Title Page

**An Analysis of Community Health Needs Assessments Among Top Kidney Transplanting Medical Centers: Recommendations for Community-Based Care and Transplantation Education**

by

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**Abstract**

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Terrence Michael Arañez Litam, MHA

University of Pittsburgh, 2020

**Abstract**

The shortage of available kidneys for transplantation in the United States presents a public health crisis that causes the death of 12 individuals a day on average. The top 10 kidney-transplanting hospitals (by 2018 volume) were assessed for programs related to kidney transplantation or kidney transplantation education. Two model organizations focused on increasing transplantation are offered as models for best practices or possible partners for healthcare organizations to take advantage of: the Minority Organ Tissue Transplantation Education Program and the National Kidney Foundation. Best practices for community engagement are offered to foster the initiation of community-based interventions to aid in screening and managing of chronic kidney disease to reduce the demand for life-saving kidney transplants and aid the reduction of organ shortage. This is relevant for public health because of the use of a community-based intervention to help reduce the demand for life-saving kidneys which the national supply cannot meet.

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List of Acronyms

CHNA: Community Health Needs Assessments

IP: Implementation Plans

PPACA: Patient Protection and Affordable Care Act, (AKA the ACA)

CKD: Chronic Kidney Disease

ESRD: End-Stage Renal Disease

OPTN: Organ Procurement and Transplantation Network

CHW: Community Health Worker

CAB: Community Advisory Board

SMOG: The Simple Measure of Gobbledygook

MOTTEP: Minority Organ and Tissue Transplantation Education Program

NKF: National Kidney Foundation

HUTC: Howard University Transplant Center

SEM: Social-Ecological Model

CDC: Centers for Disease Control and Prevention

Preface

A special thanks to my essay committee from whom I’ve learned a lot both in and out of the classroom. To Dr. Degenholtz for always making himself available and taking point as my advisor in addition to helping me get from mental point A to B, bridging the gap to where I was to where I wanted to be for this essay. To Dr. Terry for being one of my first forays into proper consideration of what community care and community principles look like. The heart of my program lays within these classes. And to Drs. Documét and Terry, the input you’ve both always given me in this essay process in addition to your perspectives in Center for Health Equity journal clubs always makes me deepen my reflection and further the discussion of several health equity issues.

Notable thanks to my siblings and their partners who supported me in different ways throughout my academic journey and acted as role models in various capacities. Thank you especially to my parents, Elmie and Patrick, who instilled the values I carry today that enabled me to succeed whether that be in terms of academic success, emotional awareness, or social capabilities.

 Special thanks to my graduate role models, especially from research at Ohio State. Drs. Strayhorn and Travers, I owe you both a lot of gratitude for giving me those training grounds in my undergrad. I’d be much less prepared without my exposure to both of you for sure.

Finally, thank you to my partner, Dominic, who set my head straight when I wasn’t sure how to get it to stop spinning, had to many times answer rhetorical questions, and deal with my multiple bad moods from stressful situations.

# Introduction and Background

Kidney transplantation is a public health concern in that the supply of transplantable kidneys has not been able to meet the demand. In 2018, an average of 12 people died every day waiting for a life-saving kidney transplant in the United States1(US). Kidney transplantation is an ideal target given that it both constitutes the majority of total transplants every year (see Appendix A) and that several chronic diseases that act as contributing factors towards needing a kidney transplant are well understood. This essay initially aimed to analyze only the top 10 kidney-transplanting programs in the US by volume (according to 2018 counts) and assess whether transplantation and transplantation education-related programs are cited in their Community Health Needs Assessments (CHNAs) and Implementation Plans (IPs). This process revealed that most health systems neglect to explicitly mention transplantation and related education programs in their CHNA and IPs. Therefore as an extension, this paper explores best practices health systems can utilize towards developing an effective community-based program for screening and managing Chronic Kidney Disease (CKD) which often progresses to necessitating dialysis or a kidney transplant for survival. The goal of being able to develop a successful CKD management program serves two purposes. First, it can potentially reduce the increasing need for kidney transplants by slowing the progression of chronic disease necessitating a transplant and second can provide education both in the form of being able to find avenues for accessing resources to manage their conditions as well as to be aware of transplantation as an option.

