/A	N/A	Single	Thai	Thailand	Yes	Yes, from Kathi, my classmate and Indy 500 as one racer represented Susan G Komen.
31	No	N/A	N/A	Single	Chinese	China	No	No.
28	No	N/A	N/A	Single	Malaysian	Malaysia	No	Yes, I have donated tissue to the Komen Tissue Bank.

## Appendix C

### FOCUS GROUP TRANSCRIPT

MODERATOR: Okay, so we can go ahead and get started. Good morning, again, everybody. My name is MODERATOR, and thank you so much for coming. I know you all know a little bit about the study we're doing, caffeine and production, but again, we're here to turn to you as experts. So we're here to listen. There are no right or wrong answers. What we're really trying to do is help improve the quality of breast cancer research, and in order to do that we need to listen to you so that's what we're here to do today. We represent 'The patient being the Core' at the Indiana CTSI and the IU School of Medicine. My name is MODERATOR, and maybe we'll go around the room and kind of introduce the study team first.

TEAM MEMBER 1: Hi. My name's TEAM MEMBER 1. It's nice to meet you guys.

TEAM MEMBER 2: My name's TEAM MEMBER 2.

MODERATOR: TEAM MEMBER 3 was just here. And this is?

RESEARCHER: I'm RESEARCHER. There's TEAM MEMBER 3.

TEAM MEMBER 3: Sorry. We just had one more participant being checked in. Nice to meet you all. Thank you so much for coming.

MODERATOR: I'm in the genus (inaudible).

MODERATOR: So we have a bunch of activities to do today. A lot of them are going to be hands on and they're going to, again, be really open. There are only right answers here because everything you have to say we're here to listen to. The first thing I wanted to do is go around the room and start on our first activity, so if you could please state your name and after you state your name, please share with us one thing that you felt really motivated to do recently; something you felt really motivated to do recently.

TEAM MEMBER 1: Do you want me to give an example?

MODERATOR: Yeah.

TEAM MEMBER 1: Awesome. So again, name's TEAM MEMBER 1 and recently I graduated from college, which was awesome, and I have been very motivated to ride my bike everywhere and it's been awesome because I've actually had time so that's cool.

MODERATOR: Would anybody like to start?

PARTICIPANT: My name is PARTICIPANT and I'm a final year PhD student at IU School of Medicine and I'm really, really motivated to finish my thesis dissertation so I can finish.

MODERATOR: Can we just go around this table? Would that be good?

PARTICIPANT: Sure. My name is PARTICIPANT and recently I've been really motivated to expand my travel horizons because I want to see more of the world.

PARTICIPANT: My name is PARTICIPANT and I recently graduated but I've not finished my thesis yet so I'm actively looking for a job so that's what I'm really motivated to do.

PARTICIPANT: Hi, my name is PARTICIPANT. I'm a recently graduated student from IU School of Liberal Arts and Communication Studies, same as her, and we have kind of like same motivation of finishing our thesis and looking for a job.

MODERATOR: We'll go to this table.

PARTICIPANT: My name is PARTICIPANT and recently I'm motivated to, yeah kind of like exercise or like I really want to be good at running, or like it because it's horrible.

PARTICIPANT: My name is PARTICIPANT and something that I've been motivated to do recently is find a job. I just also recently graduated and yeah, so on that.

PARTICIPANT: My name is PARTICIPANT and recently I've been motivated to learn more about nutrition and learn to eat healthier and cook healthier.

PARTICIPANT: Hi, my name is PARTICIPANT. I'm also a student at IU, so I really want to go back home to visit my family so I really want to finish my project in this month so I can go home.

PARTICIPANT: My name is (inaudible), Indiana University School of Medicine. So I was going to say I want too much to ask so it's hard to figure out or say what I want, the thing that I want to do, so can I say three? I want to finish my current research (inaudible) and at the same time I want to find a new job and at the same time I want to visit my home again.

PARTICIPANT: My name is PARTICIPANT. I just found out recently I'm pregnant so I'm going to try to keep myself healthy and do some exercise every day.

MODERATOR: Congratulations.

PARTICIPANT: My name is PARTICIPANT. I am a bridesmaid in like three weddings this year so I want to start working out more so I can lose some weight, so exercise more.

PARTICIPANT: My name is PARTICIPANT and I have been motivated or say just part of my responsibility to help my son healing, you know, accompany him to exercise and then help him with eating right, the right diet, (inaudible) and cleanse the body.

PARTICIPANT: My name is PARTICIPANT and I learned swimming last year, I taught myself kind of, so I will try to pick it up this summer again by swimming more.

PARTICIPANT: Sounds great. Good morning everyone. My name is PARTICIPANT and I hope I can do really well in my studies so I can get the GPA as high as I can so that I can get awesome (inaudible) to achieve my future goal.

PARTICIPANT: Hi, my name is PARTICIPANT and like most of the people here I just graduated as well so I'm trying to look for a job as well.

PARTICIPANT: Hi, my name is PARTICIPANT and I've been recently motivated to study to pass my CPA exam.

PARTICIPANT: My name is PARTICIPANT and I've recently found that I'm interested in writing poems and reading them.

MODERATOR: Okay. So, thank you so much. As you've been talking about your motivators, we've been noting them on the flipchart paper so let's have a quick look. Finish thesis, expand travel horizons,

looking for a job – we have several people who are saying that – like running, learn about nutrition, visit family. It also seemed that there were several things here going on with health, like in taking care of yourself, taking care of others. Finish research – that was a big one – stay healthy and work out – health ones – help son stay healthy, swim more, get a high GPA – a little bit before the finish thesis part, I guess – study for CPA exam and write poems. Great. Can we take just a little bit of a step back from this? We talked about the things we want to do. Are there deeper motivators that you can think of behind any of these immediate ones? Are there kind of deeper motivators that you can think of?

PARTICIPANT: Well, I personally work on breast cancer research so one of the biggest motivators is being able to help with Komen Tissue Bank in all the ways that's possible because, coincidentally, I use patient-derived samples and that's useful research and I do realize that there's a lot of samples coming from different ethnic backgrounds in normal tissue but that thankfully is being rescued by the Komen Tissue Bank, but we still need more diversity in the tissue samples that we have so that's the motivation for my thesis as well as my future goals as a researcher.

MODERATOR: So it's (inaudible). It seems like what I'm hearing is you also have an idea of kind of helpfulness, so you want to be helpful it seems like.

PARTICIPANT: Yes.

MODERATOR: Is that something that kind of characterizes some of the things you're thinking about as motivators; kind of like overall, I know it's hard to say when you're really focused on like your graduation or your thesis or finding a job or something, but yeah, I can see that. So you kind of want to have a bit of an impact.

PARTICIPANT: Yes.

MODERATOR: Are there other things out there?

PARTICIPANT: Yeah, I think when my son generated the disease, I started to like, we look alike, try to see the positive meaning, you know how to enjoy the daily life. And then also, I just try to see from his disease, how to respect it for others, how to help the whole society to realize that, you know, to know that disease and to cope with it and then to heal from it. So before, you know, I had never realized that life could be this hard until this thing happened. So actually it made me think deep and then see what's the meaning of the life and then, you know, what things you can control and that you can't control. You know, it's a lot.

MODERATOR: It's a lot.

PARTICIPANT: Yeah, that before you have never really think to that way. You were just thinking life is just so natural, it's easy. You know, like graduate school, job, start family; everything is just like natural in flow until something, you know, like a crisis happens and then you need to, you know, rethink about everything. And then maybe you shift your image or your role you play in the life, in your career, you know, in your family. You started to shift the weight and then your concentration.

MODERATOR: Yeah, right. You shift because the conditions, everything around you is shifting and maybe in ways you haven't anticipated. So you have to just kind of like look inside and then kind of see how you can kind of best manage. And, it also sounds like you were – it's important for you to also kind of share that experience.

PARTICIPANT: Yeah. Yeah, I have been pretty open, you know. Because my son got depression.

MODERATOR: I'm sorry.

PARTICIPANT: So, I try to learn from others in that I just try to get some more ways, you know, to help me to cope with it and to hopefully help him work out of it.

MODERATOR: So you have kind of a dual – you're helping - the focus is on him, but in order to help him the best you need to focus on yourself, too.

PARTICIPANT: Right and I actually need myself to step back and think, you know, how to improve myself. I'm so sorry; too much.

MODERATOR: Thank you so much for sharing. Thank you so much and we're here to...thank you.

PARTICIPANT: I have another sort of motivator things, so one of the things that I work on at work and also through IUPUI is trying to get more girls to join STEM because that is something that, you know, coming to school here and going to engineering you see how few women are represented in this field. So I try to participate in a lot of programs that try to get girls interested in science, technology, engineering, and math from like a young age so that hopefully as they go along they will get into fields, you know, so they'll feel like just because I'm a girl doesn't mean I'm not smart.

MODERATOR: So cool. Thank you. Is there anything else? Are there any other motivators out there?

PARTICIPANT: I know with like for me, like we all joke around about how we want to be skinnier from working out, but like I work in a pharmacy and I do geriatrics research so I talk to elderly people all day. And I've realized that when you work out, you're releasing the dopamine, the serotonin, the norepinephrine, and you're feeling better. And when you are the best version of yourself and you're happy, you're able to give your love and your energy to others better than you would not taking care of yourself. And just working at a pharmacy, just seeing all the – Indiana has a very high narcotic dispensing rate and it's just really sad because people will come to me "I have to have my Xanax", you know, and I think that if our culture just promoted, you know, being active – like especially Indiana. Like all my friends that live in California, they don't have this issue as much; just being more active, not having to take so many medications and then a lot of – like I do Alzheimer's research – so just seeing that exercise does help, you know, with a lot of these cognitive impairment effects, and unfortunately a lot of medicines contribute to the cognitive impairment, so it's kind of a, you know, yeah I just think promoting that is good, not just for aesthetics.

MODERATOR: Yeah. It's a deep motivator for you to actually see the evidence of it every day.

PARTICIPANT: Yeah, yeah. Instead of taking a pill maybe.



MODERATOR: Is there anything else?

PARTICIPANT: Well, I really wanted – I did my master's so that I can have a better job and so that I can earn a lot of money because my entire dream is to open a dog shelter and have a free school for children, and the only way I can ever achieve that is by having a lot of money.

MODERATOR: Ways to a means, right? This is what you need to get to the thing you actually want to do.

PARTICIPANT: Yes.

MODERATOR: Totally got it. So anything else? Okay, so this is true for any of the discussion topics that we have for today. If something just kind of like a light bulb goes off in your head about oh this other thing that MODERATOR asked about; this is something else, then please come up to me, come up to anybody in the study group and share that because, again, we're here to listen, we're here to learn. So that's great. Thank you so much. Okay, so the next activity we have involves a storyboard. One of the things we're trying to learn is how women think about the Komen Breast Tissue Bank and the donation process, kind of from the very start. So if you've never heard of it before and you see someone at a library setting, for example, behind a table like this with pink stuff all around them, what is it about their behaviors or about their language or about what the table looks like or about the setting in general, are some of those things awesome things or are some of those things kind of turnoffs? So what we're trying to do is just figure out okay if you go through the storyboard, and we'll go through this together, too, if you could help us identify where the motivating or where the kind of green lights are, like oh yeah this is cool, I'm on board or I'm getting on board, versus the kind of the red lights. So how we're going to do this is, if you could just pick up the green pens – and TEAM MEMBER 2 is going around handing out the green pens. We need another set. There you go. So maybe if we can go through this together, just quickly altogether, and if anyone has any questions then please, you know, just kind of pipe up. So on page 1 we have viewer at a community event with your family, so say it's a summer festival or a library event and you see this person, cheerful person, and she says get involved, be a tissue donor. The Komen Tissue Bank is the only repository in the world for normal breast tissue. By studying normal tissue, we can accelerate research for the causes and prevention of breast cancer. And this is the setting she's going to be in with the post-it notes and the clipboard. You were given a brochure, which I imagine would be like about this size, about this size paper. Flip it open. So you look it over and you can, you know, look this over more carefully once we – once you get to the film part. You were curious about donation and asked about how it works. And the nice lady says there are – she just explains the donation procedure. She says there are three blood draws before the donation procedure, then your skin will be cleaned and numbed with lidocaine. The physician nicks the skin with a scalpel and the needle is inserted into the incision.

