

# IDENTIFICATION OF BARRIERS TO ORGAN DONATION

Identification of Barriers to Organ Donation

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## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

### Abstract

**Background:** Organ donation in the U.S. is critically lacking, with about 17 individuals dying daily while awaiting transplants. Disparities are evident among African Americans, who make up 59% of transplant candidates but only 34% of registered donors. This gap stems from historical mistrust towards the medical establishment, exacerbated by injustices such as the Tuskegee Syphilis Study, which has fostered skepticism about healthcare and organ donation. **Problem:** The disparity in organ donor registration among African Americans is significant, contributing to the urgent need for effective interventions. **Intervention:** This quality improvement project evaluated educational interventions aimed at dispelling myths about the organ donation process in the African American community. The goal was to enhance understanding and increase donation rates. **Results:** The project assessed the impact of these interventions on participants' perceptions. Among the 51 participants, knowledge scores increased from an average of 5.43 to 8.37, and willingness to discuss organ donation with family rose from 6.59 to 8.39. Notably, 69% of those without organ designation on their driver's licenses expressed interest in adding it after an educational session. **Conclusion:** Educational sessions are essential for reducing disparities in organ donor registration and improving health outcomes in the African American community. By providing culturally sensitive information and engaging community leaders, these initiatives can foster a supportive environment for organ donation and enhance community health.

*Keywords:* organ donation, myths and misconceptions, African Americans, disparities

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## **Acknowledgments**

Without the assistance of my wife, Suzanne, and my kids, Grace, Molly, and Julia, pursuing my Doctorate in Nursing would not have been feasible. Their love and patience grounded me while Suzanne managed our family responsibilities, ensuring our children were always where they needed to be. I want to express my sincere gratitude to Dr. Bieda, my adviser, for her exceptional guidance and support throughout this process; her insights were instrumental in shaping this project. I also thank Joe Paparo from Gift of Life for his unique knowledge and invaluable expertise. In addition, I would like to acknowledge individuals who have profoundly influenced my passion for organ donation. Dominic Colleluori, a patient of mine over 20 years ago, received a life-changing liver transplant, and my connection with him and his wife, Peachy, kindled my desire to raise awareness about organ donation. Unfortunately, Dominic recently passed away, but my connection with him and his family goes on. I am deeply grateful to Dr. Chaudron Carter-Short for her invaluable guidance and support throughout my doctoral journey. Your mentorship has inspired me and provided the confidence to overcome challenges. Finally, I dedicate my work to my niece, Cecelia “CC” Ryan, who received a kidney transplant from my sister-in-law, Maureen Ryan, over three years ago. CC’s strength during her transplantation process has been a profound source of motivation for me, inspiring my advocacy for organ donation and transplantation.

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## List of Abbreviations

<i>OPO</i>	Organ Procurement Organization
<i>GOL</i>	Gift of Life
<i>AA</i>	African American
<i>TUH</i>	Temple University Hospital
<i>ESRD</i>	End Stage Renal Disease
<i>EBP</i>	Evidence-Based Practice
<i>ACF</i>	Administration on Children, Youth and Families
<i>IFA-OIC</i>	Islamic Fiqh Academies of the Organization of the Islamic Conference
<i>IMAMA</i>	Islamic Faith-based Medical Association
<i>UNOS</i>	United Network for Organ Sharing

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## **Background and Significance**

Organ donation throughout the United States continues to be in high demand related to the number of individuals waiting on transplant lists. Despite all the efforts made to encourage organ donation, according to Gift of Life (GOL), approximately 17 individuals die every day while waiting for a transplant (GOL, 2024). There is a notable disparity in the number of organ donors from minority groups within the organ donation community, particularly among African American (AA) donors. The African American communities around Temple University Hospital in Philadelphia, Pennsylvania, are not exempt from the national trend of disparities regarding organ donation rates among minorities. There are more opportunities for African Americans to donate organs, but very few choose this as an option when the opportunity arises. According to Molmenti et al. (2021), African Americans are disproportionately represented on the transplant waiting list, comprising 59% of all transplant candidates but accounting for only 34% of registered organ donors.

Many years of mistrust in the medical establishment as a whole is one of the root causes of the disparity in organ donation that is observed in the AA community. The American medical community has long been distrusted. Renowned author Harriet Washington details the difficulties that have influenced the beliefs of the AA community in her book *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present*. Medical experimentation on African Americans has a long history. Washington discusses the exploitation and maltreatment endured by African Americans under the pretense of research, highlighting infamous incidents such as the Tuskegee Syphilis Study and others. The book exposes institutional racism in the medical field, examining how these injustices contributed to a profound distrust of healthcare among Black communities. Harriet Washington

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writes that "diverse forms of racial discrimination have shaped both the relationship between white physicians and black patients and the attitude of the latter towards modern medicine in general" (Washington, 2008, p. 620).

One such experiment that has shaped the minds of the AA community was that of the Tuskegee Syphilis Study, launched by the U.S. Public Health Service (USPHS) in 1932 and conducted at the Tuskegee Institute in Macon, Alabama. The study assessed the natural progression of syphilis and included almost 600 African American men. A treatment for syphilis, Penicillin, was discovered throughout the 40-year study. Even though there were known therapies for syphilis, research participants were misled about the medicines they were receiving, and many men died as the disease progressed (Brandt, 1978). The project was not terminated until the early 1970s, following an advisory board's review of charges of unethical treatment of study participants (CDC, 2021). The controversy surrounding this study and its unethical treatment has had a profound impact on African Americans' trust in the scientific and medical community, as well as their misconceptions and mistrust of the organ donation process.

### **Problem Statement**

Organ donation throughout the United States continues to be in high demand related to the number of individuals waiting on transplant lists. Within the organ donation community, there is a significant gap associated with the number of donors from minority groups, especially those from the African American (AA) community. According to Molmenti et al. (2021), African Americans are disproportionately represented on the transplant waiting list, comprising 59% of all transplant candidates but accounting for only 34% of registered organ donors.

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### **Purpose**

Within the African American community encompassing Temple University Hospital (TUH), there is a lower organ donation rate than that of other racial and ethnic backgrounds. In 2022 at TUH, 46 potential donors were African American, and only 20% went on to donate. When comparing donation rates of Caucasians (52%) and Latinos (58%), one must wonder why there is such a disparity among different ethnicities. In the greater metropolitan Philadelphia area, over 5000 people are waiting for an organ transplant (Gift of Life [GOL], 2024). This poses a significant impact on public health, as not only are approximately 17 people dying a day while waiting for a transplant, but those waiting for transplants are congesting our healthcare system (Brand et al., 2004). For example, there are not enough hemodialysis centers to address the growing need of patients diagnosed with End Stage Renal Disease (ESRD). Those individuals who have ESRD and require hemodialysis are one of the groups currently on the list for a transplant. In the surrounding areas of Temple University Hospital, over 528 individuals are waiting for a transplant. Of those, 462, or 86%, are waiting for a kidney transplant (GOL, 2024).

This quality improvement project aims to determine whether education focused on addressing the myths and misconceptions surrounding the organ donation process within the African American community would improve the organ donation process and subsequent donation rate.