Within the Patient Protection and Affordable Care Act of 2010, more stringent requirements were implemented for not-for-profit hospitals in order to maintain their tax-exempt status. One specific aspect of this includes a CHNA and IP being conducted at least every three years. The CHNA is a public facing document evaluating existing and developing needs within a hospital’s community whereas the IP then takes those findings and either addresses how it will adjust its capacity to meet those significant needs or otherwise explain why it cannot or will not2. If a hospital fails to conduct a CHNA and IP every three years or produces an insufficient community analysis, it can face a fine of up to $50,000 for each non-compliant year as well as potentially losing its not-for-profit designation3. Such a loss could severely damage operations given that a healthcare institution’s not-for-profit designation allows access to tax-exempt loans at lower interest rates compared to similarly situated for-profit competitors in addition to relieving it from having to pay some federal and state corporate taxes and local property taxes4. It behooves a healthcare entity to develop a robust CHNA and strategic IP to show its commitment to serving its community.

With every three-year iteration of the CHNA and IP, a health system evaluates its strengths in terms of its programs and develops new or improved methods for meeting community needs. While the volume of transplants and transplantation programs themselves may speak to a community orientation, a community-based program for CKD and End-Stage Renal Disease (ESRD) management can be a valued program both by the community as a form of managing its health status and to the hospital in terms of future cost-savings and fulfilling its obligation to the local communities they serve.

Providing community-based programs also serves the health system by providing secondary prevention and reducing cost of CKD as well as ESRD. For CKD in 2016, $79 billion was spent in Medicare claims. The terminal stages of CKD which are labeled as End State Renal Disease (ESRD) was estimated to cost Medicare $35.4 billion dollars in 2016 which accounted for 7.2% of all Medicare paid claims. Collectively between CKD and ESRD, $114 billion was spent from Medicare to provide for these conditions alone5.

CKD presents in five stages that are defined by the kidney’s function as measured primarily by glomerular filtration rates shown in Table 16:

Table 1: Chronic Kidney Disease Stages by Glomerular Filtration Rate (GFR)

|  |  |
| --- | --- |
| **Stage** | **Glomerular Filtration Rate (GFR) in mL/min per 1.73m2** |
| Stage 1: Kidney damage with normal functioning | ≥90 |
| Stage 2: Kidney damage with mild loss of functioning | 60-89 |
| Stage 3: Mild-to-severe loss of kidney functioning | 30-59 |
| Stage 4: Severe loss of kidney function | 15-29 |
| Stage 5: Kidney failure requiring dialysis or transplantation for survival. “End-Stage” | <15 |

It is imperative for individuals to *know* if they are beginning to lose kidney function because being able to provide secondary prevention by treating earlier stages helps to reduce costs in further stages and especially in ESRD. Most individuals in the first three stages do not realize they have the beginning of CKD because their day-to-day life feels unaffected. According to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), on average less than 10% of those afflicted with CKD are aware they have it based on data collected from cohorts from 2001-2004, 2005-2008, and 2009-2012. Awareness is higher at stage 4 where 35-45% of those afflicted are aware of their status6. This presents an opportunity for a community-based program to not only provide linkage to services and complement a health system’s capacity but also provide reliable and accessible screening programs so vulnerable populations know their kidney health status.

 It is especially important for minority populations to know their status given their increased genetic and social predisposition to developing risk factors that contribute to CKD. For African Americans, one paper estimated 60% of factors contributing to poor CKD outcomes are due to social determinants of health across behavioral patterns, social circumstances, and environmental exposures. The other 40% is broken down as 30% genetic predisposition and 10% health care quality7. Five main domains mediate the idea of social determinants of health: Economic Stability, Education, Neighborhood/Built Environment, Social/Community Context, and Health/Health Care Access. Examples of each domain can be found in Table 27.

Altogether when compared to Caucasians, African Americans are especially risk-prone to developing ESRD. Their prevalence is 3.7 times greater compared to Native Americans (1.4 times) and Asians (1.5 times) 6. Combined with the lack of awareness at earlier stages of CKD, the increased prevalence of ESRD demonstrates a significant risk to minority populations and African Americans especially.