PARTICIPANT: What is the lidocaine? So many pharmacy people, what is the lidocaine?

PARTICIPANT: It just numbs the skin.

PARTICIPANT: Is it like the . . .

PARTICIPANT: It numbs the skin so you don't feel the pain as much.

MODERATOR: So it's a topical (inaudible).

PARTICIPANT: It's just the surface of the skin.

MODERATOR: Three sample cores are removed from the breast in quick succession. A nurse or surgeon assistant holds pressure on the incision for 10 full minutes, then applies a pressure bandage and you will be given an icepack to put inside your bra. Thank you so much for your question about the lidocaine. That's exactly . . .

PARTICIPANT: I just have no clue about all these medical words and jargon.

MODERATOR: That's all – that's the type of information that we want to learn.

PARTICIPANT: When you said three sample cores, it's kind of like your – is it liquid? Tissue? What kind of part of that is from the gland?

MODERATOR: What comes to mind? Does any kind of image come to mind? Or what's your initial understanding of that?

PARTICIPANT: I don't know what's inside. I don't know what they draw. What they take, is it a piece of muscle, is it is liquid, or is it the blood? You see what I'm what saying?

PARTICIPANT: It's actually – so your breast is made up of lobules so it's the milk-producing tissue. So you have like 14-18 depending on the individual. You have many lobules, so they just take part of that and that's processed and it's used for research purposes. So it doesn't hurt you in the long run. It's just a small part of the functional unit of your breast. So I don't know if that answers...

PARTICIPANT: Yeah, yeah. It's helpful. So it will regrow by yourself?

PARTICIPANT: No, it doesn't regrow, but you have plenty and it usually amplifies when a lady is lactating or during pregnancy, you have more amount of those cells grow up.

PARTICIPANT: Okay, thank you.

MODERATOR: How many other people had that question about what that means to kind of – what a core is? Like how many other people had that question? So one, two, three, four, five, six, seven, eight, nine, ten, eleven.

PARTICIPANT: I think that's the main concern because people do not understand like what – because it's not like donating blood. It's just very straightforward, you know that you draw the blood and that you generate it, reproduce it again, and there are no worries. You know, that's very common. It's not like this one, you know. You seldom hear about it and know about it and it's like brand new stuff. Especially, you know, if you do not have a lot of medical education, you just feel scared or shocked or like what are they going to do.

MODERATOR: Even though there's a super friendly lady talking to you about this in a library?  
(Laughing)

PARTICIPANT: Well, we still need more assurance, I know.

PARTICIPANT: Well, the funny thing was that like you were asking that question and I was like oh I actually did that during the Indy Super Cure and I still had questions about it. Like even now I

wouldn't be able to answer. I'd be like oh well it's this part. I'm just like well it came out and I know what it looks like, but I don't know like what it is. I didn't ask questions about will it regrow back. I did it, yeah and I did it.

PARTICIPANT: And now you're fine.

PARTICIPANT: Yeah, I am fine. My husband was like so like what's this mean? And my joke was always well, you know, I did one and I didn't have any more to give because I'm already lacking a little bit. So that was just my joke with him and my friends. But I didn't ask questions. I just saw what it looked like and a lot of people were doing it and I was like sure. Actually I went there doing a different project initially. I wasn't planning to donate at all actually, but I went there and then it was kind of everyone's there, it's exciting, it's groups of people, and my friend went and I supported her and then decided to do it myself. But I didn't know anything about it initially. So I thought that was interesting because it was years ago that I did it, but I still didn't have an answer for you and I was like huh; maybe if I'd thought about it more, maybe, I don't know what my decision would have been.

PARTICIPANT: Do you mind? Do you have kids?

PARTICIPANT: No, I don't have kids yet. And I was just kind of told, hey like, you know, it's safe and, you know, I'm not a science person so even if someone told me I wouldn't have been able to understand, but you know so many people were there and they felt secure and safe about it, so I was like okay. Well, if we all have issues later on I guess, you know, I'll have a (inaudible).

PARTICIPANT: I also donated, I think, last year and it was more of like a kneejerk reaction.

RESEARCHER said oh we're looking for people of like Asian decent to donate. I was like okay. Then I said okay, then I said oh what do they do? Then she explained. She basically explained this part to me and I was like okay. And then I went there and the doctor explained it and I was like okay. I mean I figured, you know, it will help people.

PARTICIPANT: It didn't seem like a really hazardous process.

PARTICIPANT: Yeah, it didn't.

PARTICIPANT: Like I think, you know, when I'm there I'm like ooh because I am not a medical person at all, but it just seemed like the whole atmosphere was friendly, like we're not taking advantage. It's a good thing and it's people who were like used to the process. They are helpful, supporting you, so it wasn't a challenging process to go through once you got your head into it. But I think when people initially hear about it, especially because it's a foreign idea, it's a little bit like whoa wait a second. If you don't think about it, you just go.

PARTICIPANT: Yeah exactly.

PARTICIPANT: I wanted to ask you, what he think. Your husband. Because my husband when he learned about that, he was really concerned because (inaudible), you know? So it's part of the body. It's important to come from a spouse for example also to know about that.

MODERATOR: How many of you folks thinks that, yeah that their spouse or the person close to them would be like well . . .

PARTICIPANT: They would just kind of have the same concern because they don't understand either.

PARTICIPANT: Yeah, coming today he was like oh don't donate anything. (Laughter) And I was like it's just a focus group. And he was like, just saying, because you already did it once.

PARTICIPANT: I also think it depends on the situation, the context, because when I am reading this, it looks kind of scary to me, but . . .

PARTICIPANT: If I was actually at IU and I'm talking to this woman here and given the body language and the cue, the expression, that might kind of, you know, smooth my mood. And if I'm in a situation like you had, a lot of people are doing that, now I feel more secure. It's like okay, I mean so many people are doing that and, you know, maybe it's safe. So it's just different kind of experience that gave me different emotional reaction to that. So if I'm just reading that, I would feel worried, risky, you know. The text, it's risky. I don't understand their terms and, you know, by reading this, there's nobody around me that I think I can talk to. It's just like a contract. I was like okay by signing that, I'm selling myself. (Laughter)

MODERATOR: So the person in front of you who's delivering these ideas, not necessarily the exact language, but the person in front of you makes a difference because . . .

PARTICIPANT: Whether she's friendly, whether she's good at explaining that lay language, and whether, you know, if I ask, you know, can I have some testimony of people who already did that. Do you have a picture about like some procedures you're doing it because I'm a visual person so that will make me feel more confident.

MODERATOR: So like pictures of what – so what kind of pictures do you think would be helpful?

PARTICIPANT: Like the work environment, some people like they're taking the procedure. I don't even need to see their face. Their face can be blurred, that's fine. It just helps me to understand like what this procedure is and, you know, some others already taking it and they feel there's no risk at all. So just like a reassurance.

MODERATOR: Right, right. So you know that other people are doing it. So would even just kind of knowing the numbers, like 10,000 people last year donated. Would that help you?

PARTICIPANT: Yeah, that would help, too.

MODERATOR: Great.

PARTICIPANT: Also I think putting into perspective how much of tissue you actually have and how much is actually taken.

PARTICIPANT: Right, yeah.

PARTICIPANT: That way you have plenty (inaudible).

PARTICIPANT: That makes sense.

PARTICIPANT: A little bit of it is taken so when the cores are taken maybe showing the individuals who are donating well we're not taking much. It's just this much and this can be used – so putting into

perspective how little you're giving, but how much impact it can have. You know, shift the balance so more women ready to donate rather than not donate because they're scared and they do not know how much tissue will be taken.

PARTICIPANT: Also like, you know, you're afraid that hey is it going to disfigure my breast. Is it going to leave me lopsided afterwards? So I think having that like hey it's going to look perfectly fine afterwards, you know.

PARTICIPANT: I think, yeah, I just have the volunteers well prepared for those questions and even like if I have a spouse who's against that, but I can evaluate enough information to reassure him that it's fine, that it's okay, other women are doing that. So maybe I can get him on board to support my donation.

MODERATOR: Yes, right. So something you can take with you.

TEAM MEMBER: Can I just ask a quick follow up question about the spouse because I think this is really interesting? Would it be helpful to hear from spouses of women who donated in terms of what their thoughts are?

GROUP: Sure, sure.

PARTICIPANT: I mean I'm wondering if that would be, you know, like I'm proud of my wife or somebody and it doesn't look any different.

PARTICIPANT: Well, the one thing that I think the reason why my husband even today was like don't donate anything – and I don't know if this is the case for a lot of people – but I have a like a small like little darker skin scar and it wasn't a big deal, but I think that was something that he was like is that ever going to go away? It has. It's not a big issue. It's like right underneath. For me, it was definitely something I was like oh yeah I donated breast tissue. But for him, he was like did you know that going in? Like was that a surprise? Like if you didn't expect it and now you have this scar, is it ever going to go away? And like before you – like and it's not something we're looking at all the time – but then before we realized, it was gone. So it was totally fine. But it wasn't like he was like oh that's ugly, but he was just worried for me.

PARTICIPANT: He was being really protective.

PARTICIPANT: Yeah, I think very protective. I did want to touch upon one thing that you said, though. When your friend was like hey we actually need someone with Asian ethnicity/decent, that was a huge pull for me because I was there and then it was a bunch of different, you know, groups of people and then they were like yeah we really need minorities, and I was like alright. (Laughter) And I was just like okay, like I'm making a valuable contribution. So that was kind of my pull, too, because everyone else they were like yeah, you know, this is great, but you know, you have especially valuable tissue.

PARTICIPANT: Yeah. That's how I felt, too.

PARTICIPANT: I had to sacrifice a little bit.

PARTICIPANT: And I think another important thing to have the spouse, they sometimes we share our decision with our significant others and sometimes men, they tend to think more rationally, which before we went to the scenario and we make a very emotional decision; oh that's so nice, I want to do it. Then they will ask for like what's the consequence for that? What's the long-term/short-term consequence? Do you know about the risk in other ones? So if you want to keep the donation continues, like become a repeated donor, I think it's important to have their spouse to back them up because, you know, that will be a rational decision to make in the long run.

PARTICIPANT: And then probably because I think it's better to clarify more like this donation will lay any impact for your marriage or for your pregnancy for breastfeeding or even for your partner life, whatever, you know. Explain it so that people fully understand that it's not just me, you know, maybe it is for my children, for my spouse, and for my other part of life. They need to be fully, understand that and then get reassured.

PARTICIPANT: Right, I like that.

MODERATOR: So what the implications, what the potential ripple effects are. You kind of want to know something about that.

PARTICIPANT: Right. Because when people generate out, you know.

MODERATOR: Right. Thank you for that.

PARTICIPANT: So there's not a consent that has all this info, these risks, these potential risks and stuff? I was assuming that there was a consent form that has all this information in it.