### **PICO(t)**

What are the barriers to organ donation in the African American community in North Philadelphia, and would an educational platform addressing those barriers increase organ donation among African Americans?

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### **Conceptual Framework**

Evidence-based practice (EBP) models are step-by-step guides that allow healthcare professionals to incorporate evidence-based research into their patient care practice. The model that fits this project's scope is the Community-Centered Evidence-Based Practice Approach Model, developed to complement the efforts of culturally competent, community-based organizations collaborating with local residents. Esperanza United initially established the model to help develop evidence-based practices impacting trauma-related domestic violence. Documenting and building the evidence for culturally appropriate services had received little funding despite the long-standing belief that such work is essential to serving the needs of families impacted. Because applying EBP methods to a broad range of services is complex, the Administration on Children, Youth and Families (ACYF) assigned Esperanza United, through a grant, the responsibility of facilitating conversations on community-relevant EBP methods (Esperanza United [EU], 2024). The transdisciplinary model served as this model's inspiration. It resulted in a strategy that aimed to bridge the gap between EBP for domestic violence and culturally relevant, community-based studies. Many similarities of this model apply to the relevance of this project of increasing organ donation awareness within African American communities.

The Community-Center Evidence-Based Practice Approach Model focuses on the people rather than the problem. Most traditional EBP models and methods, which frequently concentrate on issues rather than individuals, are developed and assessed within mainstream, white, Western cultural standards. Many EBPs, therefore, lack communal, cultural, and contextual significance (EU, 2024).

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This model takes three main components in addressing organ donation issues within the African American community: community leaders, clinical experts, and the evidence. Community leaders, religious leaders, local scholars, and influencers need to be involved to make any impact on organ donation within the African American community. In addition, regional experts who are familiar with the organ donation process also play an integral role. Those experts would be from the regional Organ Procurement Organization (OPO), health care organizations, organ donor families, and organ receipts from the African American communities. Finally, as with any EBP model, one would evaluate the documented evidence that has demonstrated an impact on the cause in the decision-making factor. Blending all three areas will give the project the best opportunity for success.

**Figure 1**



(Esperanza United [EU], 2024)

## Literature Review

### *Search Strategy*

The use of Boolean terms included in the search were AND OR. The search strategies were focused on using the search engines PubMed, Public Health Database, and CINHAL.

Keywords focused on were Black, African American, minority, people of color, black American,

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organ donation, organ donor\*, organ procurement, tissue, organ tissue donation, awareness, attitude, perception, cultur\*, religio\*, brain death, barrier\*, knowledge, and organ donor management. A search hedge on the keyword's health disparities and minority health was also performed, which provided an extensive search result. Narrowing down the search field and removing the word "tissue" from the original search was performed because that term was too broad, and many collected articles were irrelevant to the topic and related more to the surgical component of transplantation.

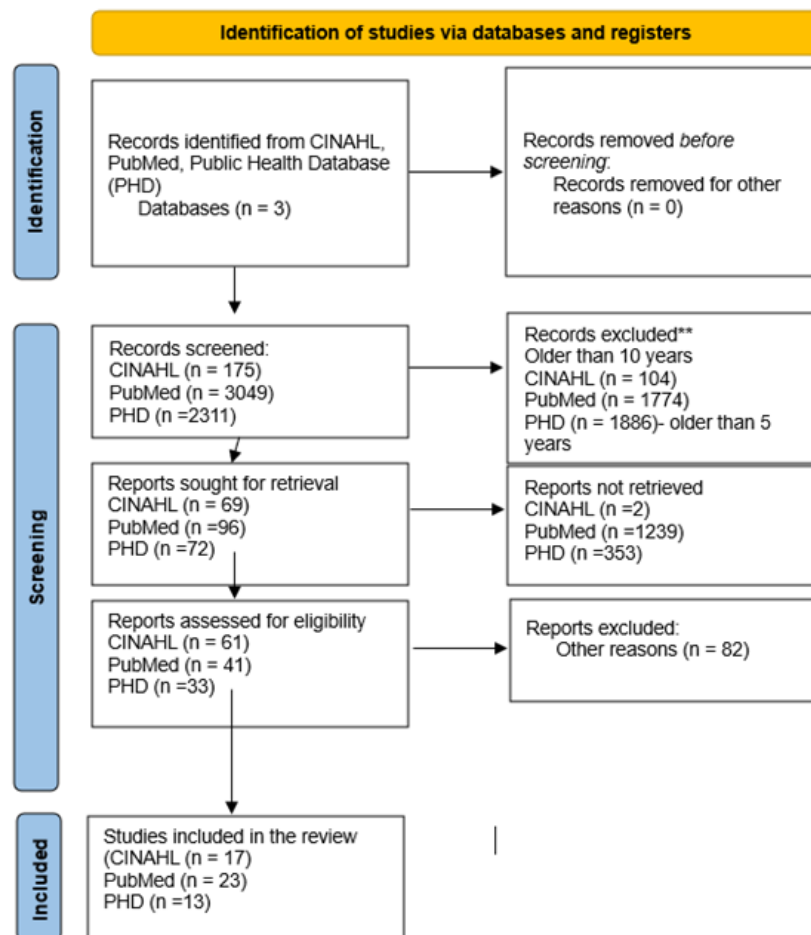
The following search was done in PubMed: (("black" OR "African American" OR "minority" OR "people of color" OR "black American") AND (("organ donation" OR "organ donor\*" OR "organ procurement" OR "organ tissue donation" OR "brain death" OR "organ donor management")) AND (("awareness" OR "attitude" OR "cultur\*" OR "religio\*" OR "barrier\*" OR "knowledge")) Total articles: 3049, Narrowing down to the last 10 years: 1335, Narrowed down to Meta-Analysis, RCT, Review and Systematic Review: 96 articles, Removed "tissue" and placed every word in quotes and narrowed down search: 41, Filtered back down to 10 years and down: 23. Same search window in CINHALL: Total articles: 175, Narrowing down to the last 10 years: 71, Academic Journals only: 69, Limited to English only: 68, Limited to Abstract Available: 61, Filtered to Full Text Available: 17. Same search window in Public Health Database: Total articles: 2311, Narrowing down to the last 10 years: 1101, Limited to English only: 1100, Limited to Scholarly Journals: 789, Filtered to Full Text Available: 732, Narrowed down to the last 5 years: 425, Limited to United States: 114, Filtered down location once again to only include US or US states: 72, Removed subject titles that were more related to the actual surgical transplantation or disease state: 23. In total after narrowing down the search, 63 articles were found that fit within the search criteria. Upon review of all the abstracts of these

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articles, 33 articles were more relevant. All 33 articles were reviewed, and upon further evaluation, only 16 applied to the initial problem statement. The removal of 3 additional articles related to educational initiatives around increasing living donation among the African American community was removed, narrowing down the final total of articles supporting the question to 13.