Table 2: Social Determinant of Health Domains and Contributing Factors

|  |  |
| --- | --- |
| **Social Determinant Domain** | **Contributing Factors** |
| Economic Stability | Income, Employment, Food Security, and Housing Stability |
| Education | Language and Literacy; Early Childhood, Primary, Secondary, and Higher Education; Vocational Training |
| Neighborhood/Built Environment | Housing Safety, Access to Nutritious Foods and Recreation, Transportation and Mobility, Social Order and Walkability, Environmental Exposures |
| Social/Community Context | Social Norms, Networks & Culture; Mistrust of Outsiders; Community Engagement; Segregation & Discrimination; Media & Technology Access |
| Healthcare Access | Health Insurance; Health System Accessibility; Health Literacy |

# Objectives

This paper aims to describe a missing opportunity for healthcare institutions to take advantage of, citing their volume in kidney transplantation as a strong competency they are already fulfilling. There are four main objectives:

1. To identify the 10 highest kidney-performing transplantation medical centers in the US and evaluate their CHNAs for mentions of keywords related to transplantation, transplantation awareness, and related education programs,
2. To explain why community-based approaches work best as an area to deploy an effective intervention,
3. To investigate best practices to integrate into an effective intervention prototype, and
4. To propose recommendations for a way for medical systems to evaluate the strengths of their CHNAs with respect to CKD.

# Methodology

The Organ Procurement and Transplantation Network (OPTN) is a website run under the US Department of Health and Human Services that both communicates policies regarding organ or tissue transplantation and allocation also serves as an outlet for transplantation data collection. One of OPTN’s best aspects is its diversity of publicly available data that can be manipulated to create customized tables. Because of this, each transplant center’s live and deceased kidney transplant volume for 2018 could be pulled and exported it as a Microsoft Excel spreadsheet which made sorting the top 10 transplant institutions able to be manually calculated.

After the top 10 kidney-transplanting performing medical centers by volume were determined (see Table 4), the CHNAs corresponding to each institution were pulled and searched using the following keywords related to transplant education information such as “organ,” “tissues,” “transplant,” “kidney,” “graft,” “donor,” “donation,” or “education.” Where a successful match was made based on the keyword, the passage was read to determine if the match truly described a program related to kidney transplantation, education about transplantation, or education about chronic disease management.

A theoretical framework was used to identify gaps between existing CHNAs and a proposed model plan.

## Framework and Identifying Potential Intervention Points

The Social-Ecological model is useful for exploring where interventions can be optimally placed by helping to visualize the interplay between factors that exist at different societal levels. As can be seen in Figure 18, every level has interplay between the sections that are both above and below it. In the context of analyzing for contributing factors to the demand of kidney transplants among African American populations with CKD, an example of a barriers at each level are provided in Table 3.



Figure 1: The Social Ecological Model

Since healthcare systems and non-profit community-based organizations typically operate at the organizational level, it makes sense to primarily focus on interventions that target this level. However, when considering what should be included into a successful intervention, an effective deployment would include aspects relating to interpersonal, individual, and community aspects as well.

Table 3: Examples of Social Ecological Barriers to Management of CKD

|  |  |
| --- | --- |
| **Level** | **Example** |
| Individual | Lack of knowledge about having early stage chronic kidney disease or not perceiving it as a threat to their lifestyle currently. |
| Interpersonal | The availability of live donors who personally know the individual in need of a kidney transplant, given that living donations are higher quality than deceased donations. |
| Organizational | Public health systems and services may not be able to provide convenient or accessible care for self-management. Operating hours at dialysis centers may be an example of this for a working person.  |
| Community | If the predominant attitude of a neighborhood is that individuals look after themselves without interacting with other community members, knowledge about resources or finding social support can be difficult to find. |
| Public Policy | If insurance does not cover certain parts of a care plan, it may be cost-prohibitive, public policy that affects public or private payor restrictions can affect one’s ability to self-manage chronic conditions. |