MODERATOR: Yeah, I think there's always a consent form. I think the question is how do you share the information because there's potentially so much of it. You know, what are the most important things and how do you, you know, if it's important for not just the safety, if it's also important for your spouse, your partner to know then what we're trying to learn is okay how can we best communicate what the study's about, what the risks are, what the benefits are, and what's involved in your participation? How can we do that in the best way? So hearing all this stuff is fantastic before the event.

TEAM MEMBER: So at the event, they would consent you and go through all the nitty gritty details, but I think part of the discussion here is like what got you to the event, what got you to want even ask the question should I donate to somebody who is, who would tell you more details? Does that make sense?

GROUP: Yes.

MODERATOR: Yeah, but there is consent. Absolutely.

PARTICIPANT: One thing with the brochure that I notice is the only person that's like a single person in the picture is the Asian person, and I think that in some ways the thing I saw with the Indy Super Cure is that groups of people going together and that was so powerful. And if it's like hey, if it's left with groups, like let's go together. I think it's harder to get one person to go because you then you can carpool, then you can like plan lunch afterwards together and it's this group sort of thing.

But I was looking here and yeah the only person that's by themselves in the picture is the Asian person, and I think it would be nice to have like a group of people together.

PARTICIPANT: The sisters.

MODERATOR: Yeah, yeah. Okay, got it.

PARTICIPANT: That actually brings up another question. Why you want to – my belief is when you want to separate by the different ethnic group is you want to understand their culture. But I'm thinking from the physical or medical purpose, is it like you have some specific research that you have to work on this ethnic group? Do you see what I mean? Like okay like maybe one ethnic group is high on the blood pressure, one ethnic group is more, you know, the Asian people might have the Mongolian spot, you know, and then you work maybe those kind of things. So I just wonder do you really just, you know, this kind of a group meeting, is it derived from the culture or is it from the other medical purpose?

MODERATOR: Are you talking about this meeting or the drive?

PARTICIPANT: You know, today is the Asian group and then you have the Hispanic group, so I just wonder if you just want to understand it from the cultural background or it's, you know, you use this specific group tissue on some medical purpose also.

MODERATOR: Oh right.

PARTICIPANT: Like the Asian people will have, it's more easy to grow the breast cancer or low?

MODERATOR: So are there specific questions we're (inaudible).

PARTICIPANT: Right, right. So I just wonder, like her first question, you know, why is it Asian faces on this? Do you have different flyer to different group or do you use this when it's a general one?

MODERATOR: Yeah, yeah.

PARTICIPANT: And then people will ask why. Why it has to be Asian? Why it has to be, you know, Hispanic?

PARTICIPANT: You think the Asian brochure so much, but just like in general. I'm like it'd be nice to have a little bit more Asian representation.

PARTICIPANT: Right.

PARTICIPANT: Also, I think it'd be kind of cool – and this is just random – but to have testimonials in different languages potentially. You know, I think that that shows that it's just an America thing, it's not just Indianapolis; it's people across the world because the tissues are going across the world, right? That's my understanding that this is the one place . . .? My understanding is that the tissue goes to research places across the world.

MODERATOR: Yes, it's international. International in scope.

PARTICIPANT: So I think it's that having that impact.

MODERATOR: So to know that you're kind of global in (inaudible).

GROUP: Yeah, absolutely.

MODERATOR: So it's not just women here in the States, it's women all over. And then so was your question, did it have to do with – so tell me if I heard this right. It could be important to know why or how Asian breast tissue is going to be used and if it's going to be used specifically for things that are specific to Asian women. So do you want to know yes Asian women have this thing and this is why we're recruiting specifically from Asian women? Is that important to know?

PARTICIPANT: Sometimes. Sometimes it makes people think why you gathered Asian people here and not other, you know, ethnic groups.

PARTICIPANT: Yeah, it's definitely important to know if this specific information is going to help other Asian women. I think it's important for me.

MODERATOR: Yeah.

PARTICIPANT: Yeah, or are you going to even get some different information from these, you know, tissues from these people.

MODERATOR: So is there something specific that we can learn about or something specific that we want to know more about.

PARTICIPANT: Right.

MODERATOR: About you.

PARTICIPANT: Because you guys are separate into the ethnic group so it makes people think, you know, what's the purpose. Are we the only group or everybody is equally, you know, contribute to this global thing?

MODERATOR: Yes.

PARTICIPANT: Yeah, what's the purpose to form this group?

MODERATOR: Yeah, I totally get it.

PARTICIPANT: Is it only the cultural? Or you want to get our opinion how we, you know.

MODERATOR: Why are you asking me for? Why are you picking on me? I'm just doing my grocery shopping. (laughter)

PARTICIPANT: I saw the video on the Facebook group so it was a little bit about why did they choose exactly Asian and Native American group. Because there's a chance for breast cancer, they found out that Asian women living in Asia, they have actually a lower rate of breast cancer in common with other ethnic groups. But then it come to resemble other, for example, United States, possibly something is changed.

PARTICIPANT: Making you want to understand that.

PARTICIPANT: For example, (inaudible) so they become, have the same rate, but it was, started all much, much worse than other breast cancers. That's why they decided to accelerate this research of Asian, breast cancer in Asian population for example.

PARTICIPANT: So giving us that information sometimes.

TEAM MEMBER: So would knowing that make a difference for you?



PARTICIPANT: Yes, exactly. Because I understood that I'm a part of the Asian community that can make and impact exactly on this.

TEAM MEMBER: How many of you were aware that what you just described. I'm just sort of curious; that the risk increases when you go from maybe your native country or you were . . .

PARTICIPANT: Ancestry is to the United States.

TEAM MEMBER: . . . ancestry is to the United States.

PARTICIPANT: I just learned it now from this video. I didn't know about that. I assumed since I was Asian, I would have the same rate.

TEAM MEMBER: I'm just curious how wide spread that knowledge was and then if you didn't know about it whether that would be a motivation for wanting to donate tissue to try and specifically figure out what was going on, you know, with Asian American women to increase their risk.

PARTICIPANT: Yeah, just know, you know, your living environment changes, you know, pollution and then your food, diet, you know. It just changed your risk then to expose to the . . .

PARTICIPANT: So that is a fact then that (inaudible)? And do we know why?

TEAM MEMBER: No, I don't think so. I think that's part of why folks are so interested in breast tissue donation among Asian women.

PARTICIPANT: Well, one of the other things that just reminded me and just kind of seeing the difference or whatever, is I think one of things that really motivated me also was that – my understanding based on just going years ago – was that, you know, a lot of breast cancer research was previously done based on already cancerous tissue whereas this was giving us the opportunity. If you donate now and if somehow you develop breast cancer later on then they can take the samples of both of those noncancerous and cancerous tissue and see what happened to, you know, for that to happen. That was huge for me because they were talking about getting all these people in and whatever and how many people had actually had that happen where they donate beforehand and then donated after they were diagnosed with cancer, and I was like shoot, like you know, I mean that would be a huge reason for me to do that. Not saying that, you know, I'm hoping that that happens, but just in case if someone had both my tissues to be able to do some kind of research on, please do.

GROUP: Yes, yeah.

PARTICIPANT: Also to other spectrum, please excuse me if I sound rude, but Asian families usually do not have a close relative going through the problems associated with breast cancer so we don't really get to see the pain involved. On the other hand, Caucasian families, they do have some instances of their grandmother or mother, someone going through it. So they are more eager to help because they see what impact it could have. So I think just putting that in perspective might push us a little bit further to, you know, just donate because it's for the good.

MODERATOR: So being more aware of the impact of the disease if it should happen to you?

PARTICIPANT: Be more personally involved in a patient who's already going through or knowing what the problem is, how significant it is.

MODERATOR: Right, right.

TEAM MEMBER: Can I just clarify something you said? So if I heard you correctly, because maybe not as many of Asian American mothers or grandmothers are being diagnosed with breast cancer as in white women they don't have that firsthand experience of seeing what the breast cancer experience is like. Is that what you're saying?

PARTICIPANT: Right.

PARTICIPANT: So the motivation is somewhat . . .

TEAM MEMBER: So then knowing that it actually increases risk once you've moved here to the United States, maybe that's why you're not experiencing family members who are going through this, for example, would be important to know that you, in fact, may be just as high a risk as your white (inaudible).

PARTICIPANT: Or maybe the emotional component, not per se that well maybe I'm not (inaudible) but the emotional part of it.

TEAM MEMBER: Yeah, okay. Thank you. I just wanted to make sure I got what you said correctly.

PARTICIPANT: So is that high risk real or is it just high diagnosed with?

MODERATOR: (To RESEARCHER) I don't know if you want to field this or not. (RESEARCHER signals she will address it later.) So my understanding, which is very rudimentary is just that prevalence increases of actual cancer diagnosis after, you know, in the United States among Asian women compared to Asian women in other countries. So it's not just that they're being screened more here as opposed to in their native country. It's not a detection difference. It's a true difference in prevalence of disease. That's my understanding.

PARTICIPANT: Another thing is, you know, like back in China in the old time, nobody worried more about the breast cancer and then, you know, and then based on, you know, how your country or your government, you know, promote that awareness. Maybe you just did not pay too much attention to that. And then when you come here and then you see, you know, all these years, you know, the whole thesis. You know, like the pink, you know, so it's make you aware of that. Like before, you know, even my son does not generate depression. I do not really care, you know, like what depression people feel until you're really in it just like yeah there's somebody in my family that got this one. I have a bunch of church people and then the office people had breast cancer, just within these three or four years. So it's just suddenly make me like oh my gosh, you know, it is in my life. It is closely connected to my life and then, yeah, and then suddenly you'll just feel like yeah let's do something, you know, since you know now I'm aware of it. Now I know it.

MODERATOR: So the more immediate kind of connection you have to it, the more you have (inaudible).

PARTICIPANT: See before China, I did not know diabetes. Who think about diabetes? You know what; you're thinking about, you know, put the good food on the table. And now we came here and I'm

like diabetes. What possible (inaudible)? Why is that? You see what I mean because it's not your focus there. Different, you know, your living, standard of living in (inaudible), you know, you just like oh diabetes will never hit me. Yeah, I get noodles, you know, I do not eat that meat. You see what I'm saying?

PARTICIPANT: I think there's a difference of social awareness built into, like here I don't know about tissue bank, but I know the pink stands for the cause of breast cancer. But in China, because I study for (inaudible), a nonprofit. We do have major campaigns like supporting a healthcare issue like breast cancer, but here we see there's normal cell, normal cell, dense.

PARTICIPANT: (Inaudible), you know, all kind of things.

PARTICIPANT: So even I come, there's nobody like probably I know has breast cancer but I was getting used to being exposed to that issue. If I'm in China, it just sounds something so far away from me so why should I care?