**Figure 2**

Prisma Flow Diagram



*Adapted from:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffman TC, Mulrow CD, et al. The PRISMA 2020 Statement.: an updated guideline for reporting systematic reviews. *BMJ* 2021; 372: n71. doi: 10.1136/bmj.n71

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## **Literature Review**

Research on organ donation among minority groups, particularly African American populations, has shown strong evidence to suggest that more enhanced education can increase organ donation rates. The main themes identified in these studies include lack of awareness, lack of trust in the medical community, fear of premature death, discrimination, and religious beliefs and misconceptions. Various educational techniques, such as small focus groups, larger church congregations, and enhanced educational videos, have shown some impact on increasing organ donation awareness and rates.

### **Myths and Misconceptions in Organ Donation**

Most published research on organ donation and the challenges surrounding the African American community is directly related to addressing myths and misconceptions. Six of the 13 articles reviewed fall within this subcategory, with six of the 13 articles being either mixed methods or qualitative studies. These articles focused on conducting focus groups with a population subset, followed by qualitative research. Brown et al., (2012) found that most participants claimed they were unaware of the African Americans' need for organ transplants, but the majority knew someone waiting for a transplant. DuBay et al., (2014) and Hyde et al., (2012) concluded that fear and lack of information were the main barriers to organ donation.

Locke et al., (2015) conducted four group interviews, including clergy, and the other group interviews focused on active community members. This mixed-method study concluded that improving knowledge about organ donation, especially regarding donor involvement and risks associated with donation, might encourage more organ donation. Reinhart et al.'s (2020) study examined African Americans in a Midwest community. It reaffirmed that there was an overall lack of knowledge about the organ donation process and that increased education should be the

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tool to increase organ donation among the African American community.

Williamson et al., (2020) focused on medical mistrust, one of the previously identified barriers. The findings were categorized into four groups: societal mistrust, mistrust of general institutions, mistrust of medical institutions, and medical mistrust specific to organ donation. Addressing the fears, myths, and misconceptions of the African American community will play a vital role in changing the tide regarding organ donations.

### **Educational Platforms Addressing Organ Donation**

Deedat and associates (2013) conducted a systematic review to examine the opportunities to improve organ donation awareness and registration among minority ethnic groups. The review comprised 18 studies, including media and educational interventions. Focused educational interventions were found to be more effective at boosting registration rates, but mass media interventions revealed no significant change in the desire to register. Molmenti et al.,(2021) studied the impact of creating an educational video on organ donation, finding that over 1900 randomized participants observed a statistically significant increase in donation intent among those randomized to the educational video versus those who did not see the video.

Thornton et al., (2019) used video interventions to evaluate the effectiveness of increasing organ donation willingness and to determine which educational platform had the most significant influence on organ donation. The study found that a brief live-action movie focusing on an emotional appeal sent online raised organ donation preparedness and desire to visit the states' online registries to consent. This type of video is essential in raising awareness of donations and willingness to consent.

### **Religion and Organ Donation**

Religion plays a significant role in the African American community, and integrating

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religious leaders as collaborators in messaging the importance of organ donation will have a lasting impact. Overcoming religious misunderstandings, falsehoods, and spiritual concerns is an essential factor in increasing donation rates since religion and religious institutions continue to play a significant role among African Americans. Miller and colleagues (2014) performed a systematic review of over 700 articles addressing the ideas of the Islamic faith, brain death, and organ donation. Though the majority of Muslim scholars and medical organizations recognize brain death as the definitive form of death, the Muslim world's consensus is not unanimous. Decisions from the Islamic Fiqh Academies of the Organization of the Islamic Conference (IFA-OIC), the Islamic Faith-based Medical Association (IMANA), other faith-based medical organizations, and legal rulings from multiple nations demonstrate this continued impasse—some advocate for definitions of death based on cardiopulmonary criteria. At the same time, others within these organizations emphasize the importance of moral and spiritual considerations in determining death. Miller et al., (2014) explored the moral and spiritual considerations of brain death in Islam, highlighting the tension between traditional definitions of death—centered on the soul's departure—and the medical definition of brain death. This debate encompassed cultural variations, ethical dilemmas regarding organ donation, and the need for dialogue between medical professionals and religious authorities to navigate these complex issues respectfully.

### **Global Efforts Addressing Organ Donation**

One country that is addressing organ donation on a larger scale is Spain. Spain has had the highest organ donation rates since instituting the opt-out option in the early 1990s. The opt-out provision establishes organ donation as the default standard of care, wherein individuals are presumed to be organ donors unless the patient or their family explicitly indicates otherwise.

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The ethical issue surrounds the apprehension over whether assumed consent adequately represents the patient's desires since it can potentially infringe upon the autonomy of a donor who did not intend to donate but did not register to opt out. Lewis et al., (2020) discussed that grassroots initiatives targeted at the minority population, emphasizing education and empowerment, still increased organ donation rates among African American communities. As Callender and Miles (2010) research article points out, the authors witnessed a quadrupling in the percentage of African American donors between 1990-2008. Their research primarily focused on creating culturally relevant health education programs intended explicitly for specific demographic groups to alter views, opinions, and choices.

### **Stakeholders**

Internal stakeholders at Temple University Hospital contribute significantly to promoting organ donation awareness. Healthcare personnel are essential because they help educate patients and families about the donation process, profoundly impacting their choices. The hospital administrator distributes resources and promotes a culture that highlights organ donation. Organ Procurement Organizations (OPOs), such as Gift of Life, partner with hospitals to streamline the donation process, providing crucial training and assistance for medical personnel. The ethics committee ensures ethical principles are upheld in discussions about consent and end-of-life choices.

The public relations team plays a crucial role in shaping the conversation about organ donation by correcting misunderstandings and fostering a positive image. Many social media posts about transplantation and the power of organ donation serve as examples of their efforts to inform and engage the public. Through strategic messaging, they aim to dispel myths and highlight the life-saving potential of organ donation. At the same time, the marketing and

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community outreach staff connect with the public through events and educational initiatives, increasing awareness in the community. These outreach efforts provide vital information and create opportunities for personal stories and testimonials, which can resonate deeply with individuals and encourage them to consider becoming donors. By building relationships with local organizations and stakeholders, the team cultivates a supportive network that reinforces the importance of organ donation and inspires collective action.

There are many external stakeholders in addition to internal stakeholders. Ensuring these external stakeholders are included is vital in promoting community organ donation awareness. At the core are patients and families whose experiences and stories inspire others to consider becoming donors, along with donor families who share powerful testimonials that highlight the impact of organ donation. The general public is a crucial audience; increasing awareness fosters greater understanding and support for organ donation initiatives. Government agencies support public education campaigns, elevating organ donation as a public health priority. At the same time, nonprofit organizations and advocacy groups work to address cultural sensitivities and build trust within diverse communities.

Finally, the key stakeholders that can make the most significant impact are the community and religious leaders. They can guide their community members with facts regarding organ donation. Combining all the internal and external stakeholders genuinely forms a very powerful network. They must work together to help promote organ donation, engage diverse populations, and create a supportive environment, increasing donor registrations and saving lives.