# Review of Findings

Ten Institutions were analyzed, Jackson Memorial University of Miami (FLJM), University of California – Los Angeles Medical Center (CAUC), University of California – San Francisco Medical Center (CASF), Mayo Clinic Hospital in Arizona (AZMC), Methodist Specialty Transplant Hospital (TXHS), Emory University Hospital (GAEM), University of Wisconsin Hospital and Clinics (WIUW), University of California – Davis Medical Center (CASM), Saint Barnabas Medical Center (NJSB), and University of Alabama Birmingham Hospital (ALUA). Their kidney transplantation volumes can be seen in Table 4. Of the 10 institutions analyzed, five (FLJM, AZMC, GAEM, NJSB, and ALUA) mentioned “transplant” as programs that were offered but nothing with respect to offering education about transplantation as an option. The Transplant Center CASM was notable in that a partnership was explicitly mentioned with the National Kidney Foundation (NKF). The lack of mentioning of educational programs despite having large kidney transplant volumes offers an opportunity for organ and tissue donation education as an element that can be added to a CHNA in the next iteration of analysis. When considering the potential for adding organ and tissue education and transplantation programs as a possible component within a CHNA, there must also be integration into a subsequent IP to ensure that the objective is properly carried out for the community’s service. While hospital environments vary widely over geographical contexts, there are several best practices that should be integrated to make the most impactful community-based interventions which will be discussed later.

Table 4: Top 10 Highest Kidney Transplant Performing Medical Centers, 2018

|  |  |  |
| --- | --- | --- |
| **Medical Center** | **Transplant Center Code** | **Total Kidney Transplants** |
| Jackson Memorial University of Miami10 | FLJM | 433 |
| University of California – Los Angeles Medical Center12 | CAUC | 398 |
| University of California – San Francisco Medical Center12 | CASF | 368 |
| Mayo Clinic Hospital (Arizona)13 | AZMC | 341 |
| Methodist Specialty Transplant Hospital14 | TXHS | 327 |
| Emory University Hospital15 | GAEM | 281 |
| University of Wisconsin Hospital and Clinics16 | WIUW | 281 |
| University of California - Davis Medical Center17 | CASM | 278 |
| Saint Barnabas Medical Center18 | NJSB | 275 |
| University of Alabama (Birmingham) Hospital19 | ALUA | 256 |

With respect to the keyword search, Table 58 describes the findings. For the keywords “Graft,” “Tissue,” and “Donation,” no matches were found and so they were excluded from the table. With respect to the “Education” category, many of the top 10 kidney transplanting institutions mentioned community-oriented education programs covering the subject of healthy lifestyles, chronic diseases overall, or diabetes management. While CHNAs commonly citing education-based programs that seek to target upstream risk factors for CKD is a good sign, education tended to produce results more related to academic centers educating medical classes in specialty care or education as a demographic data point that helped describe the community it serves.

Table 5: Keyword Matches for CHNA Search

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Medical Center** | **“Organ”** | **“Transplant”** | **“Kidney”** | **“Education”** | **“Donor”** |
| FLJM |  | **X** | **X** | **X - CD** | **X** |
| CAUC |  |  |  | **X - CD** |  |
| CASF |  |  |  |  |  |
| AZMC | **X** | **X** |  |  |  |
| TXHS |  |  |  | **X - D** | **X** |
| GAEM |  | **X** |  | **X - LS** |  |
| WIUW |  |  |  | **X - D** |  |
| CASM |  |  | **X\*** | **X - D** |  |
| NJSB |  | **X** |  | **X - D** |  |
| ALUA |  | **X** |  | **X - D** |  |

**\*** Indicates a specific partnership cited with the National Kidney Foundation

X-CD indicates education is referring to chronic disease management overall

X-D indicates life-style changing or teaching skills specifically targeted towards diabetes

X-LS indicates overall lifestyle education pertaining to exercise, healthy eating, or smoking cessation.

## Existing Models

Two predominant educational outreach programs function as national non-profit organization with localized chapters: the National Minority Organ and Tissue Transplantation Program, and the National Kidney Foundation. They use slightly different approaches to transplantation both in terms of scope as well as mission.