PARTICIPANT: And just like on top of the information that you have on your brochure, I was just thinking like before I came here, I had a chance like to help like a student (inaudible), like working on, but that was like organ donation. Because back to my country, the people are really scared of that. When they talk about organ donation, they will be like oh my god they're going to come and take my things (inaudible) too, and the lack of the knowledge about that. So then after they discover that like the different so many problems, like those who were willing to donate. There was so many qualification that you have to be this, you have to be that, you have to be 18 years or older or some sort of thing like that. So how can I say that? People will think about it when they see like oh, let's say even my case. I see that oh my qualification is just correct. Like I can do that right now today. I will just go and do that, but you know like without that qualification, you would think about it like right here. On your brochure you mention it almost now, so you try to like highlight it with normal, but for me like what normal, what normal conditions would be. Like, I'm – what if like I'm 25 years old, am I going to be too old for that? Or what if I'm like 15 years old and I want to do that, would it be possible or like some sort of thing like that. That would be more helpful for those who get, let's say those who don't have any background information about donation, like breast tissue at all, so then they would know that well there's something about me that would be helpful. Like besides that, okay, you are being Asian or something like that. And also like based on my experience, I was one to really want to do the blood donation here, but then I found out that have so many qualifications that okay you have to be here at least like six months or more, something like that, and I was like I want to do it now. Like what if I don't be here for like six, let's say like half a campaign is during that week, but I realize that I haven't been here for like six months yet, so what should I do? I would have to go back home in a few (inaudible). I cannot do that, even I really want to do that. So I think that would be an added information that you should consider adding on that it doesn't matter that you've been here for two days or like two years. You can do it as long as you are Asian and you're in a healthy condition. You don't take

any dangerous pills or something like that. I think that would be something that would be more helpful for people to consider about that besides of the benefits and the effects or something like that.

MODERATOR: So let them know that there's kind of a wide – like the window is pretty wide for them.

PARTICIPANT: Yes.

MODERATOR: Did you have something?

PARTICIPANT: Well, I just wanted to piggyback off of what she was saying. I think in the US it's very common to have blood drives and like tissue drives and more common than other countries, but I mean my family in Japan have no idea what – I mean they don't believe me that there's a blood drive that, you know, college campuses have and people just go in and get their blood drawn. And I think also another thing you have to realize is that there's a lot of like religious, but also cultural stigmas to giving something of your body for research. And I mean I don't know which countries believe it, but I mean I know my grandma, she – that's what she thinks and she thinks it's like a part of you is taken away. You know, you donate something and then you never get it back and then, you know, you become less of yourself or something. And, yeah, I feel like those would be some things that you would have to kind of like manage when you're dealing with, you know, first generation and second generation Asian Americans living.

MODERATOR: Do other folks kind of think that, too, the whole idea of like giving a part of, for research, is not (inaudible)?

PARTICIPANT: Well, the longer you stay in the States, you know, these things change, which we started to upset.

PARTICIPANT: Right. I didn't believe that, you know, because I'm an American, but you know, my family back home is like . . .

MODERATOR: Very conservative about . . .

PARTICIPANT: Yeah, absolutely. Absolutely. And it's not very common over there either. And for people who do donate blood, there's, you know, a huge reward from the government because there's not a lot of people who donate.

PARTICIPANT: Yeah. So in China, you can stay at home without working but still with pay for quite a while. So here, they say oh I know they, you know, six time of blood I'm like you go to work and then they say yes certainly, you know, I just go back to office on the same day. So it's like something different.

PARTICIPANT: I got two weeks off with pay (inaudible).

PARTICIPANT: Right. You do not need to work, right. And then you get a lot of nutrition, food, and then she'll give it to you so it make you think oh my god it's a big deal. Yeah, you really need to think over before I make this decision. Some people say oh I grow white hair; you never know, you know, if it's supposed to grow or not. (Laughing)

PARTICIPANT: And also to that point, my mom, she had to receive blood from, um after she was – or during childbirth she lost a lot of blood, was in critical condition, but first she's like that was like absolutely – I only did that and received it and took it because it was life or death. Otherwise, I wouldn't have wanted to receive someone else's blood.

PARTICIPANT: So for me when I donated, when I told my mother that I donated breast tissue and she's like why? Why would you do this? You know, why would you put yourself through that? And for me, my mentality is if everybody thought somebody else was going to do it, who's going to do it? You know, I was like they need people. If everybody says oh I (inaudible) group of people who donate. So that's kind of like what I said, even because I donate blood, too, and she's like why? Why are you donating blood? It's like because they need it in hospitals.

MODERATOR: Food is here.

PARTICIPANT: So we're sisters and I grew up with my mother way longer – I mean I stayed with my mother so I have my mother's way of thinking. RESEARCHER and I are classmates. We're best friends pretty much. She talks about it all the time and I was like no I am not letting anyone come near with a needle no matter what you say, no matter how it's good. So people like me maybe we can help out in other ways, like maybe you can explain other ways people like us who are very like scared of needles, scared of things like that, what are the methods that we can help out instead of just donating breast tissue.

PARTICIPANT: I'm scared of, you know, (inaudible). I cannot believe I got two boys born. I almost faint every time they draw blood. Yeah, I would just like, you know, freezing cold hands and feet. I was shaky.

PARTICIPANT: And I think another issue that may prevent me or some Chinese women to donate tissues or blood is accountability of how to manage that afterwards because back in China we heard a lot of scandals about people, they donate blood and they get the HIV.

GROUP: Oh.

PARTICIPANT: And then there's like the black market of trading blood and tissues and some people like, those poor people, leaving the wage to actually do that for a living. So although they call it donation on the surface, but you know, it's just a cover up for their trading. So then we have that kind of concern deep in our mind that that may get you, you know, bacteria, at least virus. So here – when we come here, we saw the same needle. That might bring up that concern again. And sometimes I would feel a little bit shameful to talk about that because we heard so many scandals and sometimes we think okay it might be just happen in China, but will that happen here? Is that okay to talk about it?

MODERATOR: So you're not sure if it's right so you're not sure (inaudible).

PARTICIPANT: Yeah, will that, you know, make our people look bad because we have those scandals?

PARTICIPANT: In Russia also they feel the same.

PARTICIPANT: Yeah, and if you ask also kind of with the same issue, but is that okay to talk about that without being, you know, maybe being feel ashamed of ourselves? So it's kind of sensitive, but you want to ask, but you're afraid to ask kind of.

MODERATOR: Right, right. So, okay accountability from the organization is an important thing so you feel safe in where your tissues or where your donation, you know, where the tissue is going, but also there's something else you said there about total affair, but also – oh yeah – also a resistance to asking questions about these really deep issues because you know that they might be specific, or you think they might be specific, to where you came from and they might not fit.

PARTICIPANT: That might be a little off the topic, but I used to work at an office of (inaudible) health fair, so I deal with many international students, some Chinese, Asian, and I find these (inaudible) were interested is they will, if I have either American coworkers at present, they will come to me for some sensitive topic that the feel not quite comfortable to ask American coworkers and sometimes that related to our stigma, our own culture, that we don't know if it's okay to talk in the US. Why don't you all bring, you know, it will make our nation look bad.

PARTICIPANT: Yeah, right.

MODERATOR: Got it. Yeah, that's right. Thank you for sharing. Is there anything else?

PARTICIPANT: I think just piggybacking off that topic, the common misconception might be being exploited by big companies or big pharma or something like that. So I think people are more willing – at least it's true for Indians – that if you explain that there's no profit or monetary benefit to anyone, like you're not being exploited, it might help people be more involved. At least that's true for Indians. Because there's a misconception of things.

MODERATOR: So to make it really clear of what the organization is about, that there's not a profit part of any part of this. Yeah, okay, which makes sense. Okay, is there anything else? I wonder if we should, because we have food here now. It's 11:20. I wonder if we should . . .

PARTICIPANT: Go eat.

MODERATOR: I know, but we've discussed so many important things that I think actually have relevance to the other, the rest of this. Shall we break for snack now, go for now, and then work on this later? The rest of this exercise is basically taking the green and the red pens and just kind of having this as a document and then you'll hand this in and we'll collect it and we'll use it to, you know, to get our ratings.

PARTICIPANT: We could do it while we're eating.

MODERATOR: Yeah, can we do that? Okay. So the green pens are what you circled to say yeah this is something that's actually a cool thing; it's motivating; it's kind of getting me closer then. The red ones are like whoa until I heard that this was cool, but now I'm ten steps back. So it's really like this is kind of helping me understand it so I can, you know, it's motivating me to think yes this is cool. This is something that's like oh I can't do that. Green go, red stop.

Break to get food.

MODERATOR: When it comes to the green and the red circles just whatever you feel is going to help us understand what you're trying to say. So if it's pretty self-evident then don't worry about the notes. If it's something that you think might need a little bit more explanation then please (inaudible). It doesn't have to be a whole lot of detail. So I think like we'll have like, Heather, maybe five or so minutes. I'll kind of scan around see and see how we're doing, so five or so minutes for this and then maybe in the meantime, do we have the surveys so for folks who are already done, there's a really, really brief survey that we can get done.

PARTICIPANT: So are we done already or is there something else?

MODERATOR: No, there's two more brief things. But we're thinking we'll be – we'll probably be able to get it done in half an hour.

MODERATOR: So maybe we'll give everyone like maybe just a couple more minutes and then if you're not able to finish it, we'll be fine because we'll have a little bit of time at the end. We have two more kind of brief exercises we'd like to do and then we'll – if you haven't filled out the survey, you'll get a chance to do that and then we'll take care of the rough notes. So a couple more minutes. And yeah, you know, if you have finished them, the next thing we're going to do has to do with fitting these new statements into – it would be worth it to donate breast tissue if. So imagine, just kind of have a look at these and imagine which of these are the most or the best answers, put in this spot. And what we'll try to do is we'll try to rank them in kind of priority order.

MODERATOR: Okay, I guess to start out with is there anything that anyone wants to add to this, to the cards? We tried to go through and note or summarize and note what folks have been saying, what we've been hearing, but is there anything that seems to, you know, something we should add? And if not then what do you think the most, you know, what do you think the more important cards are? Which ones make the highest?

PARTICIPANT: Personally?

MODERATOR: Yeah, it's for you.

PARTICIPANT: Maybe it has a personal connection. I have a personal connection that would be the highest rank for me.

MODERATOR: Personal connection, okay.

TEAM MEMBER: And by personal connection, can you expand on that just a little?

PARTICIPANT: My family or really close friends, if it helps them then yeah I'll consider it.

TEAM MEMBER: So a personal connection to breast cancer.

PARTICIPANT: Yes.

TEAM MEMBER: Or a personal connection to somebody who has donated? That's what I was trying to differentiate, but it sounds like a personal connection to breast cancer.

PARTICIPANT: Yes.

PARTICIPANT: I'd say coming is just as simple as like it helps other. I can help other people. That I can help others. That's just it for me because who knows; maybe I'll need it one day.

TEAM MEMBER: Can I ask one follow up question on that, too?

PARTICIPANT: Sure.

TEAM MEMBER: Is it people generically?

PARTICIPANT: Yeah, people generically.

PARTICIPANT: Okay.

PARTICIPANT: I think for me it's seeing the impact so how it enhance what we know about breast cancer already and how you can use that information to make lives a little better for everyone.

MODERATOR: Oh wait. Yeah, these are very similar.

PARTICIPANT: Do you have help other people like me? I mean the same group?

PARTICIPANT: Yes. It says somewhere to help others. That's a variation that seemed similar themed. Does that make sense?

PARTICIPANT: Yes.

PARTICIPANT: Yeah, I think it goes with helps women over (inaudible).

PARTICIPANT: I would choose explain well, but it's kind of an overall statement because explain well can like if the procedure is explained well, the impact is explained well, the risk is explained well, you know, just anything I want to know is explained and I can understand that.

TEAM MEMBER: So risk, impact, what was the other one you said?

PARTICIPANT: Procedure.

TEAM MEMBER: Procedure.

PARTICIPANT: And I would add to that, and this may be like a really just a physical thing, but it doesn't affect the function of our breast. I would put that in that category just to be informed and to have that awareness of what am I getting myself into and there's not going to be surprises. I don't want a regret.

PARTICIPANT: And also it doesn't affect the appearance of my breast probably goes with that, too. You know, okay it's going to look normal.

PARTICIPANT: And that's important to folks it sounds like.