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In conclusion, addressing organ donation awareness and registration among minority ethnic groups requires a multifaceted approach that includes various educational methods, religious leaders, and global efforts. By addressing these barriers and promoting education and empowerment, we can work towards increasing organ donation rates and promoting healthier lifestyles for all.

### **Methodology**

#### **Setting/Population**

The target population was North Philadelphia area community members and Temple Hospital employees. After the approval of their organization leaders, participants were invited to an in-person educational session at their institution.

#### **Implementation Plan:**

##### **Procedures Involved in the Human Research**

- Participants were invited to an in-person educational session at their institution after the approval of their organization leaders.
- Upon arrival, participants were provided a copy of the consent form with the raffle tickets stapled on the consent form. In addition, they were provided with the pre/post-survey on a piece of paper to make it easier to assess the within-subject design analysis.
- Consent was read to the group, indicating that completing the surveys was giving consent and was entirely voluntary.
- Participants were asked to complete the pre-survey.
- The project lead then provided the educational material to the participant.
- Upon completing the educational program, the project lead instructed the participants to complete the post-survey and answer any questions they may have had.
- The project lead collected the surveys after they were completed. If both surveys were completed, the project lead collected half of the raffle ticket. Once all surveys and raffle tickets were collected, one random ticket was selected, and a gift card was awarded. The surveys were placed in sealed envelopes and transported to a locked office.

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- Paper survey results were electronically scanned and placed on a password-protected computer. The responses were then entered into a password-protected electronic online survey.
- Once all data was entered, the analysis was conducted.
- Descriptive statistics of the pre/post-test were performed.

### **Protection of Human Subjects**

All paper survey responses were given directly to the project lead upon completion of the educational session. The project lead placed them in a sealed envelope prior to transport. The paper survey responses were scanned into a password-protected computer in a locked office. The responses from the survey results were uploaded to an electronic survey for easier data collation on a password-protected computer. Only the project lead had access to the computer.

### **Outcome Measures**

The desired outcome for this project was not just an increase in knowledge of the organ donation process but a significant shift in the participants' understanding and, consequently, their willingness to become organ donors. Many decades of mistrust in the medical establishment as a whole are one of the root causes of the disparity in organ donation observed in the AA community. Brown et al. (2012) concentrated on well-documented themes that revolve around the lack of awareness, lack of trust in the medical community, fear of premature death, discrimination, and religious beliefs and misconceptions. A notable finding of the research was that in addition to an overall lack of knowledge, most of the participants claimed they were unaware of African Americans' need for organ transplants. The core belief of this project is that with enhanced knowledge, the participants' inclination to contribute to organ donation would significantly rise.

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### **Economic Cost to the U.S.**

Not only does this project aim to increase knowledge and decrease the misconceptions related to organ donation, but it also holds the potential to reduce healthcare costs significantly. By increasing organ donation rates, particularly among African Americans, there is a great potential to alleviate a significant burden on the US healthcare system, particularly those patients receiving hemodialysis who are waiting for a kidney transplant. The US currently ranks as one of the countries with the highest healthcare costs and per capita healthcare spending compared to other countries (Papanicolas et al., 2018). As of December 2023, over 100,000 people were waiting for organ transplants in the US. Of that, 86% are waiting for a kidney (Health Resources & Services Administration [HRSA], 2024).

Those waiting for a kidney transplant also contribute to significant costs to our healthcare system. Those individuals awaiting a kidney transplant are placed on hemodialysis, a treatment that functions as the kidney removing harmful toxins from the body. In 2018, approximately 85% of the 554,000 patients receiving dialysis in the United States were insured by Medicare, significantly straining Medicare programs (Pockros et al., 2021). About 750,000 Americans, or 1% of the Medicare population in the United States, suffer from renal failure, yet their costs represent approximately 7% of the program's overall spending. Medicare spent over \$24% of its overall budget in 2022—roughly \$153 billion—on individuals with renal disease. Medicare's spending on End Stage Renal Disease (ESRD) has risen gradually from \$47.1 billion in 2010 to \$53 billion in 2019 (National Kidney Foundation, 2022). The average yearly cost of hemodialysis treatment to the Medicare system in the United States is \$90,000 per patient, or \$28 billion. In contrast, transplant patient care costs \$3.4 billion (National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases [NIH], 2019).

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Another desired outcome is an overall assessment of the educational program and its effectiveness. By evaluating the survey results, it was to be determined if the education content was making any significant impact on the subject's knowledge base on organ donation. Those same results can help identify areas where the education content can be improved to achieve better results or feedback. The most desired outcome would be to see a rise in subjects' willingness to be an organ donor, which would significantly affect not only the total yearly cost of treatment for individuals receiving hemodialysis but also help to address the long list of those still waiting for an organ transplant. This outcome would be determined from those who completed the surveys and were not organ donors before the education, who then decided to become organ donors after the education.

### **Sample**

For this project eligible participants must have been at least 18 years old and capable of providing informed consent. Additionally, they must have been proficient in English, which helped facilitate effective communication throughout the project.

The exclusion criteria were adults who were unable to consent for themselves, those younger than 18 years of age, and individuals who did not understand English.

### **Data Analysis**

A power analysis was conducted in G\*Power 3.1.9.7 to determine the minimum sample size target. The primary inferential analysis used was a paired sample *t*-test. With a medium effect size ( $d = 0.5$ ), a power of .80, and a significance level of .05, a minimum of 34 participants would be sufficient for the data collection and analysis.

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Frequencies and percentages will be used to summarize the survey responses. Paired sample t-tests were conducted to examine differences in participants' perceptions between pretest and posttest. Statistical analysis was conducted using Intellectus Statistics™ statistical software.

This Quality Improvement project aimed to determine whether education focused on addressing the myths and misconceptions surrounding the organ donation process within the African American community would improve the organ donation process and subsequent donation rate. In this section, the findings of the data analyses will be presented.

### **Pretest Survey Items**

The sample consisted of 51 participants. A majority of participants were Black or African American ( $n = 40$ ; 78.43%). Approximately half of the sample ( $n = 24$ ; 47.06%) had an organ designation on their driver's license or State ID card. In regard to participants, previous thoughts about organ donation, 27 participants (52.94%) indicated that hospitals check their driver's license for their donor designation status, 16 participants (31.37%) indicated that organ donation is against major religions, 11 participants (21.57%) indicated that hospitals would not do any heroic measures to save your life if you are an organ donor, and nine participants (17.65%) indicated they were not eligible to be an organ donor due to their past medical history. Most participants indicated that they did not know anyone who was in need of an organ transplant ( $n = 31$ , 62.00%), did not know anyone who was currently on dialysis ( $n = 27$ , 55.10%), or did not know anyone who was waiting for a kidney transplant ( $n = 27$ ; 54.00%). Frequencies and percentages for the pretest survey items are presented in Table 1.