### National Minority Organ and Tissue Transplantation Program

In 1978, Dr. Clive Callender was a transplant surgeon at Howard University’s Transplant Center (HUTC). He was asked to investigate leading factors as to why the African American patients in the Washington, DC (DC) area constituted a high proportion of the dialysis population (50-70%) but not of registered donors (3%). Thus African Americans elected to receive a kidney in a greater proportion than they would be willing to donate one. After developing a research plan, Dr. Callender discovered three key takeaways:

1. With respect to evaluating the transplantation data at HUTC, Dr. Callender found that in 1982, 41 of 47 (87%) and in 1982, 48 of 61 (78%) of transplants in HUTC were from Caucasian donors.
2. With respect to ESRD incidence, the 1980 DC incidence was the highest in the nation and the leading cause of ESRD is hypertension. At HUTC, the African American population was about 60%.
3. With respect to analyzing reasons for African American reluctance for organ and tissue donation, five predominant themes emerged. They were as follows
	1. Lack of awareness about renal disease and transplantation as a whole;
	2. Misconceptions and myths pertaining to religion;
	3. Lack of trust in healthcare providers and the healthcare system;
	4. Belief that signing organ donor cards (indicating intent to donate) might shift priority from life-saving measures to organ or tissue recovery and
	5. Fear that racism would allocate African American donated organs and tissues disproportionately to White recipients.

As Dr. Callender engaged with the African American population in the DC area, he conducted focus groups and found that at the beginning of his study, only 10% of those interviewed had signed organ donor cards. But after the focus group populations received culturally competent education about organ donation as well as the opportunity to ask questions of a medical professional, 100% of them signed donor cards. Grounded in the influence his focus groups had, Dr. Callender began developing strategies and in 1991, MOTTEP was founded and continues the mission of seeking to educate minority populations with a culturally-sensitive approach to increase organ donation registrants20.

In its current form, MOTTEP maintains a national office and seven chapters in Cleveland, OH; Detroit, MI; New York City, NY; Pittsburgh, PA; Chicago, IL; Nashville, TN; and Washington DC21. Previous sites include the US Virgin Islands and Honolulu, HI22. Since MOTTEP’s inception in 1991, Dr. Callender has published prolifically to establish MOTTEP as a prominent program that works and has published both its Program Strategies22 (Table 6) and Community-based Health Promotion Model22 (Table 7).

Table 6: MOTTEP Strategies

|  |  |
| --- | --- |
| **Approach** | **Description** |
| Community Participation and Direction | Each localized program aims to include various community members and organizations at each level of planning and implementation for their own community-based activities to meet MOTTEP’s mission and goals |
| Face-to-face presentations | MOTTEP makes presentations at social, civic, and faith-based events to smaller audiences to encourage discussion. |
| Collaboration and partnerships | Collaborating with local organizations towards common missions is important for sustainability and productivity. Since 1995, MOTTEP has collaborated with more than 300 organizations. |
| Media promotion | The media (radio/television/print) helps disseminate MOTTEP’s mission. More than 10 billion media impressions have been created since 1995. |
| Table 6: MOTTEP Strategies (continued) |
| Information Dissemination | MOTTEP develops culturally sensitive and informative brochures, videos, public service announcements, flyers, fact sheets, and other community-targeting information |
| Evaluation | MOTTEP evaluates its programs with pre/post surveys of its program participants to gauge effectiveness. |

Table 7: MOTTEP Community-based Health Promotion Model

|  |  |
| --- | --- |
| **Stages** | **Some Key Elements** |
| Community Analysis | * Defining the community
* Assessing community capacities, barriers and readiness to change
 |
| Design and Initiation | * Establishing a core planning group of community members and organizations, agencies
* Establishing a local MOTTEP organizational structure with clearly defined mission and goals
* Clarifying roles and responsibilities of advisory board staff, members, and volunteers
 |
| Implementation | * Developing community participation
* Developing a strategic plan for activities
* Utilizing multiple strategies to influence community norms
* Integrate community values into program, materials, health messages
 |
| Program Maintenance Consolidation | * Integrating intervention activities into networks
* Establishing regular communication links with other local MOTTEP sites.
* Developing strategies for ongoing recruitment of staff, volunteers for long-term projects
 |
| Dissemination-Reassessment | * Reviewing outcomes from program effectiveness studies
* Updating the community analysis
* Revising the strategic plan accordingly for new directions
 |

### National Kidney Foundation

The National Kidney Foundation aims to advance the awareness, prevention and treatment of kidney disease. Seemingly serving contradictory purposes, on the one hand NKF focuses on awareness and being able to prevent the advancement of chronic kidney diseases to ESRD that would require either dialysis or being listed on the waiting list for a kidney transplant. On the other hand, NKF also is a large proponent of awareness for the option of kidney transplants as a viable option for helping to treat chronic kidney failure and provide a better quality of life for its recipients.