PARTICIPANT: Yes.

PARTICIPANT: I think it'd be worth it for me if I had good friends to go with me or if there was some sort of like sisterhood or support that was – that came with that so it's not just me doing it by myself.

PARTICIPANT: I would add that it helps me to be the best version of me when I can help others. That was just a feeling that followed once you realized that what you had done can really help someone. So it's more like self-expression, pride.

TEAM MEMBER: Distinguish between those then.



PARTICIPANT: I think it's important to hear from others who have done it as well, so.

PARTICIPANT: Go under the explain this well, right? Explain well.

PARTICIPANT: You probably picked that lots of people are doing that.

PARTICIPANT: Yeah, yeah. For your first time.

PARTICIPANT: Yeah, you're absolutely right. Lots of people are doing it.

TEAM MEMBER: Would you put that with um . . .

PARTICIPANT: Maybe with the group thing about like go with my friends.

PARTICIPANT: Are we going to do my spouse is okay with it? And something about breastfeeding.

TEAM MEMBER: Yes.

PARTICIPANT: Because like I can donate blood.

TEAM MEMBER: Yes, so it doesn't affect the appearance. So under function, maybe put the breastfeeding. And then this is maybe a separate – I'm just going to add on function; breastfeeding.

PARTICIPANT: Because I can't donate when I am breastfeeding. You have to wait three months for restrictions. Is there any restrictions for donation of this tissue? Not the future breastfeeding (inaudible).

TEAM MEMBER: But also current donation, okay.

PARTICIPANT: So it's like risk.

TEAM MEMBER: So eligibility. So I am eligible specifically for breastfeeding.

PARTICIPANT: And I think for the one about I can hear from others who have done it, obviously we've talked about being, you know, culturally diverse from different backgrounds, but I think that also counts for age groups as well. I think one of the things I was inspired by when I went and one of the things that helped me have more confidence to do it was that there were a lot of people my age because I did wonder like I don't have kids yet, you know, I want to be able to breastfeed one day, but knowing that like a lot of people my age are doing this as well. One of the things I mentioned in the pamphlet also was, you know, like normal. Like what does that mean? I know my mom was like okay you're not normal though. She's like, you know, let's just say my mother's older and so she was like I don't know if that would be helpful or useful but it is, but helping to convince her of that and be like there are people your age who go. That kind of thing I think is helpful.

PARTICIPANT: After donation, it will make you look younger. (Laughter)

PARTICIPANT: You can tell my mother.

PARTICIPANT: Take (inaudible), here's the result.

TEAM MEMBER: You can be young, too.

PARTICIPANT: Wow. Yeah, a lot of people do it.

PARTICIPANT: I think it promotes a healthy lifestyle because if you want to have a country that has good health outcomes and keeps the cost low. I know it's like a weird economic thing.

MODERATOR: I'm just keeping them all in this column so we can tally. Other things that we're missing up here that you guys were thinking about would be maybe that go with that?

PARTICIPANT: One thing I want to ask for my friend, if that person has already had breast cancer, can they still donate?

TEAM MEMBER: Yes.

PARTICIPANT: Thank you. Well, effect or it will have any impact on the previous surgery or...?

PARTICIPANT: They usually use the other breast – sorry to interrupt but the one that's not affected, so.

PARTICIPANT: Oh really? So like if you already had breast cancer in one you can donate from the other?

TEAM MEMBER: Yes.

PARTICIPANT: Oh, that's kind of cool.

PARTICIPANT: I think this was brought up earlier, but the organization isn't explaining. I think that's something, like personally I wouldn't really think too much of just because the organization is pretty common, but you know people do fear that and if they have that sort of background let's look at that.

MODERATOR: So we need to make sure that's at least mentioned in one of our materials, right?

PARTICIPANT: Yeah, to know that the organization is in good standing.

MODERATOR: Is there anything else anyone wants to add or kind of move over to the blank? What would the two or three top reasons be? What do you think would be the most important one? I feel like everything up there definitely can have an impact, but then which one do you think is the most impactful?

TEAM MEMBER: Or do you want to do dots?

MODERATOR: Oh yeah, we can do dots.

TEAM MEMBER: Yeah we have some. How many do you want each person to do?

MODERATOR: Just one.

TEAM MEMBER: Okay, so if you could vote for just one. We're going to give you each a green dot. If you need to reach up high and you're not able to, I'm happy to assist you.

PARTICIPANT: Do they vote for like a grouping as one thing (inaudible)?

TEAM MEMBER: Yeah so I've made, if the grouping is fine, but just try to put it on the one that's sort of most closely resonates with what your . . . Now as you guys know, just come on up.

MODERATOR: That's cool. Okay so it seems like what we've got; impact and then kind of, yeah, the impact I think that's kind of related to it that helps women, right, are really important motivators. But up here, I think this is only the personal connection, right, so that we've actually seen or have experienced it up close to us, close to our lives. But it's explained well in lay language is also something s that one is let's see. So the procedure is explained well, the risk is explained well, the impact is explained well. That goes down here. Also it doesn't affect the function of the breast and breastfeeding and it doesn't affect the appearance. All that stuff is explained well. That's kind of

(inaudible). Oh and then also I hear from others, I can hear from other who have done that. Is that an important part of how to tell that story?

GROUP: Yeah.

MODERATOR: Yeah, okay.

TEAM MEMBER: Anybody have a close second that they felt really torn with but we didn't hit this.

PARTICIPANT: I think mainly just to know clearly what the impact is, what kind of support I can get, and then, you know, being transparent with all the information. And the support can include like peer support from my friends and knowing people are doing that as well. And so I think these are the three most important things for me.

MODERATOR: So it's definitely resonating with what was (inaudible).

PARTICIPANT: Or, also I think someone mentioned this a little bit earlier, too, but just, you know, impact and everything – everything explained well as a whole but I think one of the things that made me a little bit nervous and I think was kind of like where is someone afterwards because I think a huge part is like okay you do this and everything, but then sometimes if afterwards you're a little bit unsettled that can also impact your experience. And I think one of the things that's a little bit unsettling is like is this normal; when can I take this bandage off; when can I shower?

PARTICIPANT: Exercise.

PARTICIPANT: Those kind of questions, and I think what helped me was that like when I was there and someone was talking to me they were like hey like yes I've done it, this is that, this is what you can expect and it was just very frank. It's okay. It's going to hurt for a while. You have the ice pack. When the ice pack is gone then this, and just helped me know what was okay, what's normal whatever, so like the days afterwards that I wasn't panicking or like things that I should be looking for like total red flags like then I should call. I think those things are super helpful just to make sure I'm at peace and calm and comfortable after the fact.

PARTICIPANT: I think something for me, in particular, is like all this is great in theory like helping people and we all seem like very loving people, but I know like this is also a room of intelligent people and everyone seems pretty academic so seeing the impact. Like the place I work at, it's translational research and like for anyone who's ever looked at clinical trials, you know that it takes like 7-10 years and some of these research papers that are published in the 1990s, now we want to implement it even though the prevalence and incident rates have changed completely. So I think like for me, I mean I do research. It's great in theory, but actually implementing research into a clinical setting and because she has an MD and Ph., it's like great you can see both; like that TEAM MEMBER 3 has both the things so it's kind of nice to see that research get translated into a clinical setting as opposed to just oh we did research, great. Now we know the numbers. But what are you going to do with that?

MODERATOR: That's really interesting. So you're saying, if I'm hearing you correctly, sort of understanding like from the impact standpoint taking that a step further maybe that donation goes

to research goes to changing people lives. You know, you're implementing that research and that translational piece is actually happening.

PARTICIPANT: Yeah, because what I've seen with a lot of researchers, which kind of scares me, is they get so into their research and publishing papers and the American Journal of Medicine and I have to publish and I have to get an RO1 and I have to get a grant. It's like okay, but what are we doing this for? What is the end goal? And so the thing with me is like great you published a paper in 2000; it's 2015.

PARTICIPANT: Yeah, how is it impacting lives?

PARTICIPANT: It was just piggybacking off your point, I was thinking if – so there's a section where the publications are mentioned that are based on tissue that was collected from (inaudible) on the website, so if we could have something in a language being explained okay well this tissue was used and we came to this conclusion, even that is not necessarily translational because way littler is translated. But if you could show people where you are expanding the horizon of the knowledge by a centimeter because you donated the tissue (inaudible).

PARTICIPANT: Right, right. And like I know with the (inaudible) which was about the leukemia, they did a phenomenal job of showing that, like all the pieces that had to come together in order to help with leukemia, but it's like you want to keep doing that.

PARTICIPANT: And just to reflect on that, I was thinking some fundraising contest and what they do to kind of keep their donor giving repeated gift is by doing a (inaudible). And also like automatically adding into a new center like this is set up particularly for donors. So it's like here is our progress report was what he give and sometimes like by the end of the year they have some very awesome informatics, which is pretty and comprehensive and you can see okay here is my minor contribution but this leads to this measurable, impacting for this cause. And then that way you encourage the donor to give a second time or third time donations.

MODERATOR: Or potentially tell people exactly what their experience is and then that may lead to the personal connection and not the breast cancer personal connection, but the donation personal connection.

GROUP: Yes.

PARTICIPANT: When you have the donation campaign, do you separate by the ethnic group also?

MODERATOR: We tend to recruit it at various events and some are specific to, you know, like Black Expo for example and some aren't is my understanding. RESEARCHER (inaudible), that's my understanding.

PARTICIPANT: Like the donation campaign when you raise it, do you separate by the ethnic group?

PARTICIPANT: An actual division event?

PARTICIPANT: Yes.

RESEARCHER: Um, you're just asked, you're given a medical – you're given a questionnaire and you designate your origin or ethnicity. The actual event itself is not usually a segregated event,

although we – the KTB does travel now out of town and that is primarily for the purpose of diversifying the tissue and so we will restrict Caucasians until much later in the process of recruitment to give the diverse donors a much longer chance to (inaudible).

PARTICIPANT: Of course I'm thinking if you separate with the ethnic group, you can have interpreter, you can have the handouts and the information in that certain language and then, you know, people can have personal connections. You know, people can group it together to go. You know, you can reach some certain communities, societies.

PARTICIPANT: If there's only one donor that prefers her native tongue, we could an interpreter there.

PARTICIPANT: Yeah because I work Bose for the language of the freelance translator and I work for the Chinese newspaper so I'm thinking that's the way, you know, that you reach that certain group of people so that on the certain days you get only focus and target those market.

MODERATOR: That way it becomes a little more intimate and kind of personalized.

PARTICIPANT: And possibly to get (inaudible) still the severity of, wait I want to say the status of this intervention, because for example, before (inaudible) I didn't (inaudible). I tried to do that four times in ER and the nurse specialist told us restriction (inaudible) you have to wait six months until after periods two weeks and stuff like this, but after operation, for example, you have to wait one year. So what's type of this the nation is at? Is like (inaudible) or is this like (inaudible) or is like surgical operation.

MODERATOR: So knowing what the restrictions are before that.

PARTICIPANT: Yes.

MODERATOR: Okay.

PARTICIPANT: Those people who donate to what for example. They are poor, the nation for example (inaudible). They decided already to donate because I tried to organize my friends to donate for children (inaudible) conventions. Uh most the people, they're afraid of needles. This is just physiological reaction, I know. But some of them are just men. But they just fell. (Inaudible.)

PARTICIPANT: Kind of like a phobia.

PARTICIPANT: Yeah.