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**Table 1**

*Pretest Survey Items*

Pretest Survey Items	<i>n</i>	<i>%</i>
Ethnicity		
White or Caucasian	4	7.84
Black/African American	40	78.43
Hispanic/Latino	5	9.80
Asian/Pacific Islander	2	3.92
Do you have the organ designation on your driver's license or State ID card?		
Yes	24	47.06
No	27	52.94
What have you heard about organ donation before this lecture?		
1) Hospitals check your driver's license for your donor designation status		
Yes	27	52.94
No	24	47.06
2) Organ donation is against some major religions		
Yes	16	31.37
No	35	68.63
3) If you are an organ donor, hospitals will not do any heroic measures to save your life		
Yes	11	21.57
No	40	78.43
4) I am not eligible to be an organ donor due to my past medical history		
Yes	9	17.65
No	42	82.35
Do you know anyone who is currently in need of an organ transplant?		
Yes	19	38.00
No	31	62.00
Do you know anyone who is currently on dialysis?		
Yes	22	44.90
No	27	55.10
Do you know anyone who is waiting for a kidney transplant?		
Yes	23	46.00
No	27	54.00

A majority of participants ( $n = 41, 82.00\%$ ) indicated that it was “false” that doctors and nurses check your driver's license for donor designation status when admitted to the hospital. Most

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participants ( $n = 38$ , 76.00%) indicated that it was “true” that the only absolute rule for organ donation is metastatic cancer. A majority of participants ( $n = 45$ ; 90.00%) indicated that it was false that organ donation is against the Islamic religion. After hearing the presentation, 21 participants (42.00%) indicated that they would consider adding organ donation to their driver’s license. Most participants ( $n = 29$ ; 58.00%) indicated that their biggest fear about organ donation had been addressed, while 18 participants (36%.00) did not have a fear to begin with. Frequencies and percentages for the post-test survey responses are presented in Table 2.

**Table 2**

*Posttest Survey Items*

Posttest Survey Items	<i>n</i>	<i>%</i>
When admitted to the hospital, doctors and nurses check your driver’s license for donor designation status.		
True	9	18.00
False	41	82.00
The only absolute rule out for organ donation is metastatic cancer.		
True	38	76.00
False	12	24.00
Organ donation is against the Islamic Religion		
True	5	10.00
False	45	90.00
After hearing this presentation, would you consider adding organ donation to your driver’s license?		
Yes	21	42.00
No	10	20.00
Already an organ donor	19	38.00
Was your biggest fear around organ donation addressed?		
Yes	29	58.00
No	3	6.00
Did not have fears to begin with	18	36.00

A paired sample *t*-test was conducted to assess for changes in participants’ likeliness to have conversations with family about organ donation. A paired *t*-test is appropriate when

## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

analyzing differences in a continuous-level variable between two points in time (Pallant, 2020). The independent variable corresponded to the intervention, with two levels: pretest and posttest. The dependent variable corresponded to participants' likeliness to have conversations with family about organ donation, with possible scores ranging from 0-10.

Prior to analysis, the assumption of normality was tested on the data using a Shapiro-Wilk test. The results of the Shapiro-Wilk test were statistically significant,  $W = 0.88, p < .001$ , indicating that the data did not support the assumption of normality.

The result of the paired  $t$ -test was statistically significant,  $t(48) = -4.66, p < .001$ , indicating a significant difference in participants' likeliness to have conversations with family about organ donation. Scores increased from 6.59 to 8.39 between pretest and posttest, indicating a higher likelihood of discussing organ donation with family members. Due to the assumption of normality not being supported, a non-parametric Wilcoxon-Signed Rank test was conducted as a follow-up analysis. The findings of the Wilcoxon-Signed Rank test were also statistically significant,  $z(48) = -3.95, p < .001$ , providing further evidence of a significant increase in participants' ratings between pretest and posttest. The findings of the paired  $t$ -test are presented in Table 3. A bar chart of the means is presented in Figure 3.

**Table 3**

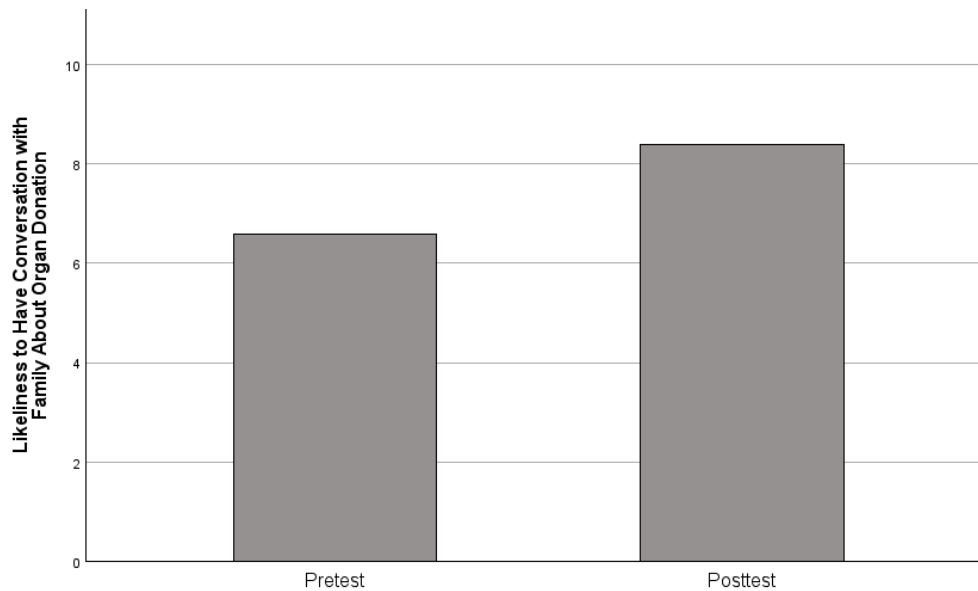
*Conversation with Family About Organ Donation*

Variable	Pretest		Posttest		$t(48)$	$p$
	$M$	$SD$	$M$	$SD$		
On a scale of 0 to 10, how would you rate your likeliness to have a conversation with your family about organ donation at this time?	6.59	3.43	8.39	2.23	-4.66	<.001

## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

**Figure 3**

*Conversation with Family About Organ Donation*



### **Current Knowledge About the Organ Donation Process**

A paired sample *t*-test was conducted to assess changes in participants' knowledge about the organ donation process. The independent variable corresponded to the intervention with two levels: pretest and posttest. The dependent variable corresponded to participants' knowledge about the organ donation process, with possible scores ranging from 0 to 10.

Prior to analysis, the assumption of normality was tested on the data using a Shapiro-Wilk test. The results of the Shapiro-Wilk test were statistically significant,  $W = 0.95$ ,  $p = .036$ , indicating that the data did not support the assumption of normality. Therefore, a non-parametric Wilcoxon-Signed Rank test was conducted as a follow-up to the proposed initially paired *t*-test.

The result of the paired *t*-test was statistically significant,  $t(48) = -7.03$ ,  $p < .001$ , indicating a significant difference in participants' knowledge about the organ donation process. Scores increased from 5.43 to 8.37 between pretest and posttest, indicating increased knowledge about organ donation. Due to the assumption of normality not being supported, a Wilcoxon-

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Signed Rank test was conducted. The findings of the Wilcoxon-Signed Rank test were also statistically significant,  $z(48) = -5.06, p < .001$ , providing further evidence of a significant increase in participants' ratings between pretest and posttest. The findings of the paired  $t$ -test are presented in Table 4. A bar chart of the means is presented in Figure 4.