NKF has been instrumental in developing legislation and medicalization around kidney disease, demonstrated in being the first organization to categorize kidney disease as its own separate illness. It has also pushed for dialysis options being made more accessible, passage of the 1968 Uniform Anatomical Git Act which standardized a framework for organ transplantation, ensured Medicare covers ESRD, and developed the conceptualization of the stages of CKD diagnosis and treatment23. More recently, it has developed a primary-care facing strategy termed CKD*Intercept*TM with the goal of improving CKD diagnosis in primary care. An online platform called *Kidney Pathways* evaluates a patient based on their family history, lab results, and medical history to provide targeted education based on kidney health status and ways to help prevent progression into further stages of CKD24.

NKF also pushes the boundaries with being able to integrate new technology into managing multiple patients in one database. This *NKF Patient Network* aims to provide patient education and support based on patients’ stage of disease, comorbidities, medical history, and demographics. It also pools data into one centralized service that allows for analysis of outcomes to further inform what strategies work and should be retained, which should be improved, and which should be cut25.

# Best Practices for Programming and CHNA Evaluation

In order for a community-based intervention to be successful, a partnership between the medical system and the community should be created on terms that both parties can agree to and ensure can be modulated as environmental and regulatory landscapes shift. The following sections aim to provide best practices that should be integrated into any community oriented intervention to ensure its success in developing a sustainable collaboration.

## Best Practices

A paper recently published by Umeukeje et al.26 sought to identify perceived barriers among African American populations for community screenings of kidney disease. These barriers fell into two categories: participant factors and logistic factors. Participant factors included many individual-level barriers such as limited kidney disease knowledge, spiritual or religious beliefs, emotional reactions, and the culture of the individual. Logistic factors tended to be community or organizational level barriers such as lack of convenience or incentives for maintaining care as well as poor advertisement. This paper recommends that screening and treatment efforts could be improved if the logistic barriers were removed such that care could be regularly accessed, that ample education both about the clinical implications of having CKD be provided, services offered to help manage their kidney disease, and to make screening more convenient. Each strategy should be culturally sensitive and ideally partnered with trusted community members to build rapport with the target population and some thought should be given towards providing incentives for participating26. With that being said, some best practices are proposed here when seeking to develop community-based outreach.

### Community Advisory Boards (CAB)

Community Advisory Boards are an essential, flexible tool for ensuring that pertinent stakeholders such as community organizations and health system representatives, as well as community members are brought to the table when it comes to developing the strategy and provision of community-based care. A CAB’s mission, vision, purpose, remunerative policies, and temporality should be established early in its inception so that all participants are fully aware of what activities would be value-adding to the community, and whether succession plans should be developed, who is replaceable, and how. Community Advisory Boards are meant to work both in favor of the health care system by providing the most comprehensive view to deploy the most effective intervention and ensure it is being implemented correctly while the community members are made aware of the intervention and can give feedback towards how to suggest changes to the interventions as they see fit.

### Considering and Integrating Public Health Resources

 Health systems should continually inform themselves about what priorities are being set by their state’s public health departments. Depending on the organizational structure, a state or local public health department may be seeking to provide improved care in a specific area that aligns with developing efforts to productively manage chronic disease. Being able to tap into health department resources can help to synergize and reduce duplication of efforts in similar service areas and in some cases may grant money.

### Community Health Workers (CHW) and Focusing on Strengths, and Capacity Building

Should a neighborhood-based clinic come out of a joint decision between a health system’s leadership and a CAB, its main mission is to improve the health of those in its neighborhood. However, it can ultimately be developed as a venture that can provide healthcare, economic development, and job training to the population it serves. One avenue for achieving these targets can come from using trained Community Health Workers.