PARTICIPANT: So they're afraid of that and afraid of HIV and hepatitis C, and other people say oh I can drink for three days beer, but people who really want to, sometimes they can't and they found out that they have asthma, this restriction, (inaudible) that this is restriction. I mean he doesn't decide to donate. He'll be able to donate this type of tissue. That's why it will be nice to know about which restriction I (inaudible) informational list.

MODERATOR: Okay, so to have more explanation upfront so that you're not caught by surprise later on seems like what you're saying.

PARTICIPANT: I mean I just have to fill the question mark before (inaudible). So just to know about it.

MODERATOR: So just to know about that right before – or well in advance of when you donate, like way before you donate.

PARTICIPANT: (inaudible) the night before what donation. After donation all this breast tissue.

MODERATOR: I think understand. So okay, so just basically explaining and making sure that it's clear so you know what you're getting in to before. I'm not sure if I'm getting it totally right.

PARTICIPANT: Just a particular question and it's possibly a question to a professional to – I don't know. And to people who somehow work with banking of lab tasks; blood, tissues, stuff like this.

MODERATOR: Okay, so it would make it more familiar with your own experience, too. So you kind of know.

PARTICIPANT: Just to know on which restriction of this donation I have.

PARTICIPANT: And I think I'll go back to explanation of everything here. I know like most of them were (inaudible) informed consent, but the informed consent only had at the (inaudible) stage where you're actually in there, which means you already give the permission kind of. I know people will still back out at the very last minute, but it's just like at the beginning when you try to recruit them. They probably want to know as much information as possible, even beyond what the informed consent. I think for us, for non-American, there are two barriers to overcome. First is the cultural one. The culture is like here mix two kind of culture. First is like Asian culture and common American culture; the language barrier. This one needs to all come in secondly is to overcome the barrier to donate tissue because it's not a common thing in my home country. So it's a struggling in our minds. We really hope somebody can hold our hand to go through the process and to ensure everything is okay. And then we will have this courage to do it and we may even want to be a long-term volunteer and help others to do that.

MODERATOR: Right and help explain the process and make it easier.

PARTICIPANT: Exactly.

PARTICIPANT: Do people take the consent forms home and read them? Or do they not have that chance?

MODERATOR: Everybody get a copy of the consent form for sure.

PARTICIPANT: Afterwards or before? I mean before they sign a consent do they have a chance to take it home and read it?

MODERATOR: No.

PARTICIPANT: You can read to as long as you'd like to on site.

PARTICIPANT: Okay.

PARTICIPANT: This event all happens in one day so if you took it home to read it, the event would be over. But you get a copy of it to look at as long as you'd like and to ask after you've signed it, though.

PARTICIPANT: But before they signed up, can they see the consent form? No.

PARTICIPANT: I don't know the answer to that question.

PARTICIPANT: But I think there are people who actually go step by step on site, right, through the whole process?

PARTICIPANT: Absolutely.

PARTICIPANT: So, I mean you can ask them all the questions before you actually physically sign your form, I guess.

PARTICIPANT: If I get a little time at the end, I'll be able to not address all this right now, but give you tools and information as to how I can go into more detail with this with you later or by email or through our website so we can address.

PARTICIPANT: To add on to that point, I think one other thing that's kind of interesting about that whole process. I remember like someone sat with me; super nice, walked me through it and everything, but I think that, you know, I felt comfortable with that because I could verify that because I could easily read it really fast, but if English is my second language, I think there's a certain sense of like inherent distrust that like someone's telling me something, telling me what is written, but maybe they don't have confidence that I can read it all, which probably might sometimes be the case, which is totally fine, but I think there is that sort of apprehension because I want to be sure that I'm signing up for something, especially if people are already afraid of being exploited and those sort of things. I don't know if that has a good or negative impact; a positive or negative impact; having someone explain it when like it's like okay but I don't know if I have confidence to read it all by myself here. It would take me longer. I think there's just a lot of those where things like if you had a translator is awesome. I'm someone who could talk someone through in their own language, kind of build that sort of connection just because I think even if someone's summarizing it there's still that sense of like why do they have to summarize it for me instead of letting me read it? Is there a reason why? Those sort of things. I did have one other question if you don't mind. Is breast tissue donation like a one-time sort of thing? Because I know they are able to take slides and you know that one donation can be used for a lot of different things or is kind of like a blood donation or blood drives where they continuously ask you to donate again?

PARTICIPANT: I'm not sure.

MODERATOR: That's the (inaudible) question. That's a RESEARCHER's question. Yeah, I was about to ask, you know, it sounds like how long it was stored, would I use it for surgery for patients or only for research purpose, or how long it can be kept, you know, just like the blood or are you going to separate them or use tissue. I do not understand those parts, but based on the name, it says the bank, you know, so I'm thinking it's like stored for, you know, probably . . .

PARTICIPANT: Indefinitely. But we can, I think what RESEARCHER was saying is we're more than happy to answer her question specific to the process after we conclude the focus group, but in order to really maximize I think there was one other activity.

MODERATOR: There's on other activity.

PARTICIPANT: And so maybe we can do that and then if folks have questions afterwards about that, the process, we'd be more than happy to answer or find out the answer to your questions, okay? Okey doke. So everybody's going to read actually.

MODERATOR: So what we're doing, this is the start of the next exercise. So everyone is going to get a set of three of these cards. Just keep the cards faced towards you like this. Hold it up.

PARTICIPANT: And then we can get started.

PARTICIPANT: So again, don't open them. Kind of keep them. It's kind of like a secret prize.

MODERATOR: Okay, so okay on this side of the park please write the name of somebody who is really close to you, kind of somebody who's like a relative, a friend, family member.

PARTICIPANT: Specific.

MODERATOR: I think keep one person specific in mind. So you can put down like brother.

PARTICIPANT: Three different people.

MODERATOR: Different people, yeah three different. So I'd say three people who you talk to a lot and whom you share a lot of things with.

PARTICIPANT: Include ourselves?

MODERATOR: Including yourselves?

PARTICIPANT: Yes, so one card can be me?

MODERATOR: Oh no. Just people you're going to be talking to.

PARTICIPANT: Do they need to be women, or male or female?

MODERATOR: Anyone. Okay, another way to think about it is who are three people whose opinions you value most? Like people whose opinions really mean a lot to you. Is that suddenly you're changing your mind? Because that's like oh it's totally different.

PARTICIPANT: Their opinions don't mean anything. (Laughter) Yep, it's really different. I'm not sure I want him.

PARTICIPANT: Yeah, that really does change it, doesn't it? I talk to my brother all the time.

MODERATOR: And on the other side of the cards . . . So now they fill out the rest of the card.

PARTICIPANT: Yeah, that's fine.

Filling out cards.

PARTICIPANT: Let me know when you're done. I'll gather them.

MODERATOR: Thanks guys. You know, we are, for all, we're just about – we're done. That was the last exercise. I was just wondering if we could just get a really quick sense what did you learn from the card experience? Are there different things? What do you think people whose opinions you value would say? And I notice on one of the cards, and actually just thinking myself about the people I talk to the most and people whose opinions matter the most, I mean how they're kind of different. Like, you know, what they think and what they might say could be totally, totally different things. Is that true for other folks?

GROUP: Yes.

MODERATOR: And then did you – how was it different?



PARTICIPANT: Some people are supportive and some aren't.

MODERATOR: And you think, so and would they say different things?

PARTICIPANT: Yeah.

PARTICIPANT: Yeah. They would say supportive or unsupportive things or oh okay. (Laughter)

PARTICIPANT: Like oh this is a terrible idea, but . . .

PARTICIPANT: No (inaudible). So, yeah, I think neutral, good, and bad.

PARTICIPANT: Because, I guess, you need to make decision.

PARTICIPANT: Yeah, exactly, because in my opinion it's like it's my body, I'm doing what I want with it, so sorry you don't have an opinion.

PARTICIPANT: But I raised you. (Laughter) What did my mom say the other day? Mom said the other day I used to wipe your butt. Okay, okay. You don't anymore.

PARTICIPANT: And some of them I don't really know their opinion because we never talked about that.

PARTICIPANT: Right.

PARTICIPANT: So I don't know how she would react to that. I mean, but, it depends on the information I got in hand in other words. I may be adequate for my idea or it's like okay you probably don't understand it, but I'm going to do it anyway because I have competence to do it.

MODERATOR: But you're saying that in order to share it with some people, you'd feel better if you had more information for them before you would consider sharing it?

PARTICIPANT: Yeah. For example, like I put my mom and my boyfriend on two cards. Well, my mom, I'm pretty sure she will be supportive because she is a blood donor herself and she got mad when I told her I donate blood twice a year. She's like that's too much, but she donates three times a year so she has no stance to say that. I'm confident, though, that she'll be on my side if I made a decision because she's used to seeing things like that. But my boyfriend, he's not quite philanthropic. He didn't participate in a lot of volunteering things. He might think this is a good idea to contribute to the public good of the women society. I don't know. He might think I'm crazy. I don't know. And he's also like the rational type of person so if I have information that I can share with him, maybe finally he will become less clinging then.

PARTICIPANT: Right, so have more information. Great.

PARTICIPANT: I just want to say one thing. If that person whose opinion matters to you the most is really educated and supportive, that might change your decision. Like at the beginning you might not want to, but since that person's opinion matters the most for you, you might change it and you might donate. So educating more people would actually help.

MODERATOR: So do you think – so in the scenario you are approached by someone and they tell you the different donation times. Would it be helpful to have a significant amount of information specifically so you can share it with somebody beforehand? So just before you make the total decision it's like yes.

GROUP: Yes.

MODERATOR: Okay.

PARTICIPANT: Yeah, something like, you know, if I'm interested in knowing hey here's a packet you can take home with you and look over instead of a brochure.

PARTICIPANT: Or just online, just having more. I feel like a lot of webs are generic. You look for our research study, it's so generic and it's like then people get really into the HIPAA and really into everything and then they're like wait what's HIPAA? Oh my gosh. So maybe having more information on the website itself in that specific link or tab might help, I don't know.

MODERATOR: You mean so it's – so you don't have so much all in one spot, you can just specific things you're looking for?

PARTICIPANT: No, no, no. I mean like with – because I recruit patients for our study – and it's like some of them are like PhDs, gung ho, I want to know everything before they participate. And I get it at school. I have no qualms. But having a lot of information is better than little information. I don't know, but it depends on the person and you have to like cater to the ethos, pathos, logos, all three, for each person so I feel like what she's saying, just having a lot of information. And some people can take a packet but having the internet when we all have phones, we all have the internet. So that would helpful.

PARTICIPANT: I think the package that comes with “Be the Match Foundation,” I don't know if you guys (inaudible). So they gave a very comprehensive package, like what to expect before you donate, why you donate, and after you have donated. So that's very helpful to know what you're going into a little ahead so something like that could be good.

PARTICIPANT: And also I feel like sometimes because I am a researcher and sometimes I'm being the researcher for so long and then I find I have this tunnel vision that I just assume everybody else is just knowing this subject as much as I do. And if I'm caring too much about a cause and I just assume everybody that I talk to should care about this cause as much as I do. But it not happen most oftentimes. Sometimes I got frustrated, like why don't you understand? But that's common because they're new to this. So it's really helpful to work through that pass and maybe kind of inspiring them if it's really something they're related to. And also back to the information packages. I was thinking like I don't know the website design of the Tissue Bank, but whether it's possible to have like a form and to have, you know, volunteers, (inaudible), donors to share their stories there and then they can answer questions for people who are interested or have concerns. And that might be even more, you know, inspiring then, you know, a researcher is answering the question because we are addressed in the (inaudible) and that will help the common people to understand that and just to understand the part that they want to understand not in a really deep academic context.