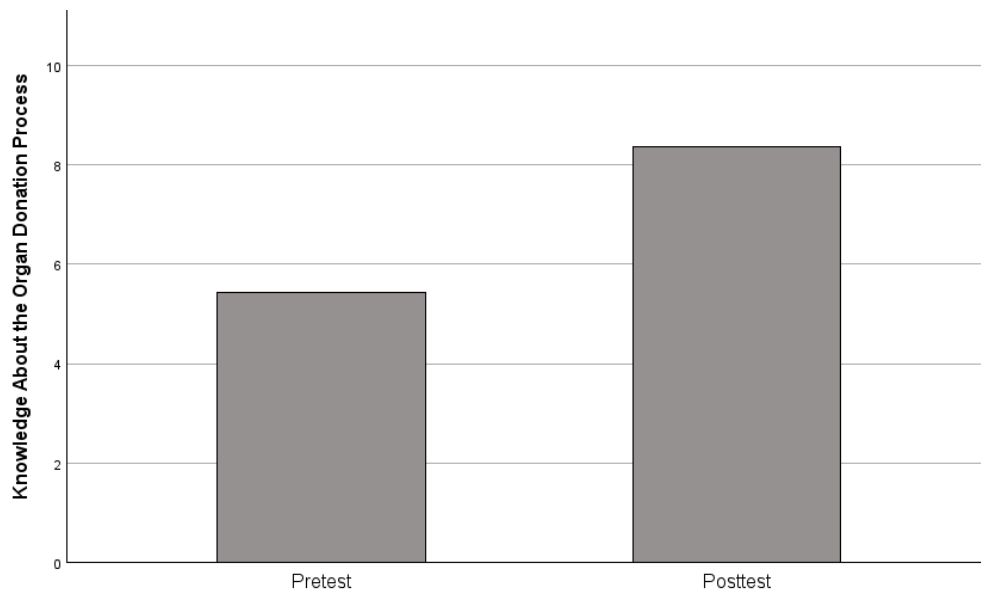
**Table 4**

*Knowledge About the Organ Donation Process*

Variable	Pretest		Posttest		$t(48)$	$p$
	$M$	$SD$	$M$	$SD$		
On a scale of 0 to 10, how would you rate your current knowledge about the organ donation process?	5.43	3.07	8.37	1.74	7.03	< .001

**Figure 4**

*Knowledge About the Organ Donation Process*



## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

### Organ Designation on Driver's License

Among the 26 participants at the pretest who indicated “No” to having an organ designation on their driver's license or state ID card, 18 (69.23%) changed their response to a “Yes” at the post-test. Table 5 presents the crosstabulation for the comparisons at the pretest and posttest.

**Table 5**

*Organ Donation Added to Driver's License (Pretest vs Posttest)*

Variable	Pretest: Do you have the organ designation on your driver's license or State ID card?	
	Yes	No
Posttest: After hearing this presentation, would you consider adding organ donation to your driver's license?		
Yes	3 (12.50%)	18 (69.23%)
No	2 (8.33%)	8 (30.77%)
Already an organ donor	19 (79.17%)	0 (0.00%)
Total	24 (100.00%)	26 (100.00%)

### Discussion

The improvement project's findings provide significant insight into the power of education and participants' views on organ donation. Most participants were African American (78.43%), as the project targeted a predominantly African American area in North Philadelphia.

Before the educational session, many of the participants surveyed did indeed have misconceptions about organ donation. Of significance, many (52.94%) believed that hospitals checked driver's licenses for donor designation upon arrival at the hospital. Many (31.37%) also were under the impression that organ donation was not permissible by some major religions. These misconceptions validated the existing evidence that the knowledge gap that exists may

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contribute to a hesitancy to organ donation. After the presentation, these misconceptions were largely addressed, with 82% of participants correctly stating that doctors do not check driver's licenses for donor status upon admission. This shift indicates that targeted educational efforts can effectively alter misconceptions and enhance understanding of the organ donation process.

A significant outcome was the increase in participants' likelihood to discuss organ donation with family, rising from an average rating of 6.59 to 8.39 post-intervention. This change suggests that the educational session improved knowledge and influenced participants to discuss organ donation with their loved ones.

The analysis revealed a notable change in attitudes towards organ donation designation. Among participants who initially indicated they did not have an organ designation on their driver's license, 69.23% expressed a willingness to add this designation after the presentation. This dramatic shift emphasizes the potential of educational interventions to influence knowledge and behavior regarding organ donation.

Most participants (58%) said the presentation had alleviated their primary concerns about organ donation. This is a crucial element since fears and misconceptions may substantially impede organ donation rates. The education provided must continue to address these concerns, ensuring that the knowledge is conveyed in a manner that is both effective and culturally appropriate.

The findings highlight the efficacy of focused educational interventions in enhancing knowledge, addressing misunderstandings, and promoting discussion around organ donation. The observed changes in knowledge and attitudes underscore the potential of such programs to enhance organ donation rates.

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### **Limitations/Barriers of the Study**

The project met several barriers in its effort to promote organ donation throughout the community. One of the project's most challenging aspects was identifying the primary contacts at local organizations. Not having a point of contact slowed down the ability to contact community leaders directly to inform them of the project. In addition, scheduling challenges occurred after finding the point contact, as many organizations were unavailable during the summer months or did not offer any educational workshops. The overall lack of awareness regarding the potential impact of organ donation on the community exacerbated the situation and restricted engagement.

In addition, the limited time frame of only six to eight weeks to establish contacts and coordinate a program proved challenging. Recruitment letters and flyers were distributed to more than 50 local religious organizations in the vicinity of Temple University Hospital; however, no responses were received. Despite the evidence presented regarding the positive effects of organ donation, the need for more involvement emphasized a broader reluctance to change. Many individuals remained skeptical. These challenges continue to underscore the complexity of our goal and the importance of ongoing efforts to promote knowledge and encouragement within the community.

### **Implications for Nursing Practice**

The implications for nursing practice regarding organ donation are very complex. One of the most critical issues is the need for nurses to know about organ donation. Unless nurses are directly involved in the care or management of an organ donor patient, their knowledge is poor. This lack of understanding can hamper their ability to educate patients and families about the organ donation process, which could be critical for informed decision-making should an opportunity for organ donation arise.

## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

To address this, nurses must be equipped with a toolbox that includes education about the organ donation process and common myths and misconceptions. The training should also include strategies for effectively communicating with patients and families about sensitive topics such as people's fears or misconceptions. Ensuring that nurses have all the right tools can play a critical role in helping to promote a better understanding of the organ donation process for their patients and families.