Any manager considering using CHWs should be aware of terminology in their state’s licensing laws. Some states or municipalities have stricter guidelines for what CHWs are required to achieve in order to get licensure whereas other states have less stringent, perhaps no, requirements. (Such information can be found here: https://www.astho.org/Public-Policy/Public-Health-Law/Scope-of-Practice/CHW-Certification-Standards-Map/)27. State differences with regard to licensure of CHWs may determine if CHW-related work is reimbursable by public insurances or not. Regardless of legal designation, CHWs are regarded as an important aspect of community-level interventions because they serve as knowledgeable peer navigators who are from the community and are aware of its internal capacity. Multiple studies have described the positive impact from integrating CHWs such as the Colorectal Cancer Male Navigation Program, which helped both increase participants’ life expectancy and save more than $1,100 per patient compared to non-participants27.

 While the specialized knowledge specific to managing chronic conditions is in no way limited to CHWs, one strength they bring to a multidisciplinary team stems from the cultural capital they bring with them that will help them engage their own communities. Strong examples come from communities that have a high prevalence of bilingualism or where the community has an attitude of mistrust towards healthcare systems. CHWs also tend to have a better inventory of what their community capacity can fulfill and what leverageable resources have yet to be tapped to their fullest potential28. Additionally, when serving populations that may have more entrenched distrust of the medical system, having representatives from one’s community is more acceptable than having someone from the medical system doing the frontline work29. By collaborating with a health system, ideally a proper mix of cultural, social, economic, and intellectual capital is brought together to best impact a localized issue with a community-based program.

 By using CHWs, collaboration focuses on a community’s strengths seeks to build on existing community infrastructure. By focusing on developing a community’s capacity to complement its own needs, it becomes empowered and creates an example of what a strong collaboration can accomplish. Especially for communities that had been wary of medical systems, a productive collaboration can create a foundational program that helps develop sustainable partnerships.

### Targeting Health Literacy and Incorporating Cultural Humility

Health literacy is an essential consideration for addressing a community’s average educational attainment level and separating the skills of speaking a language and reading or writing. Some readability tests such as the Simple Measure of Gobbledygook (SMOG) assess a document’s readability by counting sentences at the beginning, middle, and end of a document (or the entire document if it is less than 30 sentences) and tallys how many words in each section have three or more syllables. This aggregate number is then compared to a SMOG table (see Appendix B)30 which relates it to a reading grade level. Being able to adjust for readability is essential both for printed and electronic media to ensure that the targeted population is able to incorporate all of the information needed to inform their best health choices.

Cultural humility is a way of developing a process-oriented approach to cultural competency. Three factors guide this construct: having a lifelong commitment to learning with internal evaluation and critique, inherently wanting to fix power imbalances that affect social determinants of health, and developing partnerships with people and groups who advocate for others31. Integrating a cultural humility-informed approach allows the hybridization of information from academic research that may not be completely generalizable to the target population and complementing that research with community feedback. Thus, cultural humility allows a proper community assessment to be done from the top down but that is also strengthened by the contextualization of academic research the community itself to fill in gaps in knowledge.

## Assessing CHNA and IP Strength

 When assessing the strength of a CHNA, it is important to realize that the guidelines proposed by the IRS are general so that health institutions can have latitude to conduct a CHNA within their geographical and medical contexts. As a result, some CHNAs can be ambiguously worded and not have in-depth metrics to measure the impact of a community-based health program’s progress. Therefore, being able to build a strong CHNA and IP with regards to kidney health allows for integrating strong language and surveying methodology that clearly states a dedication to kidney health along multiple disease states. For example, a CHNA could explicitly commit to improving kidney health by addressing cardiovascular illness, diabetes, obesity, and CKD along with measurable goals and metrics that measure intervention impact.

Methodology should be assessed as well. Often, community organizations and representatives are brought on in focus groups to communicate needs that usually regard necessities in managing diabetes or in implementing and maintaining healthy lifestyle health changes but that do not extend into downstream needs. While diabetes and lifestyle changes are undoubtedly contributing factors to the development and progression of CKD, what programs are available for those who are screened positive in earlier or mid stages of CKD? Further, in such focus groups, what questions are asked and how is discussion allowed to take place? Is it strictly a monologue from the community leading the discussion or how does the health system play into the dialogue as well? Were all data collection methodologies of one type such as solely surveys distributed through hard copies or only focus groups? How were accommodations made for handicapped individuals or for those working non-first shift jobs?