MODERATOR: Right. Yeah, so a form so you can ask, you can post messages up there and they have people who donated previously respond to them.

PARTICIPANT: Yeah.

PARTICIPANT: And that always happens. It's once you are a donor you kind of care more about this cause than common people then you are self-motivated to be there to answer questions. And I'd be you are here, can you join the folks (inaudible).

PARTICIPANT: Yeah, I guess there are some great ideas there. It's inspiring to do more.

MODERATOR: So that we could kind of build and you could help in more than just the . . .

PARTICIPANT: And have some like Asian classes like to build up the rapport with people, even ethnicity groups.

MODERATOR: That's a great idea. Is there anything else?

PARTICIPANT: We can continue some conversation also for people. I just I'm also aware of the time and I don't want to keep people too much longer so please feel free to stay and talk to one of us if you have more to add. As MODERATOR said at the beginning, we really cherish what you have shared with us. It's really just so eye-opening to have at least even a little better understanding of, you know, how we can make this more available to Asian American women, so thank you for your time and for everything that you have shared with us. We do have gift cards. Stay where you are and I'll divide and conquer so we can get this done very quickly.

RESEARCHER: Everybody, my name is RESEARCHER (inaudible). I'm actually one of the very few employees of the Komen Tissue Bank. There are only seven people and first and foremost, we want to thank so very, very much for being here today. This is like I'm going to be talk of the town when I get back to work because this was such a successful turnout. I really, really – I cannot express enough how important your presence is here today. One really interesting thing is I sent out a lot of emails because I was doing the recruiting but it was, you know, I wasn't running the focus group and we did not want to bias your opinions or anything. We really want to know how you feel. It doesn't matter if it's what we want to hear. We really want to know what you want to feel. So more than a couple of you asked what is this about and got an answer. I don't really want to tell you that much, but you're just going to – so we're all information seekers – so for those of you that came anyway even though I didn't want to tell you that much I'm really grateful. There are several things that came up that I just wanted to kind of run through very quickly in case you wanted some quick answers. First and foremost, our website is, I think, really very informative. So if you did receive an email from me it does have the website address on there. Feel free to go through and scour and if you have any further questions after today email me. I will be more than thrilled to answer you. Some things that I just wanted to, just kind of hit my mind. The young lady right here talked about the pictures that are on the brochure and there only being – the only picture of the Asian was a single Asian person. We only put real pictures on our communications. They are real people who have signed releases. They're not like fake pictures from the website or anything. We would have had to have faked a picture to find more than one Asian woman at an event, donating at an event. And I won't say there haven't been any, but we actually have, now have an outstanding professional photographer who comes to all of our events and so there may

have been some, but it hasn't been in the past three or probably since Super Cure, so that's one of (inaudible) of why we're here is, you know, the lone wolf decides dang it; I'm going to go. I'm going to go for it and then donate all the blood myself. So I just wanted to address that. If somebody had a buddy, I would have put them on the front. Just very briefly, why seek separate tissue; culture or medical? Kitty I think asked that question. It's a big long question that I can't get into, but in short it's both. But the reason I wanted to speak at the end was to let you guys know primarily the reason why this type of focus group has to happen. Breast cancer affects women so very differently from race to race, from ethnicity to ethnicity. The culture surrounding those races and in which those races and ethnicities are immersed are a big part of why you will or will not come to do something like this. It's definitely a part of it. So it's both medical insofar as it's medical and biological that Asian women do absolutely have a lower rate of breast cancer in general, which actually is not a reason not to donate. It's a reason to donate because that's so valuable. Why is that? We want to know that. And then yes when they move, particularly to the States, they present like Caucasian women and their rate increases. So just something like that. Black women die more of triple negative breast cancer. Black women get triple negative cancer much more often, they die more. Hispanic women get breast cancer much younger. They present at 34, 36 years old with stage III and stage IV breast cancer and insurance doesn't even pay for their mammograms yet. If we want to find out why that is and if we want groups to be able to help their own, they must – we must have that tissue. That's all. And so, I'm a black woman and so, you know, I talk to a lot of African American groups and African American groups are very much about legacy and very much about my children, my grandchildren being there for them. And so all of us are really, but it's something to just kind of know that no one has any power. We can't do anything – nobody can do anything for your particular group. It has to be that group has to do it, and so if researchers don't have the tissue to work to help either other Asian women who get breast cancer or to help the black women and Hispanic women who might benefit from knowing why the Asian women in Asia don't get breast cancer as much, they just won't be able to find that out without that. So it's very particular that the – it's very distinct that the diversity of tissue must happen. The culture comes in when we go to seek looking at things like, you know, maybe it's affected by their food and whatever, but it also comes in in why you will or won't come to take part in medical trials. And so we need to know what we can, what can be done to help. What do you need is why you're here. We need to know what Asian women need and focus groups – the number one rule of focus groups is like people. So we had to separate you out so that you're in a group like yourselves. And somebody asked, our youngest donor is, of course, 18 because that's as young as you can be. Our oldest donor was a fantastic Indian woman of 92 – of 92 years old. And she beat out our previous oldest donor by about six months when she donated. Our previous one was, yes, and that was a family. That was awesome. About nine Indian women came and donated. The husbands came. Everybody came to the event. Yeah, it was pretty awesome. So the only other

thing I wanted to let you know, oh what are the restrictions, given permission – oh I was kind of answering that. I did get a very wishy-washy answer to the consent question which was I think so. So if anybody is interested in seeing the consent, email me and I'll get a better answer from my boss than "I think so" and it just really hasn't come up so until we – and our only hesitation will probably be that a lay person would get it and not have anybody there with them to really kind of go through it. So, you know, I would guess, I'm not sure, but if you wanted one and you said I'm a consentor, I'm a researcher, I know what consent forms look like; I just want to look it over. I bet it's a case by case kind of a basis. I 'm not really sure about that though. But if it's something you want to follow up on, please, please do. So that's pretty much it. Like I said, our website is there and I'm happy to answer anything. Everything is on their videos and everything. If anybody has any feedback afterwards for me, ideas, recruitment ideas or anything like that, you know, please let me. We're just interested in all of that because we're really – this is our focus now is to really educate the minorities as to why this might something that they might want to know about so let me know if you have any ideas. Thank you so very much. I really appreciate you being here.

(Applause)

**Appendix D**  
**PEOPLE CARD RESULTS**

<b>If I decided to donate breast tissue, I...</b>	<b>would/wouldn't</b>	<b>tell my...</b>	<b>because...</b>
Card #1	Wouldn't	Mom	She worries a lot even if everything is well explained. And we may share different opinions.
	Would	Boyfriend	He is more rational and I trust / will consider his opinion.
	Would	Dad	He would support me if this is important to me.
Card #2	Would	Sister	They would know this in case it needs to be said on a medical form in the future
	Would	Mother	It is my body and I can do what I want with it
	Would	Best Friend	I am proud of my donation to society and encourage her to do the same.
Card #3	Would	Sister & Mother	She's important to me as she's the oldest in my family and she takes care of my in terms of financially and other stuff.
	Would	Husband	He's my husband. I respect him and we most of the time discuss things together before making the decisions, especially regarding my body parts.
	Would	Best Friend in Indonesia	I talk a lot with her even she's far away and we normally give suggestions and support me.
Card #4	Would	Brother	I hope he can support me.
	Would	Close Friend	Hope them can join me to help people.
	Wouldn't	Crushes	They are past crushes. Hahaha.
Card #5	Would	Boyfriend	It is important to let him understand the procedures and consequences/risks/benefits, and also to get his support
	Would	Best Friend	I want to seek for peer opinions, share my thoughts and concerns with her.
	Would	Mother	I want her to know everything that I am doing and to get her support and understanding.
Card #6	Would	Spouse	I share everything with him.
	Wouldn't	Mom	She'll be worried.

	Would	Child	N/A
Card #7	Would	Brother	We are very close to each other and best friends. We discuss things we do on a regular basis.
	Would	Fiancé	He needs to know - we share our lives so everything we decide to do is not a secret.
	Would	Mom & Dad	They are a part of my life even though they will not influence my decision, they have a right to know.
Card #8	Would	Sister	I like to let her know about opportunities to volunteer, etc.
	Would	Husband	He would notice..
	Would	Mama	I think it'd be great for her to participate.
Card #9	Would	Spouse	I would want them to know the pros and cons of it.
	Would	Girlfriends	They would be proud of me.
	Would	Mama	I would want her to hear about my experience and possibly consider doing it herself, or tell her friends more about it.
Card #10	Would	Sister	She is the closest person I can get opinions from from the same generation.
	Would	Husband	He will know the impact, risk and I'd like to show him respect and get support from him.
	Would	Friend	I need to hear what their concerns are. They will listen, care and support as well.
Card #11	Wouldn't	Mom	She might not like it.
	Wouldn't	Dad	I don't want him to worry about me.
	Would	Husband	I need his support.
Card #12	Would	Boyfriend	N/A
	Would	Mom	N/A
	Would	Friend	N/A
Card #13	Would	Sisters	Both my sisters are into medical research so they think it's good/great to contribute to medical research.
	N/A	Best Friend	"Oh no! It will hurt but I will support you! "Go for it."
	Wouldn't	Mom	"It's unnecessary." "No! You should respect your body."
Card #14	Would	Aunt	N/A
	Would	Spouse	N/A
	Would	Mom	N/A
Card #15	Would	Sister	We just talk about stuff.
	Would	Mom	I tell her everything.
	Would	Dad	I just would.

Card #16	Would	Brother	I trust him, he is involved with health care, and I would want to know if he had any objections.
	Would	Mom	Even though she might worry/argue, she should know about my health.
	Would	Best Friend	I tell them everything and know I would have a pros/cons discussion.
Card #17	Wouldn't	Best Friend	She will not really care about this.
	Would	Parents	I'm very close to them and they should know about this.
	Would	Boyfriend	I'm very close to him and would like to share this with him.



## Appendix E STORYBOARD



You are curious about donating and ask about how it works.

Komen Tissue Bank team member explains the breast tissue donation procedure:

There are three blood draws before the donation procedure.

1. Then, your skin will be cleaned and numbed with lidocaine.
2. The physician nicks the skin with a scalpel, and the needle is inserted into this incision.

3. Three sample cores are removed from the breast in quick succession.
4. A nurse/surgeon's assistant holds pressure on the incision for 10 full minutes, then applies a pressure bandage.
5. You will be given an ice pack to put inside your bra.



We have 4 donation events each year.

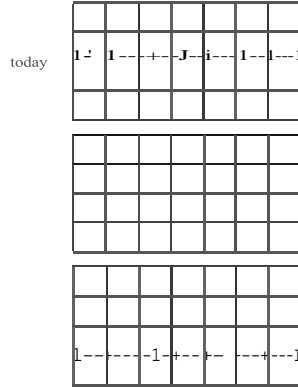
If you want to donate, sign up for our donor list and we'll email you to let you know how to get signed up for our next event!

You sign up for the donor list using your email address.

Later, you get an email from the Komen Tissue Bank team asking you to sign up online for an appointment

at the next donation event.

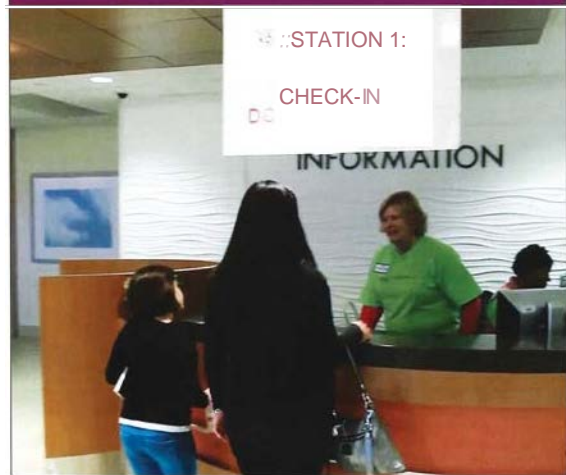
The next event is 9 weeks.