Policy development and advocacy are other areas in which nurses could play a vital role. Current policy issues around organ donation awareness in the U.S. include addressing disparities in donor registration, particularly among underserved and minority populations, and exploring the shift from an opt-in to an opt-out system to increase donor participation. Efforts to improve public awareness also focus on cultural sensitivity, combating misinformation, and utilizing digital platforms for outreach. Additionally, there is an ongoing push to enhance healthcare provider training and build public trust in the organ donation and allocation process. We need nurses who can be champions fighting to support policies that help garner more awareness around organ donation initiatives (United Network for Organ Sharing [UNOS], 2023). Through advocacy, nurses can help create an atmosphere that promotes organ donation and streamlines the process for potential organ donors.

Research is crucial for improving nursing practices related to organ donation, and more research is necessary to explore the issues faced by diverse populations. The nursing profession may significantly enhance organ donation rates by undertaking research that further assesses the effectiveness of education initiatives and tailored communication strategies.

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### **Sustainability Plan**

To ensure the sustainability of an educational program promoting organ donation awareness, it is essential to identify and involve key personnel who can support the implementation of change. Collaborating with organizations such as local Organ Procurement Organizations such as Gift of Life, local public health departments, and the Organ Donation Committee at Temple University Hospital is crucial. These organizations bring valuable resources and expertise that can enhance the program's effectiveness and reach within the community.

Specific indicators will be essential for assessing the program's effectiveness. Following educational sessions, pre- and post-surveys will continue to offer insights into participants' comprehension and perspectives about organ donation. Furthermore, monitoring new organ donor registration figures and organ donation rates within the African American community would help validate the program's success in meeting its objectives and engaging its intended demographics.

Activities in the community that include organizations such as Gift of Life are essential for cultivating awareness and confidence. Engaging in tabling activities provides a critical chance to begin discussions around organ donation among community members. Nevertheless, it is imperative to acknowledge that the educational content provided during these events is frequently insufficient, as it is limited to two to three minutes. Participants must be granted uninterrupted time to engage with the content and analyze the information to develop a more profound comprehension.

A comprehensive approach that addresses all the aspects discussed can enhance the community's understanding of organ donation. This will empower individuals to make informed

## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

decisions by ensuring they are aware of all relevant details, ultimately benefiting the community as a whole.

### **Implications for Future Projects**

When planning future programs for further sustainability, it will be essential to prioritize improving collaboration and relationships with key stakeholders. We recognize and respect their expertise as healthcare professionals, community organizers, and advocacy groups, and developing a more robust partnership with them will only help expand our outreach efforts. Developing a unified message about organ donation through these collaborations can substantially enhance community engagement. In addition, it is imperative to prioritize long-term educational strategies. Customizing such programs to meet the community's specific requirements will ensure that organ donation remains a topic of significance and awareness.

Modifying educational materials is essential to ensure they remain current. Future initiatives should prioritize the development of material that embodies the cultural sensitivities and distinct challenges of varied communities, including the African American community. Modifying the information to align with diverse populations may improve the comprehension and acceptability of organ donation. In addition, the pre-and post-survey outcomes will be evaluated to identify knowledge gaps and highlight areas requiring further educational initiatives. Regular input is essential for making required revisions to the material, ensuring the program's effectiveness.

Lastly, identifying community leaders committed to organ donation will continue to support programs that raise awareness and can enhance local efforts. Giving these community-based leaders the power to lead conversations and drive community projects can raise awareness about organ donation and get more people to sign up. Future projects can build on the sustainable

## IDENTIFICATION OF BARRIERS TO ORGAN DONATION

plan, which will have a long-lasting effect on raising knowledge about organ donation and, ultimately, increase the number of donors in the community.

### **Conclusion**

In summary, implementing an educational session to enhance organ donation awareness within the African American community is critical in reducing disparities in donor registration and strengthening overall health outcomes. This project focused on educating participants about the fears and misconceptions surrounding organ donation, and I learned that addressing these concerns through clear, accurate information significantly improves participants' understanding and willingness to consider organ donation. By providing education on common myths, such as fears about medical neglect or the belief that organ donation is against certain religious teachings, the project helped participants make more informed decisions. The positive impact was evident, as many reported feeling more confident and open to registering as organ donors, reflecting the power of targeted education in overcoming barriers to donation. These sessions can enable individuals and families to make informed decisions by providing culturally sensitive information and promoting open dialogue about the significance of organ donation. Additionally, utilizing targeted outreach strategies and engaging trusted community leaders will increase trust and participation. Ultimately, this initiative contributes to the health and well-being of the entire community by increasing awareness and fostering a more supportive environment for organ donation.

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Appendix A

Site Approval/Administrator Approval Letter (Form E)



Temple University  
College of Public Health  
Department of Nursing

Form E

Administrator Approval Letter

Date: 5/20/2024

Student: Joseph DiMartino

Agency/Site Mentor: Dr. Chaudron Carter

Project Title: Organ Donation Challenges among the African American Community in North Philadelphia

Healthcare Institution: Temple University Hospital

Project Agency Site (unit): Various locations in hospital and surrounding communities

To: Temple University Faculty & Temple University IRB

(Please check the appropriate statement)

This student has my approval to conduct this project on the above unit/agency. I have the authority to provide this approval as indicated by my credentials and title below. I understand that this project is a quality improvement initiative and will utilize an intervention that has been shown in the literature to improve practice. This intervention will become a standard practice on this unit/agency and will be provided to all appropriate patients/staff on the unit.

This student has my approval to conduct this project on the above unit/agency. I have the authority to provide this approval as indicated by my credentials and title below.

Administrator (with credentials): Chaudron Carter, PhD, EdD, RN, NEA-BC

Title: Chief Nurse Exec.

Date: 5-20-24

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Appendix B

Mentor Agreement Form (Form A)

Form A



DNP Project Agency Mentor Agreement Form  
Graduate Nursing Program  
Nursing Department  
College of Public Health  
Temple University

Agency Mentor Name (with credentials): Dr. Chaudron Carter

Agency Mentor Title: Chief Nurse Exec.

Clinical Site Name: Temple University Hospital

Student Name: Joseph DiMartino

Project Title: Identification of Barriers to Organ Donation

I, Chaudron Carter agree to mentor Joseph DiMartino

to support DNP Project planning and implementation of the project at my facility. I agree to do what I can to enable the student to complete the clinical hours and the Project, barring any unforeseen event that would require the clinical experience be suspended for a temporary period of time.

Preceptor Signature: Chaudron Carter Date: 5-20-2024

Appendix C

IRB determination letter of QI Project of Human Subjects Research



Research Integrity & Compliance  
Student Faculty Center  
3340 N. Broad Street, Suite 304  
Philadelphia PA 19140

Institutional Review Board  
Phone: (215) 707-3390  
Fax: (215) 204-4609  
e-mail: [irb@temple.edu](mailto:irb@temple.edu)



Approval for a Project Involving Human Subjects Research that is Approved as Exempt

Date: 09-Jul-2024

Protocol Number: 31722  
PI: AMELIA BIEDA  
Review Type: EXEMPT  
Approved On: 09-Jul-2024  
Risk: Minimal risk  
Committee: A2  
Sponsor: NO EXTERNAL SPONSOR  
Project Title: Organ Donation Challenges among the African American Community in North Philadelphia

The IRB approved the protocol 31722.