Did the hospital lead the CHNA and IP on its own or did it partner with other non-profits and academic institutions to ensure the metrics and methodologies follow best practices? How are such practices codified or chosen as best practices? Some non-profit or governmental agencies have published recommendations on how to conduct a proper CHNA such as the CDC’s *Community Needs Assessment Participant Workbook* (2013)32. This document specifically helps to situate CHNA changes into three separate domains: Policy Change, System Change, and Environmental Change before providing guidance on how to conduct a proper CHNA and mobilize learned information into a community action plan.

## Weaknesses and Limitations

The strategy for analyzing CHNAs came from an initial mission to analyze not-for-profit hospitals’ programs regarding transplantation and associated education. While for-profit hospitals are not exempt from being able to create a CHNA and IP, they are not by law required to do so because they cannot receive not-for-profit designations from the IRS. Some research indicates that the median time to kidney transplantation may be longer in for-profit hospitals in part due to the revenue that is generated from keeping a patient on dialysis rather than providing a transplant at the earliest possible date33.

One significant limitation when it came to evaluating the success of either the MOTTEP or NKF model is that they did often not have evaluations that were peer-reviewed. In NKF’s case, it sometimes publishes guidelines in academic journals which are then critiqued, but MOTTEP’s academically reviewed evaluations are written by the organization’s founder, Clive Callender.

Being able to draw inferences about a medical institution’s ability to provide proper kidney-related care is assumed based on its transplantation volume instead of assessing many commonly used quality measures such as prestigious, well-rated nephrologists, the ratings of its chronic disease management programs, hospital-related ratings from Hospital Compare, or patient ratings. In addition, kidney transplantation does not always relate to geography in that prestigious high performing institutions may develop a name for transplantation volume but whether those transplant recipients come from the surrounding community or not and how the provision of care before and after such transplants were not evaluated. An assumption was made that since the top 10 highest kidney transplanting hospitals were from urban areas, the community it serves is *primarily* the urban community where it is located.

# Conclusions

By evaluating the CHNAs from the top 10 highest kidney-transplanting medical centers, it was discovered that explicit mentioning of kidney transplantation programs, education pertaining to kidney transplantation as a treatment option, and education aimed towards CKD and ESRD chronic kidney disease is severely lacking. The business case for health institutions to implement programs regarding community care of kidney disease comes across two main avenues being that (a) hospitals are required to conduct robust CHNA and IP analyses to maintain not-for-profit designations and that (b) it would potentially drive down avoidable costs.

Therefore, after identifying two national non-profit organizations in the form the Minority Organ and Tissue Transplantation Education Program and National Kidney Foundation as models that emulate community-based educational programs, recommendations in the form of best practice strategies are offered which medical institutions are encouraged to integrate into community-based interventions to ensure a sustainable partnership with the community it desires to work within.

In order to best form a successful intervention, it is crucial for the healthcare system to develop a trusting collaboration with the communities they want to target by listening to their needs and complementing a community’s needs with their specialized capacity to provide culturally humble work. Some ways to achieve this is to establish and empower a Community Advisory Board to ensure that the community voice(s) are consistently heard and that the interventions or programs are able to account for and integrate this critical feedback. The use of community health workers can help bridge a healthcare system to communities with high levels of medical mistrust or bilingualism by leveraging their cultural capital and understanding of how the communities they participate in operate and leverage its resources. Finally, by targeting health literacy deficits within a community, a programmatic intervention is more likely to be understood, adhered to, and thus have a lasting positive outcome.

* + - * 1. Data Figures



Appendix A Figure 1: Total Transplants vs. Kidney Transplants and % Transplants that are Kidney Transplants

Data from OPTN was analyzed to produce the proportion of kidney transplants that are performed compared to the annual total. Kidney transplants have consistently accounted for ~60% of annual transplants. 32

* + - * 1. SMOG Chart Examples



Appendix B Figure 1: SMOG Charts

More information on how to conduct the readability test can be found here: http://aspiruslibrary.org/literacy/SMOG%20Readability%20Formula.pdf

Appendix C OPTN Acknowledgement of Data Usage

**OPTN Acknowledgement:**

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