7 to 8 weeks later, you get an email from the Komen Tissue Bank team reminding you that the event is coming up.

On the event day, you get up, get ready, and travel to the donation event.

You arrive at the event and get checked in.



Then a volunteer explains the informed consent form to you before you sign it.



Then, you give some health information.



Then it's time to donate.

**Appendix F**  
**STORYBOARD RESULTS**

Item/Word/Phrase	page #	Red	Green	Notes - storyboards 1
notes	1		X	consider other ethnicities at the front and registration. Also consider more than one person in the front during registration, the more calm and relaxed people can be.
"in the world for normal breast tissue"... "by studying normal tissue, we can accelerate research for the causes and prevention of breast cancer"	1		x	<i>Circled</i>
"only repertory in the world for normal breast tissue"	1		x	<i>Underlined</i>
"causes and prevention of breast cancer"	1		x	<i>Underlined</i>
notes	1		x	important for volunteers to be well educated on the process it will be nice to see diversity in the volunteers also
notes	1		x	include a poster with data strains statistics etc.
notes	1		x	maybe visit continually divers events
"normal breast tissue"	1	X		! <i>Underlined</i> ... explain a little bit about what this is maybe....
"by.....Cancer"	1		x	Circled
	1		x	circled whole page
"by.....Cancer"	1		x	Circled
	1		x	circled

circled	1		x	
notes	2		x	great diversity of people! Age range of the participants look great
notes	2	X		add more familiar pictures for Asians
"normal is now"	2	X		a bit confusing
notes	2		x	1. it is not clear is this KTB located in tissue bank at the IU Simon cancer center or is it a partner of this. 2. I'd like to see Facebook twitter and other links to social networks.
	2		x	<i>pictures and phrases are circled</i>
"ultimate goal of curing breast cancer"	2		x	
notes on the paragraph on the left side	2		x	the rate/prevalence of breast cancer in Asian American woman going up. Combining normal and abnormal breast tissue
notes	2		x	testimonials would be nice
notes	2	X		should show impact or families show strains and statistic data
"normal"	2	X		some people might not feel normal
notes	2		x	if people understand how this is so important to the whole scientific environment I think they would be more motivated.
" the KTB thinks those who have selflessly donated breast tissue or blood"	2		x	Underlined
"as....cancer"	2		x	Circled
notes	2		x	circled picture and "normal is now" ... picture for re assurance
notes on the paragraph on the left side	2		x	Circled

				better have more info about qualifications of donor or what a "normal" "cell" means so people can consider about it better donation
note	2	X		
note	2		x	how will my breast tissue help exactly
"selflessly... cancer"	2		x	
"normal is now"	2	X		
notes	4	X		have the physician make sure the patient understands all risks uninvolved and walk through every step.
"there are three blood draws"	4	X		what is tested?
"numbed with lidocaine"	4	X		identify the term?
"the needle is inserted into the incision"	4	X		<i>Underlined</i>
"lidocaine"	4		x	I am allergic on Novocain, possibly on lidocaine as well
notes	4		x	risk of HCV, HIV ... days off?
"three" "scalpel" "needle" "incision"	4	X		
"three" "scalpel" "needle" "incision"	4	X		<i>Circled</i>
"lidocaine"	4	X		<i>circled</i> and ?... Keep it simple
"lidocaine"	4	X		simplification *?
notes	4		x	Assurance of no knows risk or side effects. How much the tissue can comprises as compares to what amount of tissue left.
	4	X		
note	4		x	more details may be helpful
#2	4	X		Circled
#4	4	X		Circled

"lidocaine"	4	X		?
"nicks.... Incision"	4	X		?how? Painful? Picture or illustration?
"three blood draws"	4	X		why 2 blood draws? What are they for?
#2 circled	4			I have a huge fear of needles this would immediately turn me off
circled	4		x	I like the simple overview
"sample cores are removed"	5	X		what exactly are they?
"incision"	5	X		how deep/length how long to heal or scar to fade?
notes on #5	5		x	what about feeling this day
"holds pressure on the incision for ten full minutes"	5	X		
"incision"	5	X		<i>Circled</i>
notes	5		x	what-happened
notes	5		x	very clear instruction. Might be helpful to provide a "support" and Q&A number to read if you have any problem breast donation?
notes	5	x		on number 3 and 4... include pictures
notes	5	x		is there a recovery period? what does that look like?
notes	5	x		maybe include a brief summary of side effects or something " if there is" after the tissue donated
#5	5	x		circled... is it going to look weird
#3 #6	5	x		#3= is it going to be 3 times or one time but get to cores. #6=it would be helpful to add how to take care about itself after donation



circled with note	5		x	maybe include how much tissue from start to finish
notes	6	x		I didn't know you could donate more than once. How much breast do you take every time? What about any scars? Any marks? Permanent? Temporary?
"4 donations"	6		x	frequent is ok
NOTE	6		X	WOULD LIKE TO KNOW WHEN THE NEXT EVENT IS
notes	6	x		maybe different person
"if....event"	6		x	Circled
"we.... Year"	6		x	it would be better if specific when for example for example every three months.
"we.... Year"	6		x	good to know
circled with note	6	x		are you going to spam me
notes	7	x		don't send to many emails
"get an email from... asking...sign up online..."	8		x	no pressure email works
"sign up online"	8		x	<i>Circled</i>
"email"	8	x		circled... a phone call might be more personal and comfortable
note	8		x	soon after so that the 'yeah!' wants to feeling is still there.
notes	9	x		confused about this diagram
notes	9	x		9weeks is kinda a long period
"9 weeks"	9	x		circled.... The gap is to long the motivation might be reduced.
note	9	x		too much to over think

				honestly once this much time has pass it is difficult to monitor the participant to come back if she will be coming back alone. Maybe consider having her join a group to come with> or have a form or chat place where they can get more info/ support from others who are in the same boat as they are.
notes	10	x		
"reminding"	10		x	<i>circled</i>
"7 to 8 weeks later"	10		x	circled
"email" "reminding"	10		x	circled
"Komen....up'	10		x	underlined
"ready"	11	x		how "ready" what to eat drink can we take medicine? Or supplements?
note	11		x	Free parking?
notes	11	x		if the place is too far away people may not go. So more places blood drive bus may be helpful.
circled with note	11		x	some information about diet or anything like that before going
	11.12		x	
notes	12		x	bright pop up color is awesome for a shirt/swag
	12		x	
	13		x	
notes	13		x	need to include incision criteria as much as (wide) possible and risk/benefits
notes	13		x	the person experiencing it
notes	13	x		the small print especially if they are not confident in their English communication.
notes	13	x		put smile emoji maybe

note	13	x		depending on the content I might raise a red flag or feel more confident
note	13		x	having an illustration of procedure would be really helpful and make people feel less worried about donation procedures.
note	13		x	maybe give the info about this details in the consent form before the person comes in just to save time
notes	14		x	great to have someone walk with you to the different rooms to talk with you.
notes	14	x		what kind of health info do you need to express?
	14		x	
notes	14	x		inclusion criteria should be presented clearly. X on poster
notes	15	x		when can you go back to work? Normal life? Shower? Nutrients? Exercise?
	15		x	
notes	15	x		
	10. 1.3 14		x	circled
#2 #3 #5	4 and 5	x		circled
	6,7,8		x	
	9,10	x		
	9. 10		x	circled

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## Curriculum Vitae

Katherine E. Ridley-Merriweather, MA  
Susan G. Komen Tissue Bank at the IU Simon Cancer Center  
Indiana University Purdue University Indianapolis (IUPUI)

### Education

M.A., Applied Communication, IUPUI, December 2016

Emphasis: Health Communication

Thesis Project: “*Asian American Women’s Perspectives on Donating Healthy Breast Tissue: Implications for Recruitment Methods and Messaging*”

Thesis Committee: John Parrish-Sprowl (chair), Jennifer J. Bute, and Katharine J. Head

B.A., General Studies, IUPUI, December 2000

High Honors

Concentration: Arts and Humanities

Minor: German

### Research Interests

- Prevention in breast cancer contexts
- Persuasive health message design
- Communication-focused minority outreach for recruitment in clinical trials and medical research
- Disparities in cancer research
- Culturally oriented communication barriers

### Scholarship

#### Peer-reviewed Journal Articles

Ridley-Merriweather, K. E., Head, K. J. (2016, November). African American women’s perspectives on donating healthy breast tissue for research: implications for recruitment. *Health Communication*. doi: 10.1080/10410236.2016.1250191

#### Conference Papers/Presentations/Posters

Ridley-Merriweather, K. E., Head, K. J. (2016, April). *African American women’s perspectives on donating healthy breast tissue for research: implications for*

*recruitment*. Poster presented at the Kentucky Conference on Health Communication, Lexington, KY

Ridley-Merriweather, K. E., Head, K. J. (2016, May). *African American women's perspectives on donating healthy breast tissue for research: implications for recruitment*. Poster presented at the IU Simon Cancer Center Annual Cancer Research Day, Indianapolis, IN

#### Manuscripts/Projects in Progress

Ridley-Merriweather, K. E. (in progress). Asian American women's perspectives on donating healthy breast tissue: implications for recruitment methods and messaging.

Ridley-Merriweather, K. E. (in progress). Hispanic women's perspectives on donating healthy breast tissue: implications for recruitment methods and messaging.

Ridley-Merriweather, K. E. (in progress). Komen Tissue Bank communication and clinical research methods.

#### Professional and Grant-Related Work Experience

Susan G. Komen® Tissue Bank at the IU Simon Cancer Center (biobank of healthy breast tissue)

Communications and Minority Outreach Coordinator

January 2011 – Present, Indianapolis, IN

*Funded primarily by Susan G. Komen®, Indiana University*

St. Richard's Episcopal School (private Episcopalian PK-8 school)

Director of Aftercare and Summer Camps Programs

September 2003 – December 2010, Indianapolis, IN

Indy Youthworks (acting and speaking instruction for children grades 1-5)

Co-Founder, Owner, Executive Director

June 2001 – Present, Indianapolis, IN

#### Teaching Experience

University of Indianapolis, August 2015-present

Courses taught as instructor of record: COMM 100: Public Speaking (Fall 2015, Spring 2016, Fall 2016)

Indy Youthworks, June 2001-present

Courses taught as owner and primary instructor: Basic skills and tools of acting and public speaking

### Fellowships, Awards, & Recognition

Behavioral and Population Science/Epidemiology – Grad Student, May 2016, \$100  
Awarded by the IU Simon Cancer Center Annual Cancer Research Day,  
Indianapolis, IN

IUPUI Outstanding Graduate Paper Award, February 2015  
Awarded by the Graduate Program in Communication, IUPUI.

Graduate Travel Award, November 2015, \$500  
Awarded by the Graduate Program in Communication, IUPUI.

NCA Travel Award, November 2015, \$200  
Awarded by the NCA travel grants committee, Washington, D.C.

### Professional & Service Organizations

National Communication Association, Member: 2015 – Present

Spirit and Place, Selection Committee (catalyst for civic engagement through creative collaborations), April 2016

Actors Equity Association, Member: 1986 – Present

Alpha Kappa Alpha Sorority, Member: 1978 - Present