The study was approved under Exempt review. The IRB determined that the research **does not require a continuing review**, consequently there is not an IRB approval period.

As this research was approved as Exempt, the IRB will not stamp the consent or assent form(s).

**Note that all applicable Institutional approvals must also be secured before study implementation.** These approvals include, but are not limited to, Medical Radiation Committee ("MRC"); Radiation Safety Committee ("RSC"); Institutional Biosafety Committee ("IBC"); and Temple University Survey Coordinating Committee ("TUSCC"). Please visit these Committees' websites for further information.

**Finally, in conducting this research, you are obligated to submit the following:**

- **Amendments - Any changes to the research that may change the Exempt status of this study must be reviewed and approved by the IRB prior to implementation.** Examples of such changes are: including new, sensitive questions to a survey or interview, changing data collection such that de-identified data will now be identifiable, including an intervention in the methods, changing variables to be collected from medical charts, decreasing confidentiality measures, including minors or adults lacking capacity to consent as subjects when previously only adults with capacity to consent were to be enrolled, no longer collecting signed HIPAA Authorization, etc. Please reach out to the IRB Staff with any questions about if a change to the study warrants an Amendment.
- **Reportable New Information** - Using the Reportable New Information e-form, report new information items such as those described in HRP-071 Policy - Prompt Reporting Requirements to the IRB **within 5 days**.
- **Closure report** - Using a closure e-form, submit when the study is permanently closed to enrollment; all subjects have completed all protocol related interventions and interactions; collection of private identifiable information is complete; and analysis of private identifiable information is complete.

**For the complete list of investigator responsibilities, please see the HRP-070 Policy – Investigator Obligations, the Investigator Manual (HRP-910), and other Policies and Procedures** found on the Temple University IRB website: <https://research.temple.edu/irb-forms-standard-operating-procedures>.

Please contact the IRB at (215) 707-3390 if you have any questions.

# IDENTIFICATION OF BARRIERS TO ORGAN DONATION

## Appendix D

### Instruments

#### *Pre Survey*

##### Organ Donation Pre-Education Survey

The purpose of this survey is to help us continue improving our education efforts. Participants who complete the pre- and post-survey will be entered into a drawing for a Gift Card.

1. Do you have the organ donor designation on your driver's license or state ID card? Circle yes or no.

- Yes
- No

2. What have you heard about organ donation before this lecture? Circle what you've heard.

- Hospitals Check Your Driver's License for Your Donor Designation Status
- Organ Donation is Against Some Major Religions
- If you are an organ donor, hospitals will not do any heroic measures to save your life
- I am not eligible to be an organ donor due to my past medical history

3. Do you know anyone who is currently in need of an organ transplant? Yes or No

- Yes
- No

3. Do you know anyone who is currently on dialysis? Circle Yes or No

- Yes
- No

4. Do you know anyone who needs a kidney transplant? Circle Yes or No

- Yes
- No

5. On a scale of 0 to 10, 0 being very unlikely and 10 being very likely, how would you rate your likeliness to have a conversation with your family about organ donation at this time? (Circle One)

0 1 2 3 4 5 6 7 8 9 10

Very unlikely-----Very Likely

6. On a scale of 0 to 10, 0 being not at all and 10 being extremely well, how would you rate your current knowledge about organ donation and the process? (Circle One)

0 1 2 3 4 5 6 7 8 9 10

Not at all-----Extremely well



**Do not proceed to the back until instructed.**



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## *Post Survey*

### Organ Donation Education Post-Presentation Survey

The purpose of this survey is to help us continue improving our education efforts. Participants who complete the pre- and post-survey will be entered into a drawing for a Gift Card.

Answer the following questions by circling true or false:

1. When admitted to the hospital, doctors and nurses check your driver's license for donor designation status.

- TRUE
- FALSE

2. The only absolute rule out for organ donation is metastatic cancer.

- TRUE
- FALSE

3. Organ donation is against the Islamic religion.

- TRUE
- FALSE

4. After hearing this presentation, would you consider adding organ designation to your driver's license or state ID card? Circle one

- YES
- NO
- Already an organ donor

5. Regardless of if you are in favor of organ donation or no, after hearing this presentation, on a scale of 0 to 10, 0 being very unlikely and 10 being very likely, how would rate your likeliness to talk to your family about your wishes around organ donation.

0 1 2 3 4 5 6 7 8 9 10

Very unlikely-----Very Likely

6. After hearing this presentation, on a scale of 0 to 10, 0 being not at all and 10 being extremely well, how would you rate your current knowledge about organ donation and the process? (Circle One)

0 1 2 3 4 5 6 7 8 9 10

Not at all-----Extremely well

*Thank  
You!*

Recruitment Tool



**Addressing Fears and Misconceptions About Organ Donation:**  
*A New Educational Program*

**Now scheduling research programs at your choice of location including community events, houses of worship, and more!**

**THE ORGAN TRANSPLANT WAITING LIST**  
July 2024

<p><b>4,866</b> Total Waiting In Our Region</p> <p>4,248 Kidney 370 Liver 111 Heart 98 Lung 126 Kidney &amp; Pancreas 28 Pancreas 2 Heart &amp; Lung</p>		<p><b>523</b> Total Waiting at Temple University Hospital</p> <p>422 Kidney 12 Liver 5 Heart 66 Lung 22 Kidney &amp; Pancreas 0 Pancreas 0 Heart &amp; Lung</p>
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**GET IN TOUCH**

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# IDENTIFICATION OF BARRIERS TO ORGAN DONATION

## Appendix E

### Project Timeline

#### Project Timeline

Organ Donation Challenges among the African American Community in North Philadelphia

<b>Stage</b>	<b>Activity</b>	<b>Date or Time Period</b>
<b>PLAN</b>	Define the problem around Organ Donation	Jan 2024
	Review baseline data from 2022 and 2023 from Temple Hospital around Donation Rates and by ethnicity.	Feb 2024
	Create Education around Fear and Misconception and Survey tool	April 2024
	Review baseline results and identify underlying causes and interventions.	May 2024
<b>DO</b>	Implement Interventions of Educational Sessions with Survey distribution	August/September 2024
<b>CHECK</b>	Post-intervention data collection, analysis, and report preparation	September/October 2024
<b>ADJUST/REPLAN</b>	Review post-intervention results and identify underlying causes and adjustments that may need to be made.	November/December 2024

# IDENTIFICATION OF BARRIERS TO ORGAN DONATION

## Appendix F

### Project Budget

#### Budget Chart

Organ Donation Challenges among the African American Community in North Philadelphia

<b>Item</b>	<b>Cost to Repeat this Study</b>	<b>Cost to the Project</b>
Paper for Surveys/Recruitment flyers	One time cost	\$10
Raffle Tickets	One time cost	\$10
Wawa Gift Cards	\$10 x 4 sessions	\$40
Recruitment Posters	\$50 x 2	\$100
Salary for personnel delivering educational lecture	Volunteered	Volunteered
Costs=	Projected=\$480	Actual=\$480

IDENTIFICATION OF BARRIERS TO ORGAN DONATION